BVHG/BASL Best Practice for ODN stakeholders meeting

11–12 January 2018
The Britannia Country House Hotel, Didsbury
Welcome and introductions
Ahmed Elsharkawy and Matthew Cramp
Housekeeping

Switch phones to silent during the meeting

The meeting is being recorded to inform a post-meeting report

There is no planned fire alarm test today

See Cello Health at the registration desk for accommodation queries

Please complete the evaluation form, message card and action card at the end of the meeting
Objectives

Explore the critical challenges facing ODNs in England and discuss barriers and opportunities to overcome these issues

Share knowledge and best practice of excellence in ODN working – more importantly perhaps share what works and what does not work in delivering HCV services

Provide a platform for key ODN stakeholders to network and build good relations with peers and BVHG representatives

Discuss strategies to achieve HCV elimination targets
# Agenda – Day 1

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker/facilitator</th>
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<tbody>
<tr>
<td>13:30</td>
<td>Welcome and introductions</td>
<td>Ahmed Elsharkawy and Matthew Cramp</td>
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<tr>
<td></td>
<td><em>Perspectives on key challenges in the treatment and management of HCV</em></td>
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<tr>
<td>13:35</td>
<td>State of the nation</td>
<td>Graham Foster</td>
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<tr>
<td>13:45</td>
<td>Hub perspective: Key challenges</td>
<td>Mark Aldersley</td>
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<tr>
<td>14:00</td>
<td>Spoke perspective: Key challenges</td>
<td>Adam Lawson</td>
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<td>14:15</td>
<td>Pharmacy perspective: Current challenges in HCV treatment</td>
<td>Adele Torkington</td>
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<td>14:30</td>
<td>Nursing perspective: Treating an increasing challenging population</td>
<td>Janet Catt</td>
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<td>14:45</td>
<td>Drug and Alcohol Perspective: Barriers to HCV delivery</td>
<td>Stacey Smith</td>
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<td>15:00</td>
<td>Peer support</td>
<td>Stuart Smith</td>
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<tr>
<td>15:15</td>
<td>Panel discussion</td>
<td>Session speakers (Chairs: Ahmed Elsharkawy and Matthew Cramp)</td>
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<tr>
<td>15:35–16:05</td>
<td>Break</td>
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## Agenda – Day 1

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<tbody>
<tr>
<td>16:05</td>
<td><strong>Viral hepatitis elimination</strong></td>
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<td>PWIDS in Scotland</td>
<td>Jan Tait</td>
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<td>The lost positives: How to find and engage lost positives</td>
<td>Stuart McPherson</td>
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<td>Community HCV models: Engaging the disengaged</td>
<td>Sumita Verma</td>
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<td>Isle of Wight experience</td>
<td>Ryan Buchanan</td>
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<td>Manchester elimination plans</td>
<td>Andy Ustianowski</td>
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<tr>
<td></td>
<td>Measuring patient outcomes and experience</td>
<td>Charles Gore</td>
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<tr>
<td>17:20</td>
<td>Panel discussion</td>
<td>Session speakers (Chairs: Will Gelson and Mark Wright)</td>
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<tr>
<td>17:40</td>
<td>Day 1: Summary</td>
<td>Ahmed Elsharkawy and Matthew Cramp</td>
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<tr>
<td>18:00</td>
<td>Meeting close</td>
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<tr>
<td>18:30</td>
<td>Poster presentation, dinner and networking</td>
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State of the nation
(Networks today and tomorrow)

Graham R Foster
Professor of Hepatology
QMUL/Barts Liver Centre
Where we started
Where we started

• Idiosyncratic national service
• (Some good bits, some bad)

• No monitoring, planning, oversight

• Therapy depended on where you lived
Where we started
The first two years

- Clearing the site
- Setting up a national service with allocation of treatment slots by local need
- Getting drug prices to a sensible level
Clearing the site
Early planting

• Early access programme for decompensated cirrhosis (NOT supported by NICE)

• ‘Run-rate’ in line with NICE prioritisation ruling

• Focus on cirrhosis
Impact of therapy on mortality

Deaths from HCV or HCC in patients with HCV (PHE report on HCV 2016)

Transplants for HCV
Information

• Data is key to clearing HCV

• We need to know about who needs what to expand (help with prisons, drug services, etc)

• We need to know which areas are undertreating, which prisons are underserved, which addiction centres are failing etc etc
Information transfer

![Graph showing information transfer comparison between plan and actual with summary of YTD plan and actual for 2017/18. The graph displays months from April to March with a vertical axis representing the value in increments of 2000, ranging from 0 to 14000. The blue bars represent the plan while the red bars represent the actual. The summary for YTD plan and actual is also shown.]
The Registry

Total no. of patients shown on the registry (manual + imported)
The Registry

- The registry is now signed off – regular reports will be available online shortly……

- PHE have agreed to supply details of ‘previously diagnosed’ patients

- Tells us what more you want
What next?

- Now we have cleared the ground what do we plant?
What next?

• Now we have cleared the ground what do we plant

• We need to go for transmitters and those at risk – PWIDs, prisoners, infected in the 70s
What we need?

We need:

• Unlimited treatment capacity
• Reduced obligatory testing
• Engagement with related services
• Help finding patients
What we need?

We need:

• Unlimited treatment capacity
• Reduced obligatory testing
• Engagement with related services
• Help finding patients

• We don’t need choice of drug
Lord O’Shaughnessy 9 Jan 2018:
(Under Secretary of State for Health)

Launched first step of the new HCV procurement process inviting industry to show support

Aim is to eliminate HCV with a long-term partnership with industry

Support is contingent upon pharma working with us on a new, better deal
Getting what we need?
‘Australia +’

• The Australia deal will not work for us

• Our problem is undiagnosed patients NOT untreated patients

• We are asking for deals that incentivise pharma to help us case find
Going Forward

Please:-
• Engage with your drug services, prisons etc
• Engage with industry – tell them what you need
• Tell us what you need us to do to help
• Play for Team NHS
Towards Elimination

• We (NHSE and ODNs) have prepared the plot

• We have harvested the early stuff

• Now lets go and harvest the rest
Far, far better than the Australians
Hub perspective: Key challenges

Mark A Aldersley
West Yorkshire HCV ODN Clinical Lead
Geography/Structure
Challenges

- Other Secondary Care Centres
- GU Medicine Centres
- Community Drug Treatment Centres
- Primary Care Centres
- Prisons
- Access to Testing
- Financial
- Geographic
- ODN Lead Clinician
Other Secondary Care Centres

- Motivation
- Staffing (nursing and medical)
- Resourcing appropriately
- Loss of autonomy
- Loss of income
- Performing time-consuming tasks eg 12 month post treatment PCR with no reason/benefit for anyone
GU Medicine Centres

- Tendering of services
- Integration of treatment
- Space
- Loss of autonomy
Community Drug Treatment Centres

