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

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

Agenda – Day 1

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

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

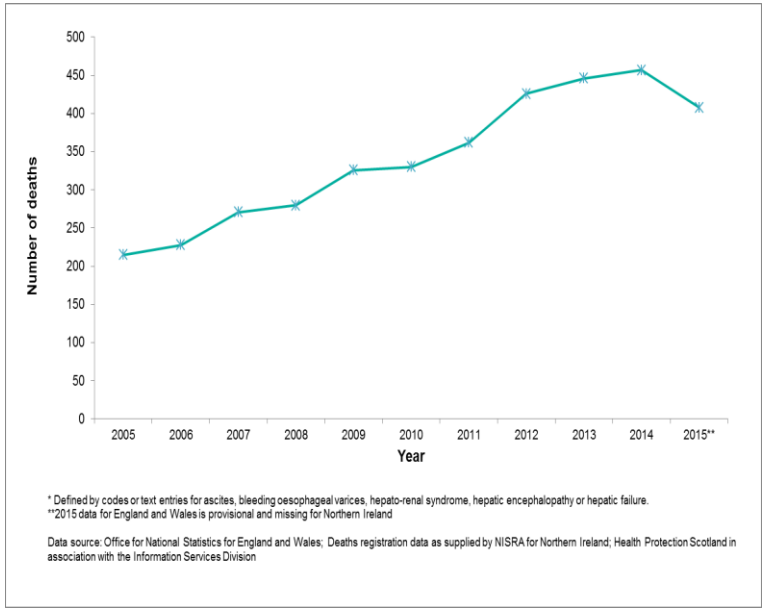
- Clearing the site
- Setting up a national service with allocation of treatment slots by local need
- Getting drug prices to a sensible level

Clearing the site

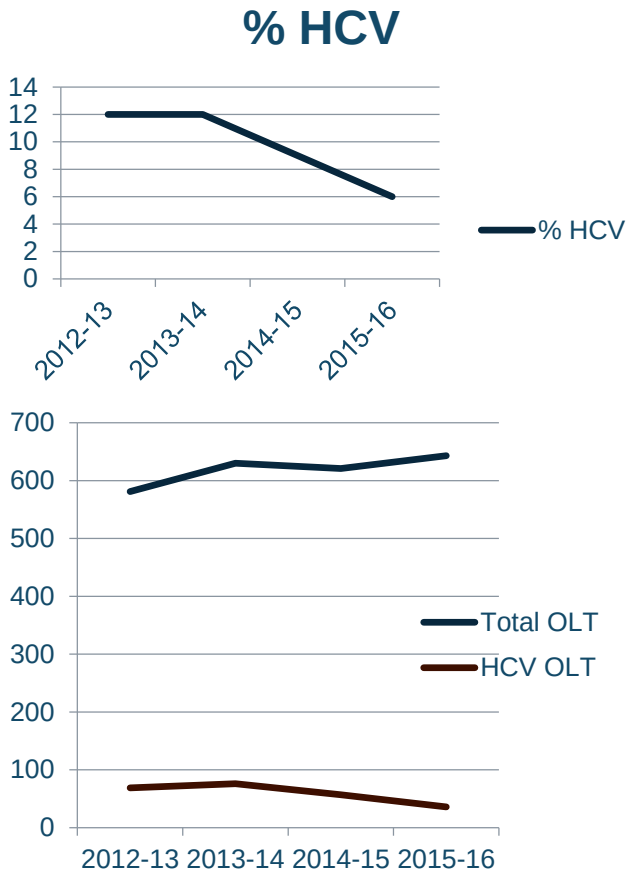
Early planting

- 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)

