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**Title:** How do people in prison feel about opt-out hepatitis C virus testing?

**Running Title:** Prisoners' views about hepatitis C testing

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## **Abstract.**

The prison population are central to the campaign to eliminate hepatitis C virus as a public health threat. In the UK this has led to the introduction of a national ‘opt-out’ policy, requiring people in prison to be tested for HCV unless they decline, with a target to test 75% of those admitted.

However, in a representative prison estate in the East Midlands of England (20,000 prison entrants per annum) testing rates were only 13.4%. This qualitative study explains why the rates of test uptake are so far short of target. This qualitative study examines the experiences of 45 people in prison about hepatitis C virus testing in an English category C (low security) prison. The data collection method was semi-structured interviews. The data were coded and analysed according to the research questions and interpretation of the data was aided by the use of a thematic network approach. The themes *Fear, Insufficient Knowledge, Stigma, Privacy, Choice* and *Prison Life* emerged as the principal barriers to test uptake. *Test Uptake Facilitators* that promoted testing were identified by participants and benefits presented of prison healthcare being a *Health Farm*. In order to increase hepatitis C virus test uptake significant changes and flexibility in the timing, location, and staff deployed to test are required. Providing information to people in prison about hepatitis C virus transmission and treatment may reduce fears and enable the test uptake target to be met and sustained.

**Key Words:** Hepatitis C, prisons, opt-out testing, dried blood spot tests, qualitative

## **Introduction**

The public health burden of end-stage liver disease attributable to hepatitis C virus (HCV) infection has prompted the World Health Organisation’s call to eliminate HCV by 2030 <sup>1</sup>. In the UK, the National Health Service has escalated this target to be achieved by 2025 <sup>2</sup>. An effective elimination campaign is however critically dependent on a robust mechanism to test those at risk and identify people previously undiagnosed. Increasing attention is turning towards the prison population due to the high concentration of people sentenced for drug related crimes who may have been exposed to HCV. A Health and Justice Report <sup>3</sup> found that in 2014 blood-borne virus (BBV) seropositivity in prisons in England and Wales was 1.5% for hepatitis B virus (HBV), 8% for HCV and 0.6% for human immunodeficiency virus (HIV). A more recent European review estimated that 15.4% of people in prison (PIP) are infected with HCV in contrast to a prevalence of 0.5% in the general population <sup>4</sup>.

However in 2013, only 7.8% of (16,309/208,552) individuals entering prisons in England and Wales were tested for BBVs<sup>5</sup>. In response to these low levels of testing, a commissioning agreement between the National Health Service, Public Health and the National Offender Management Service<sup>6</sup> instigated a national opt-out approach to testing in April 2014 with the aim of increasing testing rates. An opt-out approach comprises testing people routinely on admission to prison unless they specifically decline, in contrast to the previous opt-in approach whereby people were asked if they wished to be tested (Basu et al., 2005). A target has been set to test 75% of people entering prisons for BBVs<sup>8</sup>. However, in a representative prison estate in the East Midlands of England (20,000 prison entrants per annum) between July 2016 and June 2017, implementation of this policy resulted in testing rates of only 13.5% (median 16.6%, range 7.6% to 40.7%) (Jack et al., 2019). Whilst this figure shows an encouraging increase it remains that the majority of people in prison (PIP) do not access health screening for BBV. Therefore, achieving the goal of HCV micro-elimination of HCV in prisons remains an on-going challenge. Against this background, this paper presents findings from a qualitative study which aimed to explore the reasons why PIP opt-out of HCV testing.

## **Methods**

### **Study design**

This research forms part of a larger mixed methods study evaluating the impact of the opt-out approach to HCV testing in prisons. Data from the first stage detailing the changes to test uptake and the influential prison operational characteristics has been published elsewhere<sup>9</sup>. This qualitative study explored the responses of PIP to an opt-out blood-borne virus screening programme seeking to identify and treat people infected with HCV and is analysed thematically. The lead author (KJ) conducted all interviews which were semi-structured, shaped by a topic guide but also guided by participants' responses. Participants were asked about their views and direct experiences of the test intervention; previous test experiences and current test practices; knowledge and awareness of HCV viruses, transmission risks and treatments; felt and perceived barriers and facilitators to BBV testing. Following each interview, the lead author delivered a brief intervention explaining the risk factors for HCV infection, that the test is a dried blood spot, and that new antiviral therapies are well tolerated and have a high cure rate.