• Short-term tendering for services
• Staffing levels
• Staff turnover
• Training
• Space availability competing services
Primary Care Centres

- Some GP practices very motivated, others little interest
- Public Health perspective
- Most have space
- Convenient but attendance still variable
Prisons

- Tendering for services by healthcare providers
- Staffing of BBV nurses/healthcare
- Governor Priorities other than HCV
- Training
- Access
Access to Testing

• Drug treatment centres/pharmacies/primary care
• New GP registrations
• Emergency Department
• Immigration Centres
• Community Centres
• Funding? Short-term drug tendering makes pharma reluctant to fund
Financial

• What is a CQUIN?
• Use to motivate other secondary care centres?
• Loss of income if treatment devolved to larger centres
Geographic

- Some ODNs have huge geographical distances to cover
- Moving staff around inefficient and moving the patients impractical as try to treat patients who do not wish to attend hospital
- Pharmacy-who pays?
- GPs – only small numbers motivated
ODN Lead Clinician

• Public Health Training
ODN Lead Clinician

- Public Health Training
- Time provision
- Clerical/Administrative Support
Conclusion

• Elimination strategy with no funding other than for the drugs
• The clinicians leading it have no training in the field
• Unable to provide resource to spokes or community based programmes
• Who is responsible for the massive increase in testing required to achieve elimination?
Spoke perspective: Key challenges

Adam Lawson
Consultant Hepatologist, Royal Derby Hospital
Challenges

• Find, keep, treat (eradicate)

• Working within the ODN structure
2014

Looks like we are finally going to have some new treatments for HCV

2015

Bit of form filling (A1 – F), an MDT to phone into and some "buddy" stuff, but you can start treating your sickest patients on EAP now

EAP finished, but NHSE have announced bds for ODNs to deliver new HCV drugs. Sounds like the liver plan reshaped for HCV, but you need to be in it to win it

I thought the new drugs were meant to make it easier. Why put the decision making in hospitals, where the patients never turn up?

Phew, just met the deadline for getting all those submission docs in for Derbyshire/Staffordshire ODN expression of interest

Oh you can’t apply, you’re not a HPB cancer centre

What’s that got to do with treating HCV 😳 😩

2016

Despite run rate, have cleared waiting list. Phoning into ODN MDT a pain though

Get the nurses to do it, even better get hub to use CQUIN to pay for new nurse to do it

2017

Still not got new nurse. Trust don’t believe another hospital paying.

Need to start finding more patients, but can probably live with this ODN stuff

That’s fortunate, because they’re rolling it out for PBC and obeticholic acid

And any new HBV drugs will be next
Derby
Dr Adam Lawson
Dr Andy Austin
Dr Nick Taylor
Dr Evi Mandalou
Michele Jackson
Gillian Wilkinson
Local MDT ✓
Category B prison – inreach ✓
Women closed prison – inreach ✓
Fibroscan 430 mini

Lincoln
Dr Aravamuthan Sreedhavan
Dr Rashaad Gossiel
Karen Murray
Local MDT ✓
Category B prison – inreach ✓
Fibroscan 430 mini

Boston
Dr Sanjiv Jain
Maxine Myers – 15hrs
Local MDT ✓
Category D prison – inreach ×
Fibroscan ×

Nottingham
Dr Steve Ryder (ODN lead)
Dr Brian Thomson
Dr Emile Wilkes
Dr M James (Clinic in Grantham)
3 WTE viral nurse specialists (Kate, Sherelle, Liz, Jasmina)
ODN MDT ✓
2 x Category B and 1 x Category C prison – inreach ✓
Fibroscan ✓

Teleconference ODN MDT
Thurs 13.00
Different spokes

<table>
<thead>
<tr>
<th>Location</th>
<th>Clinicians</th>
<th>Nurses</th>
<th>Qtr 4 2016/17 to end</th>
<th>Qtr 3 2016/17 treated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Derby</td>
<td>4</td>
<td>2</td>
<td></td>
<td>86* patients</td>
</tr>
<tr>
<td>Boston</td>
<td>1</td>
<td>1</td>
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Different spokes

HMP Foston
HMP Dovegate
Ripley
Ilkeston
Burton
Swadlincote

Lincoln
Boston

Tamworth + Lichfield
Geography – CCGs and ODNs

South Derbyshire Improving Pathways Task and Finish Group

2nd November 2017

1. Welcome and Introductions
   - Iain Little, Consultant in Public Health, Derbyshire County Council (Chair)
   - Michele Jackson, Nurse Specialist, Royal Derby Hospitals
   - Gillian Wilkinson, Nurse Specialist, Royal Derby Hospitals
   - Dr Adam Lawson, Consultant Hepatologist and Gastroenterologist, Royal Derby Hospitals
   - Breanne Dills, ODN Manager
   - Nik Hewes, Commissioning Manager Substance Misuse, Derbyshire County Council
   - Jane Carroll, Senior Public Health Manager, Derbyshire County Council
   - Jo Seekings, Commissioning Manager, Derby City Council
   - Heather Walker, Service Manager, Derbyshire Healthcare Foundation Trust
   - Linda Drew, Public Health Manager, Derbyshire County and City Council

2. Apologies
   - Barry O’Neill, Service Specialist, Specialised Commissioning NHS England
   - Dr Steve Ryder, ODN Lead and Consultant Hepatologist and Gastroenterologist, Nottingham University Hospitals
   - Martin Smith, Recovery Lead, Derbyshire Healthcare Nhs Foundation Trust
   - Yvonne Bell, Senior Harm Reduction Nurse, St Andrews House

Top/down – back to front?
The view of ODNs from the spoke

Pros

- Driven local good practice – more formal, well documented local MDT
- Sharing good practice – Network of colleagues whose experience you can draw on (though this preceded ODN)
- Access to trials
- Sharing of resources? – nurses/fibroscan (Boston to Nottingham 120 mile round trip)
- Small volume centres able to continue to see patients locally with ODN support
- The potential for CQUIN targets to act as a lever in engaging with commissioners/laboratory/GPs etc
The view of ODNs from the spoke in the wheel

Cons

• Additional layer of bureaucracy – missing that one opportunity. Lack of flexibility – see patient, bluteq, prescribe, treat

• Cost of managing the bureaucracy – ODN managers, MDT coordinators; ? Better spent on frontline staff

• Inefficiency – telephone ODN MDT “very difficult to hear and feel engaged in conversation” “just reading off a list” – that has already been emailed

• Centralising services – is there any longer a reason why a HCV infected patient need visit a hospital?

• Target culture – email traffic at end of each QTR

• Viral hepatitis nurses filling in spreadsheets rather than seeing patients
## What do spokes want from ...  