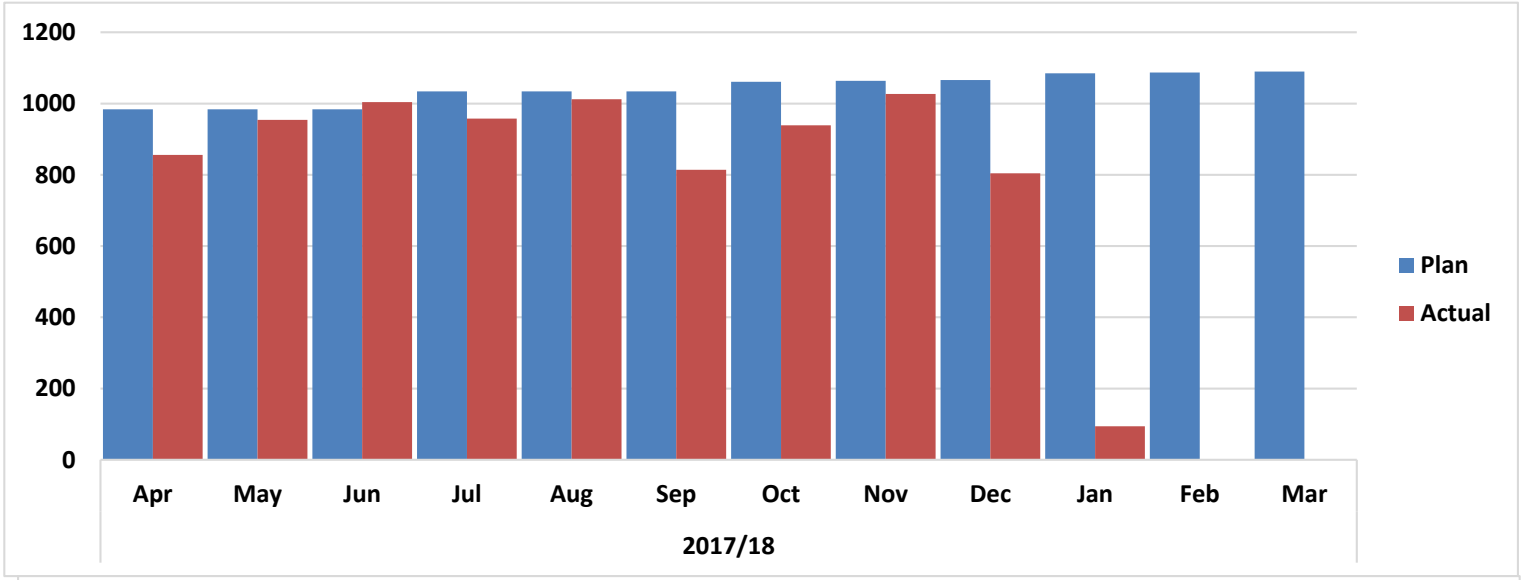


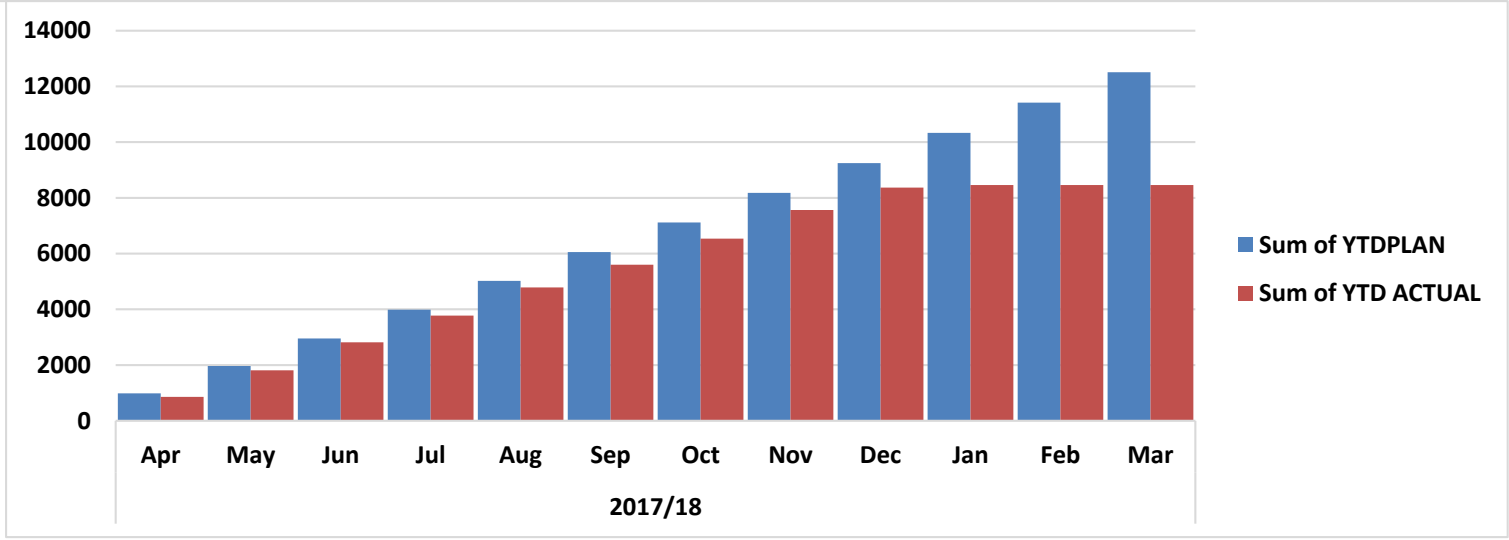
Transplants for HCV

Information

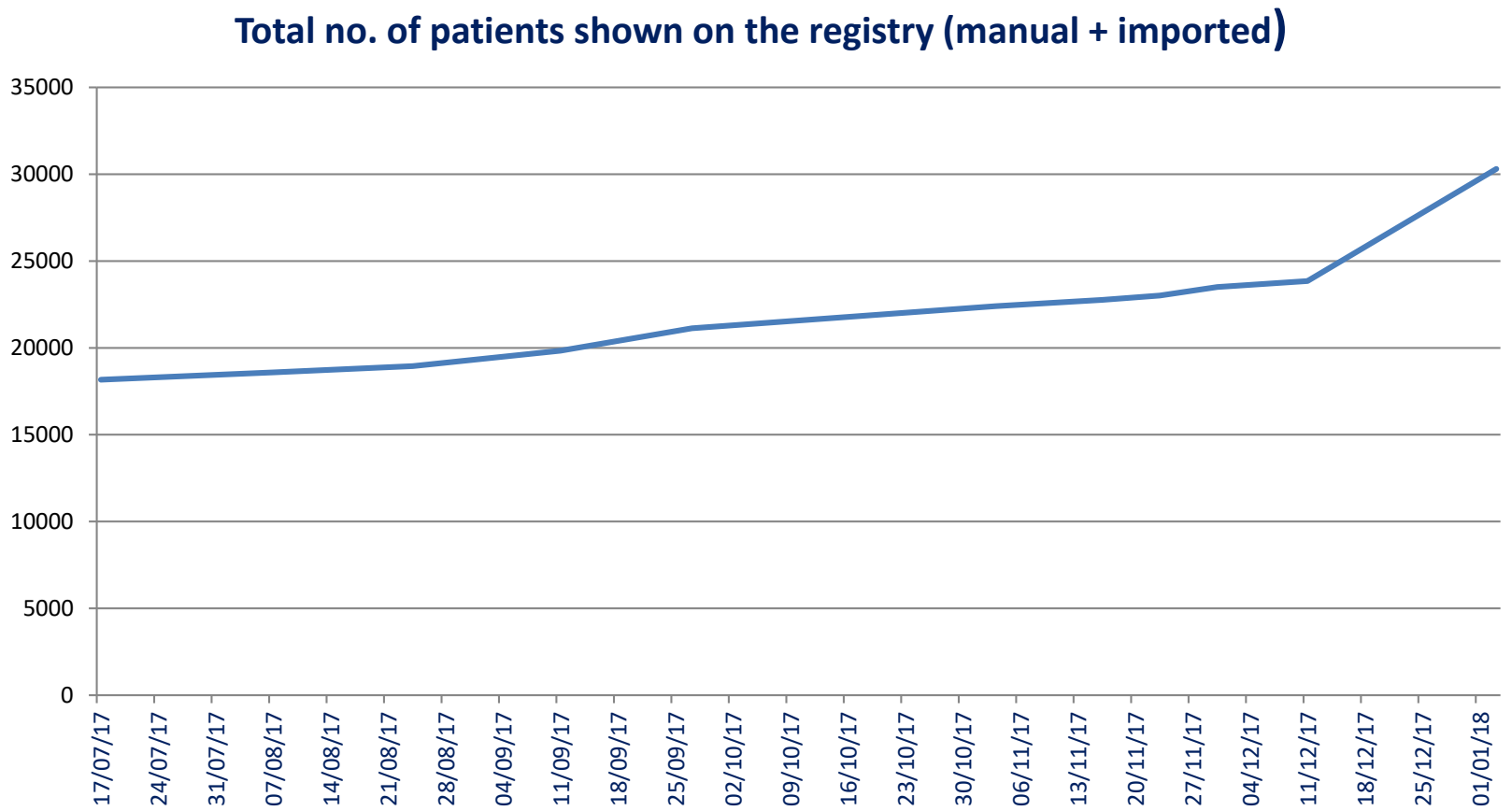
- Data is key to clearing HCV
- We need to know about who needs what to expand (? help with prisons, drug services, etc)
- We need to know which areas are undertreating, which prisons are underserved, which addiction centres are failing etc etc