## **Sample**

A category C male prison in the East Midlands, housing a representative group of approximately 1000 sentenced men, was selected for the study. This prison has a yearly intake of approximately 1800 men who are nearing the end of their sentence and preparing for resettlement on release. A breakdown of the PIP's ethnicity is: white 75%; Black 11%, Mixed Race 7% and Asian 7% .<sup>10</sup> At the time of the research, the men entering prison were asked on arrival if they would like a test for blood-borne viruses via an opt-out approach and an appointment subsequently booked for a dried blood spot test. 45 participants were recruited by the lead author (who is employed by the hospital team who provide in-reach HCV treatment) using a purposeful sampling strategy to ensure that people with a full range of experiences were interviewed. 16 PIP who were invited to participate in the study refused without supplying a reason. Interviews commenced after participants gave written informed consent and, with their permission, were audio-recorded.

## **Data Analysis**

All the participant interviews were transcribed by the lead author (KJ) and organised within NVivo software prior to analysis aided by a thematic network <sup>11</sup>. Data saturation was achieved. The coding of the findings was undertaken by the lead author (KJ) and independently checked and scrutinised by the 2nd author. The coding and themes were found to have construct and face validity. Initial emergent (inductive) codes were added to a coding framework along with a-priori (deductive) codes. Initial coding examined both a priori interests as well as inductive codes grounded in the study data. Secondary-level thematic coding was later conducted across the full dataset to further fracture the data and allow for the development of conceptually driven categories.

## **Ethics**

Ethical approval was obtained from all required bodies; West Midlands-South Birmingham NHS Research Ethics Committee [17/WM/0312], East Midlands National Offender Management Service Ethics Committee, the Health Research Authority, Nottinghamshire Healthcare NHS Trust and final approval to proceed from the prison Governor. All participants had the opportunity to read, or have read to them the participant information sheet prior to giving written consent.

## Findings.

Interviews lasted mostly between 15 and 45 minutes (range 7-73 minutes). Of the sample, fifteen men had refused HCV tests in prisons, whilst the remaining had been tested in a prison with 15 being HCV RNA positive and 15 being HCV negative. The ages of the PIP ranged between 21 and 58 years (mean 35 years). The length of time spent in the current prison varied between having just arrived and 36 months (mean 5 months). The number of prisons stayed in during their current sentence ranged from two to nine (mean 3 prisons) therefore PIP will have been offered HCV screening on arrival at each of these establishments. Thus, the population sampled were representative of a wide range of ages and experience of prison life, including the admission process.

Our study findings report on the perceptions and experiences of PIP in response to the implementation of an opt-out BBV test intervention in an English prison setting. Eight distinct thematic networks were contained in the data; *Privacy, Stigma, Fear, Insufficient Knowledge, Choice* and *Prison Life* have emerged as the principal barriers to test uptake, whilst *Test Uptake Facilitators* were however positively identified by participants and a positive notion presented of prison healthcare being a *Health Farm*. Whilst these themes are reported on separately, they did at times over-lap.

### Privacy

This theme encapsulates prisoners' struggles to deal with a lack of privacy when being screened. The location where testing was carried out was important to many PIP. In the majority of prisons, testing is undertaken in the healthcare departments and this was considered to be the most private environment, because an alternative reason for attending other than an HCV test can be given to other PIP ;

*"I think the main healthcare. Probably at the same time when people are doing other tests, you know. So it can be purely for the reason that it can be explained, you know, or it can be easily shoved off "* (Participant #22 tested positive)

Whilst the importance of location in the prison was highlighted, more weight was attributed to the disadvantage of a single nurse for having responsibility or for testing on a specific day;

*“If people know that hepatitis testing is done on a Wednesday, and someone says “oh what are you doing here”, but on a Wednesday, it’s straight away hep, so the fact that it’s a specific nurse and a specific test on that day” (Participant #6 tested negative)*

The opt-out policy’s intention to test people on arrival at prison was viewed by many PIP as a good solution to ensuring privacy was maintained, with typical responses such as;

*“You have to see healthcare anyway when you come in, I don’t know why they don’t offer it there and then when you first come in” (Participant #15 tested positive)*

The desire for privacy extended beyond simply having confidentiality maintained by staff, but to the wider context of rejecting social contexts where actions could imply they were infected with HCV.