<table>
<thead>
<tr>
<th>Hub</th>
<th>NHSE</th>
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<tr>
<td>• Day to day light touch/ no touch</td>
<td>• End to treatment numbers – treatment to who needs it and when they are ready (including ability to see and treat pre MDT if 1st line choice and straightforward)</td>
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<tr>
<td>• Continued sharing of experience/ national agendas</td>
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<tr>
<td>• Transparency re CQUIN</td>
<td>• Feedback on the use of all the data trusts are sending</td>
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Summary: Challenge 1

**Prisons** – Timing of opt out testing, retention of medical centre staff

Can identify patients in **DTCs**, but retention for long enough to treat difficult

Find, **Keep**, Treat, eradicate

On the back of **HIV** testing in ED (Derby > 2/1000 prevalence)

Reducing delays between seeing and treating. Waive need for MDT decision in straightforward cases – ie almost all

Improve delivery times and dispensing closer to patient
Summary: Challenge 2

Working within ODN structure

- Should not be one size fits all
- Transparency re CQUIN. ODN “accounts”
- Make primary concern of ODN the adoption of good practice/elimination strategies

Reduce duplication of effort. ODN MDT for non 1st line Rx/difficult cases only. Scrap buddy system

Challenge NHSE re output from data being submitted

Avoid the reflex to make ODNs the blueprint for use of all high cost drugs. Take in to account unseen staff costs
Pharmacy perspective: Current challenges in HCV treatment

Adele Torkington
Current Challenges
• NHSE
• CQUIN
• Cost of regimens
• Patient cohort
• Run rates
• Rate cards
• Spreadsheets
• Transport/logistics for community clinics
The Community Pharmacy Model
Current community model

Hep Clinic staff see patient in drug services/prison and prescribe medicines

Hospital pharmacy/Outsourced pharmacy supply medication and transport to clinic. Clinic staff need to store medication as per hospital standards

If a patient does not start treatment, most hospital pharmacies will not return medication
Payment for outsourced/homecare

Outsourced pharmacy buys drug

Outsourced pharmacy asks NHS hospital for payment

Hospital pays outsourced pharmacy

Hospital asks NHSE for money as part of monthly drug returns

NHSE pays hospital
Current Opportunities
• CQUIN – funding for pharmacists
• Potential for future savings
• Finding the undiagnosed
• Treating the DNAers
• Eradication
• Pharma projects and education
• DOT in the community
• Online community of pharmacists
Future community model

Community Pharmacist tests for HCV

Community Pharmacist gives a positive result/liaises with ODN and provides HCV treatment off the shelf and supervises consumption
Current logistical issues

- Community pharmacy buys drug
- Community pharmacy asks NHS hospital for payment
- Hospital pays community pharmacy
- Hospital asks NHSE for money as part of monthly drug returns
- NHSE pays hospital
Preferred community model

1. Community pharmacy buys drug
2. Community pharmacy asks for payment
3. Hospital pays community pharmacy
4. Hospital asks NHSE for money as part of monthly drug returns
5. NHSE pays hospital
Any questions?
Nursing perspective: Treating an increasing challenging population

Janet Catt MSc RN, Nurse Consultant
and
Chris Laker, Hep C Peer support
“Follow me” South Thames project

• Develop a network of Peers that will reach into the community of PWIDs across the South Thames local area

• Peers will use their own story

• “Buddy” support, in particular to newly diagnosed people and those accessing treatment

• Patients known to local drugs services/hostels that have previously tested HCV+ and have disengaged will be linked to the Peers

• Peers will have the ability to make direct referrals to clinic

• (Pharmacy project now referring directly into the clinic – incentivised project)
Patient cohort

• Small number of patients so far – but the “word is out”!! – especially “quick to treat” AND NO injections

• Three patients in Rehab – x1 discharged day before starting treatment due to using Heroin

  He re-engaged, started treatment and now in Rehab in South West England

• x1 living with partner and on Methadone – engaged with drugs services, but not wanting to be treated there

• x4 living in Hostels (x2 significant mental health problems – CPN)

• Other health issues: x2 cirrhosis; x1 sickle cell anaemia; x1 hard of hearing
Referral process

• Friday morning clinic at Kings college Hospital – commenced end of October 2017

• Chris will telephone to refer and confirm via email details of patient: Name, DOB, NHS (if known), address (x1 has been arranged one day before appointment)

• Admin will be contacted to book appointment

• Nurse will confirm appointment time with Chris – not rigid!!

• Clinic: Bloods performed/Fibroscan – explain to patient MDT process and treatment regimens

• Treatment start dates one week or two weeks – Chris notified and will text remind patient OR attend clinic with them
Hospital clinic

Genotype

Average Fibroscan
Cirrhotic 27.5 kPa
Non-Cirrhotic 5.8 kPa

5 of 8
Commenced treatment
x3 To commence 19th January 2018
Drug and Alcohol Perspective: Barriers to HCV delivery

Stacey Smith
Perspective of drug services

The treatment landscape has significantly improved for drug users infected with hepatitis C. We believe in an holistic approach to treating substance misuse and there is a strong drive to lower the mortality rate

• Recognise that they hold a high risk cohort
• CGL treated around 60,000 drug users in 2016
• Have a comprehensive case management system so it can identify service users who could be infected
• DBST is measured within projects
• Strong service user and peer mentor network
Delivery in drug and alcohol service

• Screening (Identification & Diagnosis) – DBST and delivery of test result
• Prevention – harm reduction, needle exchange
• Treatment – proactive partnerships
• Development of evidence based models – mobile, on site, specialist pathway and internal provision
• Partnerships – Hep C Trust, NHS, Service User Groups
Critical challenges and barriers

• Disparity on the role of Drug and Alcohol in Hep C treatment
• Funding for DBST and the need to retest
• Historical data – clients that have been sitting in services for long periods
• Ineffective models and dysfunctional pathways
• Cultures within services not seeing Hep C as a crucial intervention
• Service Users unaware of new treatments and still holding fears and concerns around previous treatment
PWIDs in Scotland

Jan Tait
Lead Clinical Nurse Specialist
Scotland and Tayside HCV statistics

- Population of 5,295,000 (2011 Census)
- 0.8–1% of population HCV positive
- 50,000 antibody positive (38,000 chronic infections)
- 90% of new HCV transmissions are in people who inject drugs (PWID)
- 1 of 14 regions of NHS Scotland. Covers 3 distinct geographical areas: Dundee City, Angus and Perth & Kinross
- Higher proportion of drug related health issues in comparison to Scottish average

http://www.hps.scot.nhs.uk/bbvsti/wrdetail.aspx?id=73581&wrtype=6#
Scottish Hepatitis C Action Plan

• Aims:
  • To prevent spread of hepatitis C, particularly among intravenous drug users
  • To diagnose hepatitis C infected people, particularly those who would most benefit from treatment.
  • To ensure that those infected receive optimal treatment, care and support
• 2006: Launch of Scotland’s Hepatitis C Action Plan Phase I: Development of a case for investment in Hepatitis C service provision
• 2008: Launch of Scotland’s Hepatitis C Action Plan Phase II: Investment of £43 million for Hepatitis C prevention, diagnosis and care services during 2008–11
• 2011: Launch of Scotland’s Sexual Health & Bloodborne Virus Framework (Phase I) incorporating continued investment in Hepatitis C services
What were the challenges pre action plan?

