Tackling Hepatitis C in Scottish Prisons

Thursday 6th December 2018
Glasgow

#nohepscotland
Welcome

Rachel Halford
Chief Executive, The Hepatitis C Trust
Developing guidance to support opt-out BBV Testing

Donna Thain
Sexual Health & BBV MCN Manager
Supporting Opt-Out BBV Testing in Scottish Prisons

Donna Thain – MCN Manager, Tayside on behalf of a short life working group
Why are we producing guidance?

The Scottish Government updated the Sexual Health and Blood Borne Virus Framework in 2015. The update recommended the introduction of opt-out BBV testing in the Scottish Prison Establishment.

“...the Scottish Government will work with NHS Boards and the Scottish Prison Service to introduce opt-out BBV testing (hepatitis B and C and HIV) for all new prisoners in Scotland during their induction period.”

“In particular there is an opportunity to test for blood borne viruses (BBVs) such as HIV and HCV using dried blood spot testing but we were told testing is inconsistent and poorly managed with access to treatment not being confidential which discourages testing and treatment.”

“We recommend the opportunity is taken through the admission process to undertake dried blood spot testing on all prisoners.”
Why is BBV testing in prisons important?

• There is a much higher prevalence of BBVs in the prison population than the general population
  – Hepatitis C prevalence (Scotland) is 19%
  – Estimated HIV prevalence (Western Europe) is 4.2%
  – Estimated HBV prevalence (Western Europe) is 2.4%

• The Scottish Government has signed up to the World Health Organisation’s goal to **eliminate hepatitis C by 2030**

• Ongoing HIV outbreak in GGC and potential for spread
Elimination is rare

Prisons are key environments where micro-elimination of hepatitis C can be achieved.

Scotland has the opportunity to rapidly eliminate Hepatitis C in our population. It’s within our grasp; let’s spend less, treat more, eliminate HCV and transform lives.
How are we doing?

Number of people newly admitted to prison, people tested for hepatitis C (HCV) antibody in prison setting, and proportion HCV antibody positive, by prison in 2017

Source: Scottish Prison Service and Health Protection Scotland
Note: HCV Test data not available for HMP Cornton Vale, HMP Dumfries, HMP Glenochil, Open Estate, YOI Polmont, and HMP Shotts.

Where an individual has been admitted to more than one prison in 2017, they are counted in the first prison only.
What guidance exists?
What have we done?

Short life working group formed March/April 2018

Draft guidance and resources out for consultation September 2018

Final draft produced November 2018
Core principles agreed

There is no “one size fits all” solution - support prison healthcare staff to develop testing pathways, protocols and monitoring arrangements that suit their environment.

- Opt-out BBV testing should be offered to those in custody regardless of their legal status e.g. remand and sentenced
- Testing should ideally be carried out within 7 days of admission but definitely within 4 weeks for those who are convicted and within 2 weeks if the person is on remand
- Testing can be undertaken by any appropriately trained member of staff, both clinical and non-clinical i.e. doctors, nurses, healthcare assistants, pharmacists, voluntary sector staff etc
- Testing and diagnosis must lead to specialist review and treatment
- BBV testing is not a one off – each interaction with an individual is an opportunity to discuss harm and risk reduction and to offer BBV testing if appropriate
- BBV testing and treatment within prison is a critical component of Scotland’s pledge to eliminate hepatitis C
Opt-Out Blood Borne Virus Testing Pathway for Scottish Prisons

**Reception Healthcare Screen (Primary care Team)**
- **Health assessment within 7 days carried out by nurse or doctor**

**During custody**
- Individual self refers or healthcare staff opportunistically identify individuals for testing/immunisation e.g. addictions clinic review; well women clinic

**Is the individual already diagnosed with HIV, Hep C or Hep B? Are they on medication?**
- **YES**
  - Refer to specialist BBV services - ensure medication is continued - Record on Vision
- **NO**

**Does the individual require/request testing for BBV and HBV immunisation?**
- **YES**
  - If possible, perform BBV test and immunisation at this assessment. Where this is not possible, schedule an appointment within 2 weeks (for remand) 4 weeks (for convicted). Record on Vision.
- **NO**
  - Individuals who decline testing should be made aware that they can self-refer at any point. Offer harm reduction advice. Record on Vision.