Information transfer





The Registry



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

Getting what we need?

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

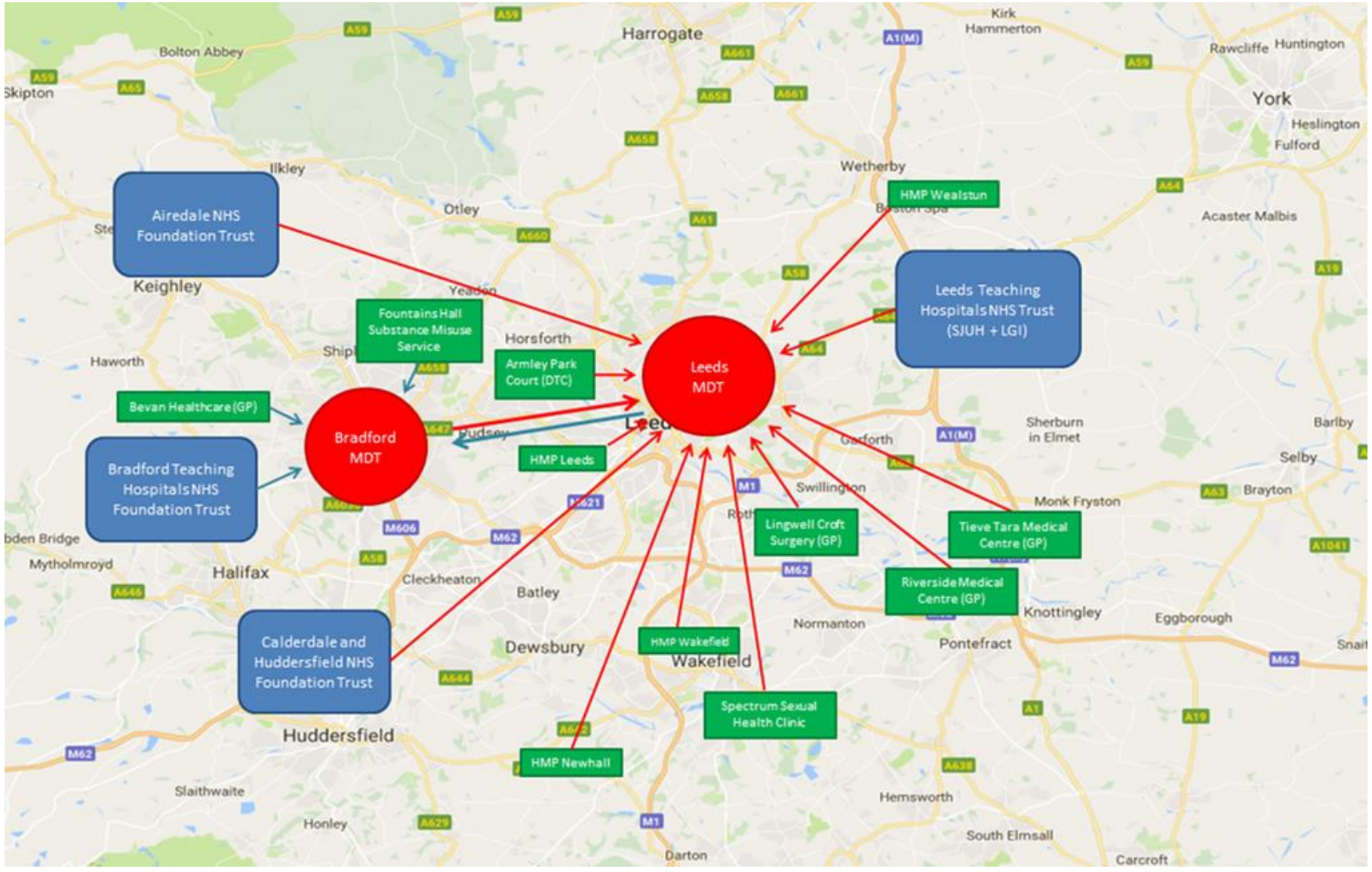
Far, far better than the Australians

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

🙂

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

😃

2015

EAP finished, but NHSE have announced bids for ODNs to deliver new HCV drugs. Sounds like the liver plan rehashed 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

Whats that got 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

😡