• 90% of individuals will be previous or current drug users

• 50% of diagnosed patients in 5th quintile (most deprived)

• Liver related deaths increasing per year, increasing admissions to hospital and hospital stay

• Lack of diagnosis, care and treatment
  • 14,500 diagnosed (38%)
  • 3,500 accessed care (9%)
  • 450 started on treatment per year (1%)
HPS: HCV database 2015

- **all records:** 23613
- **all attended:** 18046
- **treatment episodes:** 8399
- **treatment episodes resulting in SVR:** 4519
- **diagnosed with cirrhosis:** 2984
- **diagnosed with DC:** 700
- **diagnosed with HCC:** 328

http://www.hps.scot.nhs.uk/bbvsti/wrdetail.aspx?id=73581&wrtype=6#
Tayside HCV Managed Care Network 2004

- Formed in 2004 by Professor John Dillon
- Included:
  - Consultants and medical staff
  - Specialist nurses
  - Virologists
  - Pharmacists
  - General Practitioners
  - Drug Workers
  - Social Workers
  - Prison nurses

- To increase the number of people diagnosed with hepatitis C infected people
- Improve the number of people accessing treatment
- To ensure that those infected receive optimal treatment, care and support and increase the numbers achieving SVR
- To prevent spread of hepatitis C, particularly among intravenous drug users
Interventions and outcomes

- Introduced outreach clinics throughout region and increased specialist nursing input
- Open referral pathway
- Nurse led pathways
- Dried Blood spot testing introduced in 2009
- Routine blood tests in drug services
  - 2003 = 1235 tested, 2015 = 3512 tested
- Access to care
  - 2003 = 264 attended clinic, 2015 = 1917 attended clinic
- Treatment given in outreach clinics (including HMP)
  - 2003 = 100 treated, 2015 = 1100 treated
- SVRs
  - 2003 = 49, 2015 = 702
Status in 2014–2015

- Despite increase in needle exchange facilities and equipment new infections are still occurring
- Re-infection is occurring (PCR negative and SVRs)
- Significant number of PWIDs are still not been treated and cured
  - Not attended clinic
  - Attended but unable to complete assessment (ultrasounds, fibroscans, medical follow up
  - Constant cycle in and out of care
  - Treatment side effects
  - No treatment for current injecting drug users

WE HAVE TREATED THE EASY ONES
Purpose of current treatment and care pathways

- Prevention of Liver failure and HCC
- Treatment of symptoms
- So a perpetual program of treatment

- *Unless*...
  - Improved prevention
    - NSP & OST not enough
  - Treatment as Prevention
  - The Elimination agenda
The road to elimination: Epitope and E-rapid

- We will treat 300 to 500 PWID in two years
- Which is projected to reduce chronic HCV prevalence from 29% to 10% (65% reduction)
- This should reduce HCV incidence from 5% to 1.6%

Unpublished data
The first requirement of elimination

Survival HCV free in a needle exchange: the unexpected benefits!

- Treat everyone
- Find the patients
- Have easy diagnostic tests
- Develop easy pathways of care
- Make treatment uncomplicated
NHS Tayside HCV database
All positive HCV antibody tests
Have easy diagnostic tests

• Conventional testing with elution step
• HCV ab, HIV ab
• HCV-PCR & HBsAg
• Works where venepuncture difficult

• Over 170 staff trained in Blood spot testing, mainly 3rd sector
• HCV testing embedded in
  • Drug problem centres
  • Drug Testing and Treatment Order
  • Homeless outreach,
  • Social work departments,
  • Criminal Justice, Prisons
  • Minor injury units
  • Needle exchanges
• 81% of tests are carried out by support workers, without clinical qualifications

If you can test or read a test result you can refer
Treat everyone

- Engage PWID at needle exchange centres in Tayside
- Incentivise suitable participants to comply with treatment
- 42 months project; 105/125 eligible patients agreed to participate
- All treated within first 24 months

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<tr>
<th>Data</th>
<th>Genotype 1</th>
<th>Genotype 2 and 3</th>
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<tr>
<td>SVR12 (%)</td>
<td>88</td>
<td>93</td>
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<tr>
<td>Consented</td>
<td>105</td>
<td></td>
</tr>
<tr>
<td>Received treatment</td>
<td>94</td>
<td></td>
</tr>
<tr>
<td>Spontaneous resolver</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Lost to follow-up</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Stabilised drug use</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Died prior to treatment</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Prison prior to treatment</td>
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Dillon JF. Unpublished data

- SVR12: sustained virological response 12 weeks after the end of treatment
## DOT-C: A pilot cluster randomised controlled trial
### HCV testing and treatment in 8 community pharmacies

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<th>Pharmacist-led</th>
<th>Patient cohort 285 tested</th>
<th>Standard of care</th>
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<tr>
<td>89 DBST</td>
<td>63 DBST</td>
<td></td>
</tr>
<tr>
<td>29 reactive tests</td>
<td>11 reactive tests</td>
<td></td>
</tr>
<tr>
<td>3 treated</td>
<td>1 treated</td>
<td></td>
</tr>
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Radley A, et al. Unpublished data (manuscript under review)
What do we need for treatment?
New nurse led prescribing pathway

Patient attend nurse led clinic

Bloods taken for full liver screen, Fib 4 score, medical and drug history

If Fib4 score more than 1.45 or less than 3.25 discuss at MDT. May need fibroscan and/or ultrasound

If Fib 4 score more than 3.25 arrange ultrasound and review at medical clinic

Prescribe and start treatment in community pharmacy

Take HCV PCR 3 months post treatment

Arrange to review patient based on clinical need
HCV testing and treatment pathways for the PWID and OST populations

Standard HCV testing and treatment to all at risk of HCV

Primary/secondary care

At risk patients offered venous blood test by physician

HCV therapy provided in secondary care by specialist nurse-led clinics in 1 hospital and 18 outreach clinics

Enhanced HCV testing and treatment service targeting PWID

Pharmacies

OST clients offered DBS test by pharmacist

HCV therapy provided by specialist nurse-led or pharmacist-led clinics

Drug treatment centres

OST clients offered DBS test by trained addiction worker

HCV therapy provided by specialist nurse-led clinics

Prisons

Prisoners offered POC test on admission by prison nurse

HCV therapy provided by specialist nurse-led clinics

Needle exchange

Clients offered DBS test by trained needle exchange staff

HCV therapy provided by specialist nurse-led clinics at the 4 fixed site needle exchange sites

PWID defined as those who either (a) are currently injecting drugs, (b) have ever injected drugs and are currently on opioid substitute therapy, or (c) have ever injected drugs and are currently in prison

DBS: dried blood spot; OST: opioid substitution therapies; POC: point of care; PWID: people who inject drugs
Summary and learning: Elimination of HCV

• Have the data or start collecting the data
• Treat everyone, including re-infections
• Have easy diagnostic tests
  • Dry blood spot tests kits, oral swabs, etc
• Find the patients
  • Embed routine HCV testing within all drug services (OST clinics and Needle exchange and community pharmacies)
  • Opt-out testing for prisoners
• Develop easy pathways of care
  • Stop doing unnecessary tests and investigations
• Make treatment uncomplicated
  • Provide treatment daily in pharmacies with OST
  • Provide treatment in needle exchange centres
  • Provide treatment in prisons
THANKS FOR YOUR ATTENTION

jantait@nhs.net
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Engaging the “lost” hepatitis C positives in treatment?