### **Stigma**

Closely related to *Privacy* is *Stigma*. This theme captured participants’ intense feelings of discontentedness and stigma towards HCV infection, for example;

*“I know for a fact if I was a prisoner and they put someone in with me...and I knew that he had hep C, he wouldn’t be coming through the door. It’s nothing against the man, and I’m not going to judge the way he’d lived his life, but you wouldn’t want to put a loaded gun in your mouth would you?” (Participant #20 tested negative)*

And;

*“Yeah, , it’s difficult because you have to stay away from them like.....people avoid them, they do get treated different, people that know they’ve got hep C like, when smoking was involved, smoking in jail, people won’t share fags with them, or share a drink” (Participant #28 refused testing)*

Many participants who were HCV positive corroborated these opinions with their own experiences of such negative views, typically;

*“It’s like there’s an association of being dirty attached to it, and you know people’ll say ‘oh he’s got hepatitis C’, and ‘don’t go nowhere near him’”*  
(Participant #22 tested positive)

The subsequent enacted stigma experienced by some was quite profound, for example;

*“I told one person, he kept to himself, but then I got into a fight and I was bleeding, so I had to tell somebody else who was trying to help me, then it got round, and then a lot of the Muslim brothers thought I had a disease, that just breathing my air would give them the disease, they were crossing over from the walkway, not walking the same way, you know it was a horrible feeling, I really felt like I was an alien, like I wasn’t part of this world”*  
(Participant #32 tested positive)

The origins of the stigma in prisons were rooted in its’ association with injecting drug use, for example;

*“It’s like a lot of people with hep C are (drug) users, and using (drug taking) is looked down on, frowned upon, so that’s probably I think, bit of a stigma attached to it, do you know what I mean?”*(Participant #30 refused testing)

### **Fear**

Underpinning the stigmatisation of others was the *Fear* of contracting HCV infection;

*“They might pass it on to them, it’s like AIDS, when AIDS first come out, people thought they can’t share a cup with someone, can’t touch them, you can’t be near them.....it’s a threat to me”* (Participant #32 refused testing)

Being fearful of a positive HCV test result was common too and identified by PIP as rationale for not accepting a test, for example;

*“People are scared, what they don’t know don’t hurt them. If you told me I’ve got cancer I’m going to worry for months until I do pop off, that’s going to be more torture to me than not knowing”* (Participant #12 tested positive)

The concerns about a positive HCV diagnosis were linked to a lack of understanding of the consequences of infection, worries about the potential associated disease, and a lack of awareness about the new curative drug treatments. Typical examples of response included;

*“They don’t want to know, because the fear factor, for them, they’ve got a life altering disease that can take their life, and then having to go out there and say to all their mates: “we’ve been doing drugs and that, you lot need to get a hep C test because I’ve got hep C”, because they know they’re going to get chucked in the whatsit, their cell, with all these guys, “you’ve known you’ve had hep C and you’ve not told us”, you know what I mean?”*

These fears of a positive HCV test result were woven in with further concerns about transmitting HCV to others,

*“I was so scared, I was frightened, I didn’t really understand what she said to me, I felt very apprehensive about telling my partner, very scared for my daughter who hadn’t been born by then, and I was very, very upset that I could have put her and her Mum through it as well” (Participant #24 tested positive)*

In addition, many participants indicated how a fear of being found out that they had HCV led to a fear of rejection by others, with this notion connecting also to *Privacy* and *Stigma*.