**Target time from reception to test = 2 weeks (for remand) 4 weeks (for convicted)**
Frequently Asked Questions to support opt-out Blood Borne Virus (BBV) testing

1. What do we mean by BBVs?

The BBVs being looked at in this context are B (HBV) and hepatitis C (HCV).

2. What is hepatitis B?

The hepatitis B virus (HBV) causes hepatitis (inflammation of the liver) and can also cause long term liver disease. Failure to clear hepatitis B infection after six months is considered chronic infection. The main treatment for chronic hepatitis B is antiviral medication, which can stop the hepatitis B virus from causing liver damage. However, it is unusual for this treatment to permanently clear the infection. Hepatitis B is an infection that can be prevented through vaccination and people are recommended to be vaccinated. Consult CHBV hepatitis B vaccination in the Green book: in and against infectious disease.

3. What is hepatitis C?

Hepatitis C is a virus that predominantly affects the liver and untreated can lead to severe liver disease and in most cases it can be cured. The acute stage refers to the first six months and does not necessarily result in any noticeable symptoms. Approximately 15–20% of those infected with hepatitis C will naturally clear the virus from within the first six months. After the remaining chronic (long term) infection will develop.

4. What is HIV?

HIV is a virus that attacks the body’s immune system’s defence against diseases. Without effective treatment the immune system will become weaker and no longer be able to fight off illnesses. HIV is transmitted with the introduction of Anti-Reverse Transcriptase (ART). There is no cure for HIV but ART with an undetectable viral load for more than six months cannot pass the virus on to others. In other words, undetectable equals untransmissible or even cured. On HIV treatment can live a long, healthy an

Educational Resources and Training to Support BBV Testing

- **Hepatitis Scotland**

  Hepatitis Scotland is the national voluntary sector organisation funded by the Scottish Government to help improve responses to viral hepatitis prevention, treatment and support. [www.hepatitiscotland.org.uk/publications-and-resources/resources](http://www.hepatitiscotland.org.uk/publications-and-resources/resources)

  This website also provides access to webinars on a range of topics and issues related to Hepatitis C. [www.hepatitiscotland.org.uk/e-bulletin-and-webinars](http://www.hepatitiscotland.org.uk/e-bulletin-and-webinars)

- **Nationality**

  The World Health Organization provides a guide to Hepatitis C. [www.who.int/publications/i](http://www.who.int/publications/i)

- **HIV**

  HIV Scotland provides information on HIV and AIDS. [www.hiv-scotland.org.uk](http://www.hiv-scotland.org.uk)

- **UK**

  The British Liver Trust developed a ‘blood-borne virus awareness’ series of leaflets and posters aimed at prisoners. Hard copies have been previously circulated throughout the prison estate. The leaflets can be downloaded at: [www.britishlivertrust.org.uk/topics/infectious-diseases/infections/hiv-aids/passing-on-hiv-aids-in-prisons](http://www.britishlivertrust.org.uk/topics/infectious-diseases/infections/hiv-aids/passing-on-hiv-aids-in-prisons)

  The Hepatitis C Trust is the national UK charity for hepatitis C. It was founded in 1990 and is now led and run by people with personal experience of hepatitis C. The website has various guidance and resources available: [www.hepatitis-c-trust.org.uk/resources/resources](http://www.hepatitis-c-trust.org.uk/resources/resources)

- **The Hepatitis C Trust Prison Helpline**

  A free and confidential hepatitis C helpline is available in all prisons across the UK provided by The Hepatitis C Trust. [0800 099 2052](http://0800 099 2052)

- **NAM prodrug**

  The site offers a variety of information.