Dr Stuart McPherson
Consultant Hepatologist
Liver Unit, Freeman Hospital, Newcastle
Introduction

PWID
In England 50% of people who inject drugs (PWID) are thought to be infected. 16% of PWID share needles.

81,000
F0-F2
About 20% have symptoms related to HCV

Cirrhosis
3,500 prevalence
NHS England Clinical Policy from May 2015

End Stage Liver Disease
2015 prevalence. 1,000 treated per year
NHS England Clinical Policy from April 2014

Risk in numbers as we do not know how many of prevalence will come forward

Advanced Fibrosis
1,650 from this group develop cirrhosis each year.
NICE TA for oral drugs for all this group

NICE oral drug access if GT1. GT3 access if interferon based treatments have failed

10,20,000 expected to come forward for treatment each year

Many patients won’t come forward because they don’t access healthcare with chaotic lives. Some in this group are most likely to cause cross infection

Blood products

13,000
F3
20-30% will develop cirrhosis over 20 years

3,471
F4

67,000
Don’t know they have HCV

GT3
44%
4 main genotypes of HCV

GT1
47%
All F3/F4 patients have access to new drugs.

GT2
All this group have access to new drugs regardless of disease severity

Public Health England focus on increased testing, opt out testing in prisons. Strategies to reduce transmission

From Feb 2016

A1
The North East and North Cumbria

Newcastle Upon Tyne Hospitals NHS Trust
  Freeman
  RVI
  Outreach
  Prison (Northumberland and Durham)

James Cook University Hospital
  JCUH
  Prison (Teesside)
  Outreach

Sunderland Hospitals NHS trust

Queen Elizabeth Hospital, Gateshead
  Outreach

North Cumbria Hospitals
  Carlisle
  Whitehaven
Estimated burden in the North East

9000 HCV antibody positive (0.35%)

Of which

6500 HCV RNA positive

Of whom

60% estimated already diagnosed

42% current people who inject drugs

42% previously used drugs (no longer inject)

16% never injected drugs (1/3 of whom are from South Asia)

Newcastle and North of Tyne region

HCV Ab +VE  n=286

- HCV RNA –VE  n=71 (25%)
- HCV RNA +VE  n=192 (67%)
- HCV RNA Not Done  n=23 (8%)

HCV RNA +ve referred  n=169 (88%)

Started treatment  n=80  (47% of ref pts)

Treatment outcomes:
- SVR =53
  - 31% of ref pts,
  - 66% of started pts
- Treatment on-going = 2
- Non-responder = 13
- Non-compliance/lost to FU = 9
- Stopped side-effects = 3

2011–2
Newcastle and North of Tyne region

HCV Ab +VE
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HCV RNA Not Done
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Started treatment
n=80  (47% of ref pts)

NOT started treatment
n=89 (53% of ref pts)

Treatment outcomes:
▪ SVR =53
  - 31% of ref pts,
  - 66% of started pts
▪ Treatment on-going = 2
▪ Non-responder = 13
▪ Non-compliance/lost to FU = 9
▪ Stopped side-effects = 3

Reasons for not starting treatment:
▪ DNA >2 appointments = 47
  (28% of ref pts)
▪ Delay treatment – patient = 23
▪ Consultant concerns - compliance = 4
▪ Contraindications = 12
▪ Spontaneous clearance = 2

2011–2
Could we find the patients not attending the clinic?

89 Patients

4 (4.5%) patients deceased
8 (9%) couldn't contact GP

Letter sent to GP of 77 Patients

15 HCV Ab POS
No RNA tested
- 4 responses received
- No referrals received

18 HCV RNA POS
Not referred
- 6 responses received

44 HCV RNA POS
DNA CLINIC + DISCHARGED
- 8 responses received
- 4 referrals received

4 responses received
No referrals received
2 referrals received

Overall 8% (6/77) of letters led to referral
Response from GP in 24 (31%) patients
Conclusions from this review

• Reasonable rate of referral in Newcastle

• Major reason for non-treatment was non-attendance (28%)

• Only 8% of the “lost” positives were brought back into the service with a letter to the GP

• Lots of problems with this approach
  • Single letter to GP inadequate
  • Trying to track patients down 3 years later
  • Only looking at a small part of our ODN – may not be representative of the whole network
Mapping of untreated HCV in the North East of England

• Overall aim was to find out where all known but untreated HCV was in the region to help strategically set up HCV treatment services

• To track down known cases of HCV to try and engage or re-engage them in treatment services
Methodology

• All HCV infections reported from 1997-2016 in NEE were identified from PHE North East surveillance data (all reported HCV infections (Ab, Ag and PCR)

• Treatment outcome data was provided for patients treated at hospitals in the North East and Cumbria ODN from 2007-2016

• Epidemiologist “fuzzy matched” cases from surveillance and treatment outcome datasets using string distance algorithms

• Individuals from the surveillance cohort who were not matched to treated cases were classified as “untreated”

• Postcodes of residence for treated and untreated individuals were geocoded and integrated in a geographical information system with existing HCV treatment services and other drug and alcohol services (considered alternative treatment locations)
• 4243 reported HCV cases were identified.
• 858 (20%) were matched and had been treated,
• 3385 (80%) cases were untreated.
Map of untreated cases

Currently 45% of untreated cases are 5km from a treatment service

If all drug services used this can increase to 70%

Figure 1

- Untreated cases
- Rate of untreated cases*
  - Current treatment services
    - Drug/alcohol treatment centre
    - Secondary Care treatment hubs
  - Other Services
    - Drug/alcohol treatment centre

*Number of cases reported to PHE North East per year from 1997-2016, per 10,000 population
Problems with this approach

- Only 27% of individuals on the surveillance database were known HCV Ag or PCR pos so some spontaneous clearers are called “untreated”

- Unknown outcome from treatment patients were considered as “untreated”

- Individuals move in and out of the region

- Five prisons on our patch can complicate mapping

- Undiagnosed cases can’t be mapped
How are we using this data?