*“They’d probably try and get you off the wing” (Participant #8 tested positive)*

The emotion of *Fear* was also associated with the process of blood testing;

*“I’m scared of needles, if you’re going to want a blood sample, I’m not willing to provide”*

### **Knowledge**

The fear and stigmatising behaviours expressed were provoked by a lack of understanding and knowledge of HCV infection or how it is transmitted, for example;

*“In (different prison), we pack cereal packs with tea bags in, and he’s got hepatitis and making people’s cereal packs with no gloves on, if he gets blood in a tea bag or whatever then then someone else could contract it” (Participant #29 refused testing)*

And;

*“In my last prison there was a guy serving people food who had hepatitis and I didn’t know this until someone said “I don’t want that guy in here, you got hepatitis” and I was like, I don’t think he can work on the server, how is he serving me my food if he’s got hepatitis?” (Participant #2 refused testing)*

A surprisingly high number of PIP believed that HCV infection can be transmitted by sharing electronic cigarettes and one participant indicated the possible source of this mis-information;

*“If you can catch it by sharing a crack pipe, if someone passes you a cigarette and they’ve got blood on the end of the cigarette, you can catch it can’t you? So it’s not just through a dirty way of catching it, you can catch it in a lot of ways”*

*(Participant #44 tested negative)*

Furthermore, whilst the majority of PIP were aware about HCV, there were a small number of PIP whose knowledge was non-existent;

*“I don’t even know what hepatitis is. Never heard of it before, people can catch it from having sex in prison I guess? “*

*(Participant #18 refused testing)*

### **Choice**

The deprivation of liberty associated with a prison sentence means that any opportunity to exercise choice and challenge the system is an important feature of prison life. Illustrations of this standpoint include;

*“It’s a unique kind of community in prison, it’s got little sections, rules, quirks and that, but that stems from choice, you know, because prisoners who are restricted behave in a way, people resist against compulsory things, and if it’s their choice they’ll do it more”*

*(Participant #6 tested negative)*

And;

*“It’s (healthcare) the only freedom that we’ve got. Something like that (BBV test) if it’s an option, and you’re trying to force it onto somebody, some of them will just go against it just for the sake of going against it, anti-establishment”*

*(Participant #20 tested negative)*

Emphatic views were expressed stated which emphasised the importance of choice, for example;

*“It’s an invasive process isn’t it, and anything that’s an assault basically, it’s got to be a choice”*

*(Participant #6 tested negative)*

An individual’s perception of their risk of acquiring HCV infection clearly plays a role when choosing to accept a test, particularly when being moved to other prisons;

*“I wouldn’t need it (another test), because I don’t do nothing, I’m drug free now so I don’t share nothing, I don’t do nothing, chances of getting it are very slim”*

*(Participant #44 tested negative)*

Decisions were also made about whether it was safe to leave the prison wing and attend appointments in the healthcare department, for example;

*“If people take drugs and they’re in debt from other wings, you can’t go to healthcare and simply bump into people that they don’t want to see because they’ll get their head smashed in”*

*(Participant #29 refused testing)*

### **Prison Life**

Possibly the biggest barrier to getting tested was prison life itself which was depicted principally as harsh. Barriers to meeting health needs were an intrinsic feature resulting from the prison’s culture, security and rehabilitation regime. For example, insufficient numbers of nurses were reported;

*“I mean these poor guys they’re run ragged as it is, the healthcare team here, They’ve got to multitask all the time, they’ve got people at them all the time for this that and everything, as though their thing is priority you know what I mean? ”*

*(Participant #12 tested positive)*

Additionally the lack of prison officers to escort people to the healthcare clinic was observed;

*“It’s the logistics of moving about the jail with officers, so like in here if you’ve got a healthcare appointment you can just walk down there, it’s a bit more relaxed, some cat Bs it’s not, so if that officer’s busy and they haven’t got the staff to do that stuff all the time, it’s hard isn’t it?”*

*(Participant #43 tested negative)*

The timing of the test was frequently commented on, with a variety of views expressed that indicates the need for multiple occasions and locations;

*“You’ll probably find people more receptive a month later once they’ve settled in, got into their stride, it’s bad enough having to land here as it is and going through the whole induction process, you’ve got a lot on your plate anyway, thinking “oh who have I got to share with, who got to do this with” (Participant #12 positive)*

And;

*“People are lazy, especially in healthcare, for them to have an appointment, especially if it’s raining...”I ain’t walking over there, and getting soaking wet”, so do it (test) when they first come in, then you’d get everyone”*