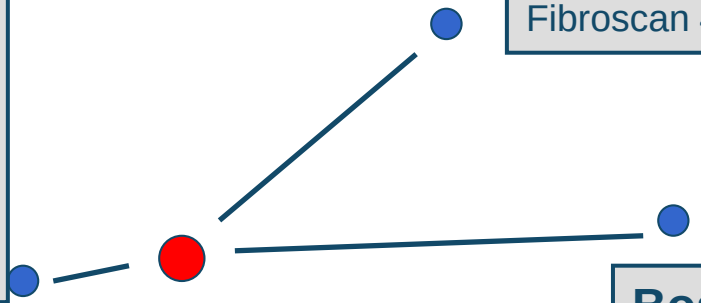
Nottinghamshire, Lincolnshire and Derbyshire ODN

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 402

Lincoln
Dr Aravamuthan Sreedhavan
Dr Rashaad Gossiel
Karen Murray

Local MDT ✓
Category B prison – inreach ✓
Fibroscan 430 mini



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 ✓

Boston
Dr Sanjiv Jain
Maxine Myers – 15hrs

Local MDT ✓
Category D prison – inreach ×
Fibroscan ×

Teleconference ODN MDT
Thurs 13.00

Different spokes

- **Derby**

4 clinicians, 2 nurses

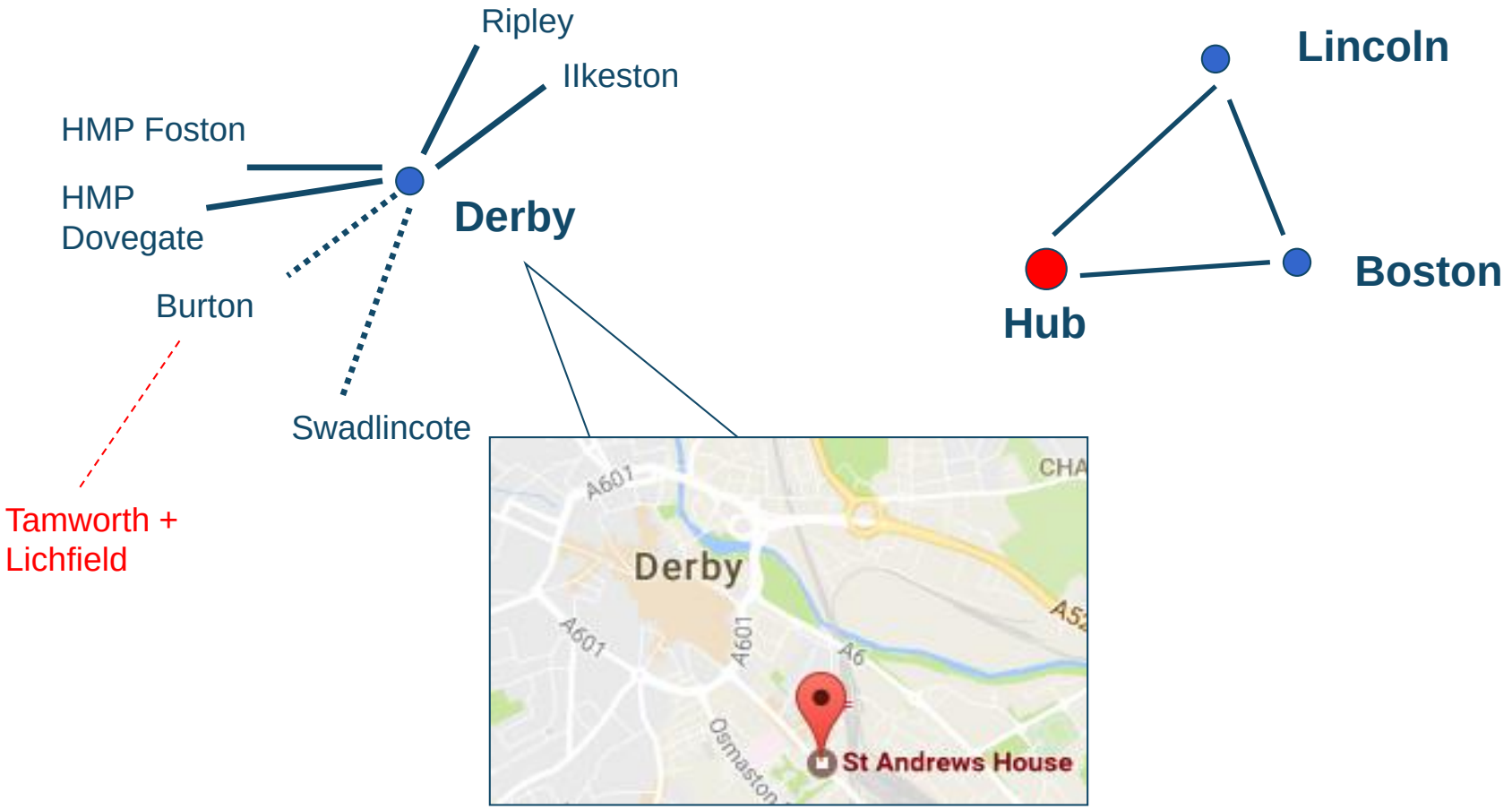
Qtr 4 2016/17 to end
Qtr 3 2016/17 treated
86* patients