• Expanded outreach approx. 15 locations in region

• PHE supplied details of all “untreated” individuals to our ODN

• Employed two hepatology assistants who are trying to engage these patients and get them back into care
  • 3800 to try and track!
  • Now established monthly reporting from Trust/PHE lab of all new cases to the hepatology assistants to track cases
Information received from Virology Labs

Use Summary care/Mermaid, E-record to filter out the deceased patients, treatment responders and those on treatment

Use Summary Care to access up to date contact patient information. Patients remaining should be cross referenced against E-record and referral databases to establish if they are aware of their diagnosis

Patient aware of their diagnosis who have previously DNA'd/lost to follow up and have a pathway can be contacted and re-appointed once contact details have been confirmed. Appt. slots can be reserved.

Patients who are unaware of their diagnosis should NOT be contacted directly. Contact should be made with their GP/DTC for discussion with the patient – follow up after duration of time and then if diagnosis awareness is confirmed the patient can be contacted and appt slot reserved and confirmed when referral received
What happened to the 2016 new HCV diagnoses in NE England?

214 HCV Ab pos

36 (17%) Spont Clearance

178 RNA/Ag pos

7 (4%) Died

113 (63%) referred

64 (36%) been through MDT

58 (33%) not referred

49 (27%) in work up or DNA
Treatment rates by postcode

Durham (n=25)
- MDT: 40%
- Spont Clear: 16%
- Work up: 4%
- Not referred: 36%
- Died: 4%

Darlington (n=36)
- MDT: 27%
- Spont Clear: 12%
- Work up: 40%
- Not referred: 21%
- Died: 0%

Sunderland (n=23)
- MDT: 22%
- Spont Clear: 31%
- Work up: 26%
- Not referred: 17%
- Died: 4%

Newcastle (n=70)
- MDT: 43%
- Spont Clear: 17%
- Work up: 28%
- Not referred: 6%
- Died: 6%

Teesside (n=61)
- MDT: 15%
- Spont Clear: 56%
- Work up: 18%
- Not referred: 0%
- Died: 0%
Conclusions

• Approx. 100,000 individuals have been diagnosed with HCV in England
• The majority have not been treated and a large proportion have been lost to follow up
• Mapping untreated HCV can help strategically design treatment services
• Tracking known HCV positive individuals to engage them in treatment using PHE records is likely to be a cost-effective method or increasing treatment rates
Acknowledgments

Hope Simpson
Sarah Welsh
Ashley Young
Trevor Croft
Dr Manoj Valappil
Dr Ashley Price
Dr Mathias Schmid
Dr Steve Masson
Carolyn Miller
Emma Robinson
Tina Young

Brendan McCarron
Jane Knowles
Margaret Hewett
Harriet Mitchison
Julie Walker
Community HCV models: Engaging the Disengaged

Sumita Verma
Reader in Medicine, BSMS
Hon Consultant Hepatology, BSUH
Estimated Global Number of Deaths Due to Viral Hepatitis, HIV, Malaria and TB (2000–2015)

Deaths (millions)


Hepatitis HIV Malaria TB

HCV Treatment in People who Inject Drugs (PWID)

Data
- No scale up from baseline (3 per 1000 PWID annually)
- Scale up 10 per 1000 PWID annually
- Scale up 20 per 1000 PWID annually
- Scale up 40 per 1000 PWID annually
- Scale up 80 per 1000 PWID annually

More cost effective to treat PWID

- Moderate fibrosis mean net monetary benefit (MMB) if early treatment: £60,640 and £23,968 at 20% and 40% HCV prevalence
- Mild fibrosis NMB £59,258 and £19,421 respectively

Prioritisation of HCV Treatment Amongst PWID

PS-129
Treatment as prevention for hepatitis C in Iceland (TRAP HEP C).
A real-world experience from a nationwide elimination program using direct acting antiviral agents
S. Olafsson¹,², T. Tyrkingsson³, V. Runarsdottir³, O.M. Bergmann¹, E.S. Björnsson¹,², B. Johannsson⁴, B. Sigurdardottir⁴, R.H. Fridriksdottir¹, A. Löve²,⁵, T.J. Löve²,⁶, G. Sigmundsdottir⁷, M. Heimisdottir²,⁸, M. Gottfredsson²,⁴,⁶ and the TRAP HEP C Working Group. ¹Gastroenterology and Hepatology, Landspitali University Hospital; ²Faculty of Medicine, School of Health Sciences, University of Iceland; ³Vogur Addiction Treatment Center; ⁴Infectious Diseases; ⁵Virology; ⁶Department of Science, Landspitali University Hospital; ⁷State Epidemiologist, Directorate of Health; ⁸Department of Finance, Landspitali University Hospital, Reykavik, Iceland
E-mail: sigurdol@landspitali.is

## Trying to Engage PWID

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<tr>
<td>73 with positive BBV screen</td>
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<td>• 14 (19%) known to Hepatology services – 2 (3%) treated</td>
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<table>
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<tr>
<th>40 eligible for HCV treatment</th>
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<tr>
<td>• 8 (20%) accepted referral</td>
</tr>
<tr>
<td>• 2 (5%) attended, none treated !!</td>
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**Gender Differences in Hepatitis C Seroprevalence and Suboptimal Vaccination and Hepatology Services Uptake Amongst Substance Misusers**

Muchandidemba Marufu,1 Hugh Williams,2 Samuel L Hill,3 Jeremy Tibble,1 and Sumita Verma1,3*

1Department of Gastroenterology and Hepatology, Brighton and Sussex University Hospital, Brighton, UK
2Substance Misuse Service, Sussex Partnership NHS Foundation Trust, Brighton, UK
3Department of Medicine, Brighton and Sussex Medical School, Brighton, UK

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*BBV: blood-borne virus*
Stages in Developing a Community HCV Service

1. Establish unmet need for Community HCV service (2011)
2. Engage with stakeholders: Commissioners, Hepatitis C Trust, British Liver Trust, Substance Misuse Service (SMS), Pharma (2011–2013)
4. Successful 2-yr funding BH Commissioners and National Gilead Fellowship (2013) Two years additional funding Gilead ISR and BH Commissioners (2015)
5. Service set up 2013
Project ITTREAT (Integrated Community-Based Test-stage-TREAT) HCV service for PWID

- Set up a ‘one-stop’ community HCV service at SMS in Brighton, UK
  - Community hepatitis nurse, onsite FibroScan®
  - 2013–2017
  - Successful business case (Nov 2017) thereby ensuring permanency of service

- Evaluate service by data collection
  - Clinical
  - PRO (SF12, SFLDQOL)
  - Health Economics (QALY) ‘cost per cure’
  - Concurrent embedded qualitative study

- Ethical approval (REC ref 13/EM/0275)

PRO: patient-reported outcomes; QALY: quality-adjusted life years; SMS: Substance Misuse Service
VALID (Vulnerable Adults Liver Disease) Study 2015–2018

- **Primary Objective**
  - Prevalence of clinically significant chronic liver disease (LSM > 8kPa) in vulnerable elderly vs. non-elderly

- **Secondary Objectives**
  - Service uptake including HCV treatment outcomes
  - Mechanisms for more aggressive liver disease in the elderly (Th17, mRNA122, senescence biomarkers)

- **Funding from** Dunhill Medical Trust, KSS Deanery, National Gilead Fellowship

- **Ethical approval** (REC ref 15/SC/0112)
Participants fulfill national/exceptional criteria.