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Challenges

• **Resources** – no additional funding to support this work is an issue for PHC teams and laboratories

• **Timing of test offer** - priority for healthcare staff at initial reception is the immediate safety of those entering custody

• **Prioritisation** – BBV not always top priority for individuals, SPS staff or PHC

• **Monitoring** – SLWG recommend BBV testing data is improved and included by new Health & Justice Collaboration

• **Governance** - lack of national accountability. The Health and Justice Collaboration, established by Scottish Government is exploring ways to enhance and support national co-ordination of improvement work, including through the National Prison Healthcare Network
Next Steps

• Final guidance to be presented to national groups:
  – SHPN Viral Hep Leads /Prevention Leads/ Exec Leads
  – SPS & NHS Health Protection Advisory Group
  – Scottish Prison Healthcare Network
  – Prison Healthcare Leads Network

• National BBV Networks to work closely with National Prison Healthcare Network and its associated working groups to support implementation

• Continue to liaise with Health & Justice Collaboration to look at ways to improve monitoring data and advocate for publication of BBV testing data in prison settings nationally
Thanks to the SLWG

Short Life Working Group Membership

<table>
<thead>
<tr>
<th>Member</th>
<th>Role</th>
<th>Representing</th>
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<tbody>
<tr>
<td>Dr Rory Gunson</td>
<td>Consultant Virologist, NHS GGC</td>
<td>Laboratories</td>
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<td>Lesley McDowall</td>
<td>Health Strategy &amp; Suicide Prevention Manager</td>
<td>Scottish Prison Service</td>
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<td>Leon Wylie</td>
<td>CEO Hepatitis Scotland</td>
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<td>Trish Tougher</td>
<td>BBV Network Manager, NHS Lanarkshire</td>
<td>BBV Coordination Network</td>
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<td>Allan McLeod</td>
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<td>Donna Thain (Chair)</td>
<td>Sexual Health &amp; BBV MCN Manager, NHS Tayside</td>
<td>BBV Coordination Network &amp; Viral Hepatitis Clinical Leads</td>
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<td>Mina O’Hara</td>
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<td>Jacky Shaw</td>
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<tr>
<td>Grant Scott</td>
<td>PNA Prison Health Care and Police Custody Suites, NHS GGC</td>
<td>Prisoner Healthcare</td>
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Good practice case study: Hepatitis C testing and treatment in HMPs Lothian

Jacky Shaw – Community BBC Clinical Nurse Specialist, NHS Lothian
Fiona Rose – BBV Clinical Nurse Specialist, NHS Lothian
HEPATITIS C TESTING & TREATMENT IN HMP’S LOTHIAN

Jacky Shaw & Fiona Rose
The journey to Opt Out in Lothian

• Assist colleague

• Training

• Events – Love your Liver / Peer involvement

• In reach
Cont.....

• Introduction of Opt Out

HMP Edinburgh – Mid 2016
HMP Addiewell – Feb 2017

• Testing numbers have increased
Annual hepatitis C antibody testing in Lothian prisons: total tests by financial year

Number of tests


HMP Addiewell
HMP Edinburgh
Opt-Out Blood Borne Virus Testing Pathway for Scottish Prisons

**Reception**
Healthcare Screen (Primary care Team)

- **Health assessment within 7 days carried out by nurse or doctor**
  - **Is the individual already diagnosed with HIV, Hep C or Hep B? Are they on medication?**
    - **YES**
      - Refer to specialist BBV services - ensure medication is continued - Record on Vision
    - **NO**
      - **Does the individual require/request testing for BBV and HBV immunisation?**
        - **YES**
          - **NO**
            - Individuals who decline testing should be made aware that they can self-refer at any point. Offer harm reduction advice. Record on Vision.
        - **NO**
          - If possible, perform BBV test and immunisation at this assessment. Where this is not possible, schedule an appointment within **2 weeks** (for remand) **4 weeks** (for convicted). Record on Vision.