*(Participant #16 tested positive)*

And;

*“A waste of time in a cat B (remand prison) because don’t know if they’re coming or going, by the time they get the results they could be out. It’s probably better when they are in a C cat (sentenced prisoners)”*

*(Participant #28 refused testing)*

Some PIP were concerned that the prison officers could deduce the reason for attendance and that this could breach confidentiality and *Privacy*;



*“If I were to go up there, even though the officers not taking me into the consulting room, if the officer gets to know what the appointment is, that would be a problem”*

*(Participant #27 tested positive)*

Nonetheless the majority of PIP felt that a prison officer escort would not dissuade them from attending, for example;

*“No, because a member of staff’s not going to be in there while you have it done, they wait outside. It’s only going to be you and that health worker what’s there”*

*(Participant #19 refused testing)*

Furthermore, it is common practice for PIP to be contacted only if their BBV test result is positive. Not receiving confirmation of a negative result and considerable delays with receiving a positive test result were common sources of disgruntlement and discouraged repeat testing;

*“Yeah, not knowing, and not getting the results. To be behind your door, locked up all the time and have that on your mind, have I got something, have I not got it? That’s a lot of stress that someone don’t need, and I think that’ll put a lot of people off”*

*(Participant #44 tested negative)*

### **Health Uptake Facilitators**

A variety of ideas emerged from the interviews about ways to increase testing and these can be divided into two groups, Education and Procedural. Firstly, increasing opportunities for health education about HCV transmission and treatment were considered important;

*“Maybe give out hep C information packages, booklets, as part of the induction pack or something, put a few more posters up about it in healthcare, you can be there an hour and a half sometimes, people always end up reading what’s on the wall”*

*(Participant #12 tested positive)*

There was strong appetite for the notion of peer-led support and education, for example;

*“Have somebody that’s actually got hepatitis or HIV sitting in, how its affected their life to have HIV or hepatitis, that will probably help the prisoner decide if he wants it or not. Explain it prisoner to prisoner, it could make him feel a lot more comfortable”*

*(Participant #18 refused testing)*

Secondly, the procedural suggestions focussed on working flexibly and creatively;

*“At (another prison) they actually come on the wing, a lot more people sitting down having it done, think most of the wing were done to be honest, that’s how I’d do it”*

*(Participant #15 tested positive)*

And;

*“If you say, look its 3 words, “we’re testing everybody”, and you have to sign a form if you don’t want to do it, people will just do it”*

*(Participant #17 refused testing)*

The theory that an opt-out testing procedure would normalise the process was evident;

*“They’ll think, ‘well everyone’s getting it done, I’ll get it done’, more than singling certain people out. If they think everyone’s getting it done it’s like it’s a bit of the norm isn’t it?”*

However many PIP felt that this wasn’t a robust enough approach;

*“I think it should be mandatory,”*

*(Participant #37 tested negative)*

Furthermore, the dried blood spot test was viewed by the majority as a highly preferable alternative to venepuncture;

*“The fingerprick is good because a lot of people who use drugs intravenously it’s hard to get themselves, so there is a lot of fear, you know, “oh you’re not going to get me” and stuff like this, and that puts up a barrier straight away. With the needleprick there’s no barriers, it’s just like having a diabetes test or whatever”*

*(Participant #35 tested positive)*

### **Health farm**

This final theme groups the extracts from interviews which highlights that many PIP use the opportunity of incarceration to address health needs.

*“I call it the health farm. To be honest with you without this place I think I’d have been dead a long time ago”*

*(Participant #15 tested positive)*

And;

*“Nurses are more like Mummies, they’re like Nanna’s, you go see a nurse and you know you’re getting alright”* (Participant #39 tested negative)

The opportunity for a check-up by a nurse on arrival at prison was appreciated by some PIP;

*“It’s like a MoT Miss, it’s nice when you come into a prison and they ask you all these things, to help you for when you get out”* (Participant #5 tested negative)

Furthermore, prison was described by many who were HCV positive as a good environment in which to receive antiviral therapy, for example;

*“Probably because in prison you’ve got a lot of spare time on your hands, and it’s an ideal place to have treatment like this rather than outside, life outside is very, you’re a lot more going on that what you would if you was inside, if you’ve got kids, the missus or whatever, family issues, so being in prison you know you’ve got a lot of time, spare time”*

However receiving a diagnosis of HCV in prison was clearly an inconsolable experience for some PIP,

*“It just smashed my world, I were crying, I weren’t expecting, tears rolling down my eyes...it was worsen than finding my Mum dead”*

(Participant #35 tested positive)

These excerpts illustrate that there are a sub-group of PIP who are willing to spend time in prison constructively addressing actual or potential diagnosis which could be harnessed regarding BBV screening.