- **HCV Ab -ve**
  - Follow up as SOC

- **HCV PCR -ve**
  - Follow up as SOC

- **HCV PCR +ve**
  - Test for viral load/genotype, community TE, liver screen, USG and OGD if indicated
  - Assess if stable for HCV treatment

Not suitable for HCV treatment. Community hepatitis nurse continues to monitor.

Suitable for HCV treatment. Assessed by Hepatologist and discussed at hospital Liver MDM.

- Commence HCV treatment in community; clinical, PRO and HE data collection
- Participant fulfills national/exceptional criteria
- Peer advocates (buddy) support participants throughout their journey
- Community nurse/Research Fellow monitor and assesses for SVR12, provide additional support
- Encourage yearly HCV PCR test
### ITTREAT and VALID: Interim Clinical Outcomes

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<tr>
<th>Description</th>
<th>Value</th>
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<td>659 (80% men)</td>
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<td>Age (yrs)</td>
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<tr>
<td>ITTREAT</td>
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<td>Underwent fibroscan</td>
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<tr>
<td>LSM &gt; 7.5 kPa</td>
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<td>LSM &gt; 12 kPa</td>
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<td>P/R</td>
<td>16 (12%)</td>
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<tr>
<td>P/R/DAA</td>
<td>18 (14%)</td>
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<tr>
<td>DAA</td>
<td>96 (74%)</td>
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<td>EOTR</td>
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<td>16 (12%)</td>
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<td>On going</td>
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<tr>
<td>Other outcomes</td>
<td>11 (8%): 5RR, 1PR, 3D/C, 2 RIP, 1 lost FU</td>
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<tr>
<td><strong>P/R</strong></td>
<td>16 (12%)</td>
</tr>
<tr>
<td><strong>P/R/DAA</strong></td>
<td>18 (14%)</td>
</tr>
<tr>
<td><strong>DAA</strong></td>
<td>96 (74%)</td>
</tr>
<tr>
<td><strong>SVR</strong></td>
<td><strong>85/96 (88%)</strong></td>
</tr>
<tr>
<td><strong>EOTR</strong></td>
<td>18 (14%)</td>
</tr>
<tr>
<td><strong>On going</strong></td>
<td>16 (12%)</td>
</tr>
<tr>
<td><strong>Other outcomes</strong></td>
<td>11 (8%): 5RR, 1PR, 3D/C, 2 RIP, 1 lost FU</td>
</tr>
<tr>
<td><strong>Compliance with clinic visit</strong></td>
<td>97%</td>
</tr>
<tr>
<td><strong>Reinfection till date</strong></td>
<td>1/41</td>
</tr>
</tbody>
</table>

Updated data from ASSLD 2017
C-EDGE CO-STAR: Elbasvir + Grazeprevir in PWID
N=199 followed up for 3 years

ERADICATE STUDY
- 94 actively injecting PWID
- Needle exchange Tayside Scotland
- Contingency management
- PI + Peg INF + RBV
- SVR 83%
- Reinfection 18/100 person years (John Dillon personal communication)
Lessons learnt!!

▪ “People who inject drugs represent a hard to reach population who find it difficult to access traditional models of care. A service that relies on a traditional secondary care model of care for these groups will fail, with high levels of “did not attends”

▪ Not “one size fits all” but **ALL** aspects of care provided at **ONE** site

▪ Cares about vulnerable adults, works collaboratively to provide holistic/personalised service

▪ Easy access: mobile phone, flexible drop in clinics

▪ Non-judgemental service: stigma and shame a huge barrier - on going IDU and alcohol not a bar to HCV treatment

▪ Unrestricted access to pangenotypic 8 weeks non-ribavirin DAA regimens

Ryder S et al., HSJ May 2014
What Next

- Can such models of care work nationally? - need to generate evidence on a larger scale

- Conduct a national study
  - Nurse led complex intervention in GP practices that cater to homeless: BBV testing, non-invasive assessment of hepatic fibrosis and HCV treatment
  - Evaluate the complex intervention by a step wedge cluster RCT collecting clinical, qualitative, patient reported and health economic outcomes

What is a Step Wedge Design?

Many variations on a theme

Towards the elimination of Hepatitis C on the Isle of Wight

Ryan Buchanan
Are you 1 of the missing 200?

50% of hepatitis C is undiagnosed on the island

If you feel you have been exposed to risk

Get tested at your local pharmacy for free

You may not know you are infected

For more information on risks visit www.hepctrust.org.uk
Pharmacy-based case finding

186 DBS tests for HCV → 173 negative for HCV RNA

13 positive for HCV RNA

12 seen in community pharmacy by Hepatology team

5 attended local hospital for further investigations

8 lost to follow up

3 on waiting list for treatment

2 treated with SVR12
Locally available treatment

38 patients treated
100% SVR*

*For those cases >3 months post treatment

Unpublished data Sept ‘17
Challenges to meet elimination

Not treated

59 known cases remain untreated

Unpublished real-time data
Redefining the Hepatitis C disease burden

\[
\frac{\hat{D}_B \cdot \hat{C}_{B,A}}{\hat{D}_A \cdot \hat{C}_{A,B} + \hat{D}_B \cdot \hat{C}_{B,A}} = \hat{P}_A
\]

HCV RNA estimate population prevalence = 29% (CI 13-45)
Redefining the Hepatitis C disease burden

Kernel plots showing 1000 bootstrap estimates for the size of the PWID population on the IOW
## Redefining the Hepatitis C disease burden

<table>
<thead>
<tr>
<th>Risk Group</th>
<th>Number in group</th>
<th>HCV Prevalence in group (%)</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWID</td>
<td>474</td>
<td>262</td>
<td>39</td>
</tr>
<tr>
<td>Ex-PWID</td>
<td>311</td>
<td>24</td>
<td>75</td>
</tr>
<tr>
<td>General pop.</td>
<td>130,000</td>
<td>0.006</td>
<td>65</td>
</tr>
<tr>
<td>Non-white ethnic.</td>
<td>400</td>
<td>0.01</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>323</strong></td>
<td></td>
<td><strong>218</strong></td>
</tr>
</tbody>
</table>
Engaging the disengaged

<table>
<thead>
<tr>
<th></th>
<th>Specificity</th>
<th>Sensitivity</th>
<th>PPV</th>
<th>NPV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ego-alter HCV status report accuracy</td>
<td>0.81</td>
<td>0.82</td>
<td>0.84</td>
<td>0.79</td>
</tr>
<tr>
<td>Network-nodal report accurately</td>
<td>0.90</td>
<td>0.78</td>
<td>0.74</td>
<td>0.92</td>
</tr>
</tbody>
</table>
Treatment as prevention – an efficient elimination?
Treatment as prevention – an efficient elimination?