**During custody**
Individual self refers or healthcare staff opportunistically identify individuals for testing/immunisation e.g. addictions clinic review; well women clinic

**Target time from reception to test** = 2 weeks (for remand) 4 weeks (for convicted)
How does it work in Lothian?

• New into custody
• Information collated onto spreadsheet
• Seen within a few days of admission
• Venepuncture and DBST
• Results letter in 7-10 days
Continued ...

- Offered 2 appts
- Positive are seen face to face
- Swift referral for treatment
- Recall for repeat testing
- Community follow up
Challenges

- Security
- Confidentiality
- Staff turnover
- Workload in reception
- Transfers from other prisons
Where are we now in Lothian?
Moving Forward

- MCN led audit
- Building capacity & shared care & consistency
- Regular training & connecting with staff
- Health promotion events
- Treating patients on remand
Treatment in prison

- Past, present and future......
Advantages

- Easier access to patients
- Reduced substance misuse
- Desire to change/move on
- Adherence
- Possibility of DOT (particularly advantageous with newer, more expensive drugs)
- Easier access to substitute prescriptions
- Easier access to mental health support
- Reduced social stressors
Aims and Challenges

• Be able to prioritize a high risk group
• Increase treatment of patients serving short sentences or on remand
• Successfully transition these patients from prison to community and vice versa without losing them to follow up or incurring excess costs
The Evolution of Hep C Treatment

From 72 weeks and 47% success rates

Peg/Riba
Telaprevir/Boceprevir
Simeprevir
Sofosbuvir
Daclatasvir
Harvoni (Sofosbuvir/Ledipasvir)
Abbvie (Viekirax/Exviera)
Epclusa
Zepatier
Maviret

To 8-12 weeks and > 95% success rates
Lothian Prisons Treatment numbers

Year

Series 1

Series 2
How?

• Rapid testing and referral on admission to prison
• Reducing appointments from assessment to treatment-Nurse led service

1. Test/known HCV +ve on admission
2. Refer
3. Assess
4. If required -medic review

• The support of a specialized pharmacist and enthusiastic community pharmacies
• The addition to our team of a community support worker
• Good cross country networks of specialists and 3rd sector groups
Difficulties

- Unexpected transfer/liberation/admission of patients
- Sentence length
- Availability of equipment – blood tubes etc
- Healthcare not priority, security comes first
- Others perception of prison healthcare
- Confidentiality
- Communication
- Education of staff
- Staff turnover
Outcomes

- Treatment target 10%-now achieving 21% of total Lothian treatment numbers
- Increase in numbers attending for testing and assessment
- Increased self-referral of patients
- Improvement in quality of care
- Improvement in safety
- Improvement in access to care
- Improved referral pathway for patients liberated
- Audit to look at SVR and lost to f/up rates
The peer support model in prisons

Julia Sheehan
Women’s Prisons Peer Coordinator, The Hepatitis C Trust
The peer support model in prisons

Julia Sheehan

Women’s Prison Peer Coordinator, The Hepatitis C Trust
Women’s Prison
P2P Programme

• Started in July 2018
• Deliver staff training
• Conduct awareness-raising talks
• Aim to tackle stigma, increase knowledge and encourage testing
Achievements so far

• **13** women trained to be peers – helps with rehabilitation by growing confidence and skills

• Hep Awareness Training delivered to **160** women and **72** staff

• P2P Talks delivered to **180** women
Good practice case study: Opt-out testing and the BBV service in HMP Barlinnie

Mary Mitchell – Clinical Manager, HMP Barlinnie
Brenda Bissett – Senior Addiction Nurse
Karen Cassells – HCSW
BBV’s in Prison

Mary Mitchell – Clinical Manager
Brenda Bissett- Senior Addiction Nurse- BBV
Karen Cassells- HCSW
Prison Healthcare

• Barlinnie built in 1872
• Built to hold 792 prisoners, optimal numbers are 1050- currently holds 1400 – most 1750
Historically