## **Discussion**

There is a paucity of published studies presenting the process and utility of opt-out screening programmes for blood borne viruses in UK prisons. Furthermore, this study is one of the few to

look at the lived experience of PIP and why they may not take up the offer of BBV screening in custodial establishments.

Taken together the themes underscore the complexities in prison regarding accessing health screening and communication about risk of future disease. The emergent leitmotif is *Fear* and this strong emotion expressed is the hidden layer where PIP related barriers to testing reside. There were multiple expressions of fears which discouraged test uptake; of acquiring HCV in prison, of a positive diagnosis, of being found out if infected and excluded from other PIP, of needles used for blood testing, and the anxiety of waiting for the test result which was provided only for those testing positive. The dried blood spot test results can take up to four weeks to be returned because the tests are sent in batches to the laboratory and this delay compounds PIP's worries. *Fear* of a positive diagnosis has been observed by other authors exploring HCV testing<sup>12-17</sup> and needle-phobia amongst PWID has been frequently reported<sup>16,18,19</sup>. A fear of disclosure of being HCV positive has been noted too by several authors<sup>12,14-16</sup>.

These anxieties were all woven into additional themes. It was expected by the researchers that confidentiality would be raised as an important need by the PIP because this has been widely acknowledged in this patient population<sup>15,20</sup>. However *Privacy*, which applies to the person and includes their right to be concealed from other's views or intrusion, illustrates the importance of also minimising environmental cues from which other PIP may deduce a diagnosis. Therefore designated clinics for BBV testing or treatment, whilst arguably easier for staff to manage, were less popular amongst the participants interviewed and discouraged attendance amongst some participants.

*Stigma* was an expected theme as it is widely reported in the literature discussing HCV<sup>15,21,22</sup>. Specifically, HCV related stigma is associated with IDU<sup>15,22,23</sup> so this too was an a-priori observation. There was evidence of both felt stigma (associated with being infected) and enacted stigma (episodes of discrimination)<sup>24</sup> in the interviews. It is argued that "stigma is entirely dependent on social, economic and political power because it takes power to stigmatise"<sup>25</sup>. The people who might stigmatize in an environment or situation may be asked if they have the following powers to: ensure that the human difference they recognize and label is broadly identified in the culture; ensure that the culture recognizes and deeply accepts the stereotypes they connect to the labelled differences; separate "us" from "them" and to have the designation stick;

control access to major life domains like educational institutions, jobs, housing, and health care in order to insert consequential teeth into the distinctions they draw<sup>25</sup>. If the answers are yes, as they will be in prisons, then stigma is to be expected. Therefore whilst the notion of increasing knowledge to PIP and all relevant stakeholders regarding HCV may be considered a means of resolving stigma, this approach fails to recognise that firstly many types of stigma are embedded in the prison culture<sup>26</sup> and secondly it is unlikely to change the PIP's felt stigma which is based on their prior experiences<sup>27</sup>.

However, it is still necessary to introduce information to PIP and prison officers about the need to test for HCV so that people infected can be identified and treated. One emerging intervention showing success is the creation of prison peer educators specifically for HCV. Peer support in prisons is an established feature in England and Wales, for example the *Listeners* service created by the Samaritans to offer emotional support, and peer work offering advice with housing, language translation and supporting healthcare in general<sup>28</sup>. Benefits observed are that peer support is highly acceptable in prisons, there are reductions in risky behaviours, and both practical and emotional support are provided<sup>28</sup>. The Health and Justice Prison Peer Project was launched in England during 2017<sup>29</sup> to deliver peer-led training and one-to-one support in order to encourage the uptake of HCV testing and treatment if required. A study in Eire<sup>30</sup> evaluated the role of prison peer educators to create educational material for the prison and undertake peer supported HCV screening and links to treatment. Over the course of six days, 425 PIP were tested, 12% (50/425) found to be HCV RNA positive of whom 43 were linked to a hospital based treatment service.