- **Boston**

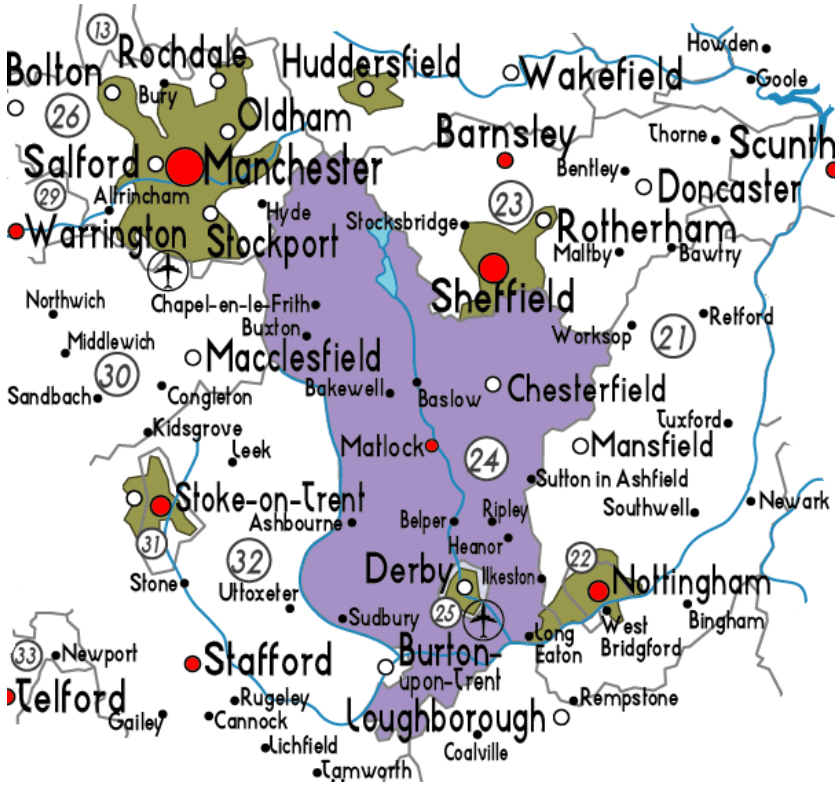
1 clinician, 1 nurse

Qtr 4 2016/17 to end
Qtr 3 2016/17 treated
26 patients

Different spokes



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 Dilks, ODN Manager

Nik Howes, Commissioning Manager Substance Misuse, Derbyshire County Council

Jane Careless, 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

Apologies

Barry O'Neil, 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 …

Hub

- Day to day light touch/ no touch
- Continued sharing of experience/ national agendas
- Transparency re CQUIN