- Prisoners who were resident within prisons for a minimum of 9 months
- Referred to external BBV services (Brownlee) for all work up
- Exceptionally difficult due to unavailability of any joined up working – SPS vs NHS

• SLA developed between GG&C and HMP Barlinnie to manage services in-house
• Dedicated 2 nursing staff to develop a BBV service
• Increased the availability of testing for those with risk factors
• Developed nursing staff skills to manage treatments in house
• Complex due to venous testing only
BBV 2011- present

- NHS assume responsibility for PHC
- Increased Testing availability
- Team consists of 1 nurse and 1 Healthcare support worker
- Complete liver assessment bloods/fibroscans/work up for all positive diagnosis
- If not in custody: Liaise with GP’s, hospitals, community teams, other boards
- Arrange for vaccinations
- Arrange consultant clinics
- Support from 3rd Sector
Scottish Government Initiative

- Test all prisoners at point of admission – opt out testing
- Increase Testing
- Increase Positive Diagnosis Hep C
- Increase identifying HIV postive diagnosis in line with Glasgow outbreak
- Increase in Hep B positive diagnosis
- Increase in Treatments initiated/completed
- Better monitoring for end of treatment results

- Ability to link in with Sexual Health Services
Successes Of Hep C Services in HMP Barlinnie

😊 Numbers tested
😊 Introduction in DBS Testing
😊 Increase in +ve Hep C/B diagnosis
😊 Increase in +ve HIV diagnosis
😊 Numbers initiated into treatment
😊 ↑ numbers of SVR’s
😊 Staff development
😊 Cepheid Pilot
😊 Waverley Care
😊 Joined up working with Sexual Health Services
Our challenges

😊 Limited Resources
😊 Non engagement upon liberation
😊 Population
😊 Environmental Factors
😊 Lack of Understanding of prison
Increasing Treatment: Our Plans and Ideas

Introduction of Drug, Alcohol and Tobacco Strategy for 3 Glasgow Prisons

Outreach Support

One Team to support 3 Glasgow Prisons

Resources increased

Modern building to deliver modern healthcare
Healthcare links between prisons and the community in Glasgow

Claire Kofman
Senior Manager, Waverley Care
Healthcare links between prison and the community: an example from Glasgow

Claire Kofman, Senior Manager, Waverley Care
Background

Waverley Care is Scotland’s HIV and hepatitis C charity

19% of prisoners living with hepatitis C

Scottish Government’s Sexual Health and Blood Borne Virus Framework identifies testing in prisons as a priority

Need for service became evident from our existing service users:

- Lack of general support for prisoners upon liberation
- Prisoners lost to follow up when accessing hepatitis C specialist care in the community

www.waverleycare.org
Introduction to the Prison Link Work Project

- Funded by AbbVie
- Initially a pilot running out of HMP Barlinnie
- Project set up stage from October 2016 to January 2017
- Clinic set up in Barlinnie from February 2017 onwards
- Began work in HMP Low Moss in October 2017
- Currently speaking to HMP Low Moss about working there too

www.waverleycare.org
Aims of the Project

- Pre-release support working with the BBV Nursing Team and prison staff to identify individuals living with hepatitis C who are approaching liberation
- To provide education about BBVs to prisoners upon induction (specific to Low Moss)
- Support on release including meeting at the prison gates and then back into the community
- To work closely with community criminal justice agencies to identify individuals living with hepatitis C who have recently been released from prison
- To provide hepatitis C testing to individuals in criminal justice agencies

www.waverleycare.org
Outcomes for first year of the pilot

<table>
<thead>
<tr>
<th>Description</th>
<th>Number</th>
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<tbody>
<tr>
<td>Number of clinics attended at HMP Barlinnie</td>
<td>38</td>
</tr>
<tr>
<td>Number of people who have accessed the service in total</td>
<td>45</td>
</tr>
<tr>
<td>Number of these people who cleared Hep C during the reporting year</td>
<td>6</td>
</tr>
<tr>
<td>Number of Hepatitis C education/testing sessions delivered at criminal justice projects</td>
<td>12 (reaching 108 people)</td>
</tr>
<tr>
<td>Number of Hepatitis C and/or HIV tests conducted</td>
<td>45 (11 HCV positive, 5 HCV antibody positive, 0 HIV positive)</td>
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Linking prison and the community