Low levels of *Knowledge* means that PIP are not sufficiently well informed to understand if they are at risk of HCV or not and this is leading to missed opportunities of testing people genuinely at risk. Poor levels of knowledge amongst PIP surrounding modes of transmission have been noted by other authors<sup>15,21,31</sup>. Whilst increasing PIP's knowledge is important to encourage test uptake, it is also possible that accurate information about HCV transmission may lead to PIP opting-out of testing if they accurately self-assess that they are not at risk of having acquired HCV infection.

Exercising *Choice* regarding healthcare emerged as being hugely important to the PIP in a context where liberty and freedom to choose are restricted. PIP are often referred to as being a "captive audience"<sup>32</sup> but the data shows this is not necessarily true. Whilst PIP are held captive, they are not automatically interested and engaged in preventative health measures and several participants indicated that they would refuse testing if they felt it was too forcefully proposed. This was

observed too by prison officers in a previous study<sup>23</sup> and further illustrates the need for skilled communicators to encourage PIP to be tested.

One feature of *Prison Life* is that healthcare is a commissioned element, not the sole raison d'être as it is in designated primary, secondary or tertiary healthcare settings. Prisons' core focus is on punishment, offender rehabilitation and maintaining a safe environment and is achieved by enforcing a strict regime of daily activities, which results in limited flexibility for non-urgent healthcare delivery. This contributes to PIP not being given negative BBV test results, along with associated health education and harm reduction advice, because there are insufficient healthcare appointments available to facilitate this. Maintaining a safe environment is also one of the 12 activities of daily living underpinning nursing care<sup>33</sup>. In the context of BBV testing it applies to maintaining both individual patient safety by eliminating an infection that can lead to liver disease, and to maintaining prison safety by reducing the pool of infection that could be transmitted to other PIP or staff. This is perhaps the shared goal that could enable increased engagement and support from prisons and facilitate the delivery of a HCV micro-elimination strategy. It is in the prison staffs' interest for BBVs to be eliminated given the altercations that require intervention and subsequent anxiety experienced by the prison officers who have been exposed to body fluids

23.

Many of the PIP interviewed spoke very warmly about the nurses and appreciated their time in the *Health Farm* where prison nurses are required to practice at the top of their professional ability as physician availability is limited. Supporting prison nurses and understanding the challenges faced are the key to a significant increase in testing rates. It is perhaps unreasonable to expect prison nurses to facilitate the delivery of an HCV elimination strategy without their inclusion in the Hepatitis Operational Delivery Network's (the English HCV treatment networks) discussions and plans. The *Test Uptake Facilitators* suggested by participants all fall into the jurisdiction of the prison nurses' domain so closer collaboration is essential. A need to provide multiple options of test location, timing of test offer, test method and staff allocated to conduct BBV screening is evident within the themes.

This research is not without limitations. The authors acknowledge that the qualitative data produced within this particular study context may limit the transferability of the study findings beyond the cohort interviewed. Specifically, this was a single site study and women were not

interviewed. The experiences between people of differing ethnicity were not captured, nor the participant's history of risk factors for HCV infection.

Additional research is required to further understand and quantify the reasons why PIP decline HCV testing in order to refine and embed the care pathway into a routine process.

## Conclusion

This is the first study that has recorded interviews with people in prison, to the authors' knowledge, exploring their views about the process of opt-out testing for HCV infection. The data presented shows that a single approach to the timing, location and method of testing will not meet the needs of a population whose views on the acceptability of being repeatedly screened for BBVs in prison are heterogenic. The findings illustrate that *Fear* is an important driver of *Stigma*, and that *Fear* in this context is a consequence of insufficient *Knowledge*. There is thus an urgent need to increase the education about HCV transmission and treatment in order to sustainably increase the uptake of HCV testing in prisons and achieve micro-elimination in this population.

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