Individual based model of HCV treatment in the network of PWID on the IOW. *P<0.01, ***P<0.0001

Unpublished data
Acknowledgements

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Leonie Grellier

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Regent pharmacy, East Cowes, IOW
IRIS drug support centre, Newport, IOW
St Mary’s Hospital R&D department, IOW

Survey participants

Patients with HCV on the Isle of Wight
Thank you for listening
Greater Manchester Elimination Plans

Andy Ustianowski
Elimination is possible

Wedemeyer et al, JVH April 2014
There is modelling – People Who Inject Drugs

Modelling HCV prevalence at 15 years with DAAs

- No scale-up
- Scale-up to 10/1000 PWID
- Scale-up to 20/1000 PWID
- Scale-up to 40/1000 PWID
- Scale-up to 80/1000 PWID

Relative prevalence reduction (%) at 15 years (2027)

Edinburgh: 25% baseline chronic prevalence
- 25% baseline chronic prevalence

Melbourne: 50% baseline chronic prevalence
- 50% baseline chronic prevalence

Vancouver: 65% baseline chronic prevalence
- 65% baseline chronic prevalence

*8/1000, 3/1000 and 5/1000 PWID annually in Edinburgh, Melbourne and Vancouver respectively. Bars indicate the mean relative prevalence reductions; whiskers represent the 95% confidence interval for the simulations. PWID: people who inject drugs; Rx: therapy; SVR: sustained virological response.

There is modelling – Men who have Sex with Men

HCV chronic (RNA+) prevalence among HIV-diagnosed MSM (%)

Year

No treatment
PEG-IFN + RBV
Current treatment rate
DAAs from 2015 (SVR 90%)
Current treatment rate
DAAs from 2015 (SVR 90%)
Scale-up treatment for recent diagnoses (<1 year) to 80%
DAAs from 2015 (SVR 90%)
Scale-up treatment for recent diagnoses to 80% AND non-recent diagnoses to 20%
DAAs from 2015 (SVR 90%)
Scale-up treatment for recent diagnoses to 80% AND non-recent diagnoses to 20% AND 20% risk-reduction from 2015

DAA: direct-acting antiviral; MSM: men who have sex with men; PEG-IFN: pegylated interferon; SVR: sustained virological response

GM HCV Elimination
Attrition Tree... Greater Manchester

- **17450** people living with chronic HCV
- **10470** people diagnosed with HCV
- **2932** people engaged with specialist services

Based on data from [Health Protection](https://www.gov.uk/government/publications/hepatitis-c-commissioning-template-for-estimating-disease-prevalence)

- **60%** aware of diagnosis
- **28%** patients diagnosed with chronic HCV seen by specialist in 2014

GM HCV Elimination Strategic Pillars

Community Pharmacies

Doing what we should be doing optimally
Analysis of pharmacies who dispense heroin substitutes identifies concentration within CCG’s (hotspots)

Source: QuintilesIMS PBS Qtr to July ‘17. Dispensed buprenorphine; buprenorphine+naloxone; methadone
GM HCV Elimination Plan

Informatics & Data

Community Pharmacies
Network Treating
Interrogation of Records
Rapid Prison Diagnosis & Treatment
Primary Care + A&E Testing

Doing what we should be doing optimally
Where are we now?

• An ‘HCV Elimination Alliance’ has been created

• We have buy-in from the Health & Social Care Partnership (‘DevoManc’) –
  • “Exemplar project”

• Formal business case being finalised

• Scoping continuing
• Multiple meetings with stakeholders

• Planned commencement first quarter 2018/19
IT TOOK US 25 YEARS TO BRING HIM TO HIS KNEES... NOW LET'S FINISH HIM OFF...
Measuring Patient Outcomes/Experience

Charles Gore
CEO, The Hepatitis C Trust
ODN Service Specification

Domain 4 Ensuring that people have a positive experience of care

Overarching indicator:
Patient experience of hospital care

Improvement area:
Patient experience of outpatient services

This service specification will ensure that patients receive care through an Operational Delivery Network. Outpatient hepatitis C treatment and care will be delivered in a setting that is appropriate, and by staff who are appropriate, for each patient – as an example by a blood-borne virus nurse in community drug services but as part of a specialist service with the optimum specialist oversight. Research indicates that in areas where treatment is exclusively available in a hospital setting this is a barrier for some patients, reducing the numbers coming forward for curative treatment.

Service providers will provide outcomes data on:
Patient experience of outpatient services through a patient questionnaire developed and validated with appropriate patient representative groups
Things to consider in measuring outcomes/experience
Purpose

• To improve patient health?

• To compare ODNs?

• To improve services?

• To measure patient-perceived improvements in health?

• To measure wider impacts of HCV treatment?
Method

• A survey?
  ❖ Paper?
  ❖ Online?

• Interviews?
  ❖ In person?
  ❖ By telephone?

• Who, how and when to engage the patients to participate?

• Ease of collecting data/response rate/ease of analysis

• Who? Everyone or a sample?
Timing and location

• Over what time period? How often?
• One survey or more?
• As soon as possible after what the survey is intended to measure?
• At first clinic appointment or initiation of treatment (e.g. to capture the experience of getting to clinic/start of treatment)?
• At end of treatment (e.g. to measure the whole experience?)
• Where?
• What about people who drop out of the pathway/services?
Accessibility

• Language?

• Simplicity?

• Length/number of questions?

• Assistance?
The questions

• Free form questions?

• What scale to use when rating things (0 – ?)

• How much about the respondent?
The questions – an ODN example

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes definitely</th>
<th>Yes to some extent</th>
<th>Not really</th>
<th>Definitely not</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Was the doctor/nurse polite and considerate?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Did the doctor/nurse listen to what you had to say?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Did the doctor/nurse give you enough opportunity to ask questions?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Did the doctor/nurse answer all your questions?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Did the doctor/nurse explain things in a way you could understand?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6. Are you involved as much as you want to be in the decisions about your care and treatment?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>7. Did you have confidence in the doctor/nurse?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>8. Did the doctor/nurse respect your views?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>9. Did the doctor/nurse respect your privacy and dignity?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>10. By the end of the consultation did you feel better able to understand and/or manage your condition and your care?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Overall, how satisfied were you with the doctor/nurse that you saw?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. About you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What transport did you use to get here today?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Please tell us what would help you in getting to future appointments?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Brief discussion

• Purpose
  ❖ To improve patient health?
  ❖ To compare ODNs?
  ❖ To improve services?
  ❖ To measure patient-perceived improvements in health?
  ❖ To measure wider impacts of HCV treatment?

• Next steps?
  ❖ A short life working group?