- Prison Link Worker a central point of contact
- Specialist nurses both in the prisons and in the community aware of the project
- The ‘link’ element of the role can work both ways: linking people about to be liberated into the community but also linking people in the community into prison healthcare if they are detained
- Treatment regimens can be moved through this

www.waverleycare.org
Case studies

Roy, 45:
- Coinfected
- Referred whilst in prison
- Plan made for liberation as Roy was to be treated in the community
- Change of plan upon liberation due to drug misuse

James, 29:
- Treatment due to begin in the community
- DNA on day of treatment beginning due to return to prison
- Able to move treatment to prison from the community

www.waverleycare.org
Wider impact than hepatitis C healthcare

- 12% of interventions relate to something other than Hepatitis C
- 19% of the people we've worked with are living with both HIV and Hepatitis C. This is linked to a recent rise in HIV cases among people who inject drugs in the Glasgow area
- Healthcare often a low priority in general, rather than just hepatitis C
- Reducing poverty and isolation
Challenges

- The physical constraints of working in HMP Barlinnie
- Access to hepatitis C testing in HMP Low Moss
- Liberation to homelessness
- People returning to prison frequently
- Stigma – disengagement both in the community and in prison
- Contacting people once they have been liberated (and sometimes beforehand)

www.waverleycare.org
The future

- Year 3 of pilot
- Working in HMP Low Moss – currently group work but hoping to expand
- Group work in HMP Barlinnie?
- Partnership working
- Work in other areas

www.waverleycare.org
Patient perspective
The Story So Far
Background

• Active addiction / criminality for over 20 years

• Hepatitis C ......Didn't know what that was

• Got vaccinated in Glenochil 1994 (Hep B) thought that was for Hep C

• I thought I couldn't get it, I thought I was immune (Lack of knowledge)
Background

• 1990s HIV was prevalent... Harm reduction agenda
• Between mid 90s -2004 tested a few times
• I'm ok or I would know they would have told me?
• Hospital tested 3 times (Never told I was positive)
• I could have been and probably was infecting others
• Prison 2004  I still don't think I have it
• 2008 Marjory (Nurse)in prison tells me I have it
Treatment

Started Treatment in the prison: 2008/9

(Attitude towards treatment - didn’t care no i didn't have any visible side affects)

- In prison motivation/Incentive No work fruit supplied and most importantly 7.5mg Zopiclone supplied
- Side affects Weight loss, skin, rash, eye infections, sore stomachs
- I felt worth it as I got sleepers (Zopiclone)
- Partner also motivated her to access treatment in community
- Enclosed environment of prison helped me with treatment
My Recovery

• Accessed recovery for me NA CA (abstinence based)
• Changes support group met Billy/ADP (opportunities)
• Volunteering turning a negative in to a positive (Lived experience)

Paid Employment  6 hrs  16 hrs  35

• Further Education  both College and SVQ3 achieved in workplace
• Qualified Worker: I provide Assertive outreach in the community and my main emphasis is getting those most isolated to engage in support both for Hepatitis C and generic services
Prison work

• Genuine empathy....I was in prison with a lot of people who are still detained
• Work with TPS attend allocation meetings for prisoners with a BBV and or seeking recovery.
• Provide a through care service of connecting people with community services
• Facilitate a recovery meeting within the prison and provide a link to recovery services in the community
Now/future

- Abstinent nearly five years clean
- In a happy relationship

- Free from Hep C - no longer at risk

- Now employed and have been taken on as workers by statutory services where we used to be service users (a proud moment)

- Looking forward to life
Thank You