NHSE

- 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)
- Feedback on the use of all the data trusts are sending

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

Should not be one size fits all

Transparency re CQUIN. ODN “accounts”

Make primary concern of ODN the adoption of good practice/ elimination strategies

Working within ODN structure

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

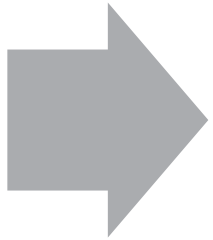
Payment for outsourced/homecare

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

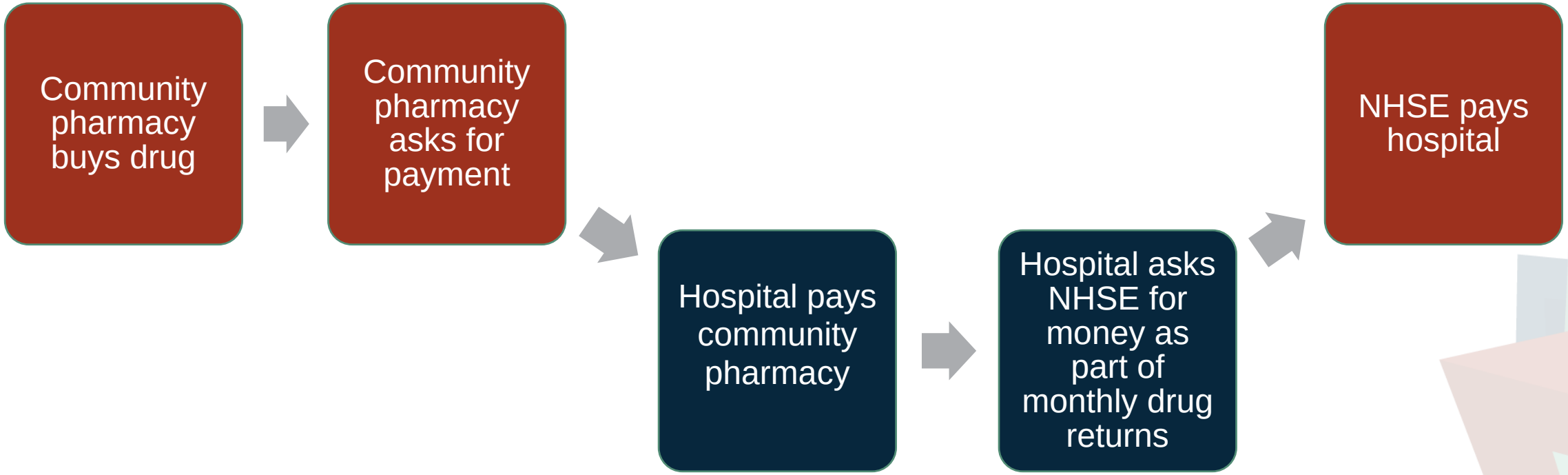
Community Pharmacist tests for HCV



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

Current logistical issues

Preferred community model



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

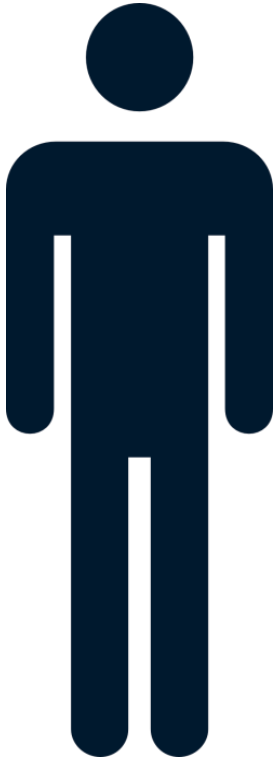
- Small number of patients so far – but the “word is out”!! – especially **“quick to treat” AND NO injections**
- **Three patients in Rehab – x1 discharged day before starting treatment due to using Heroin**

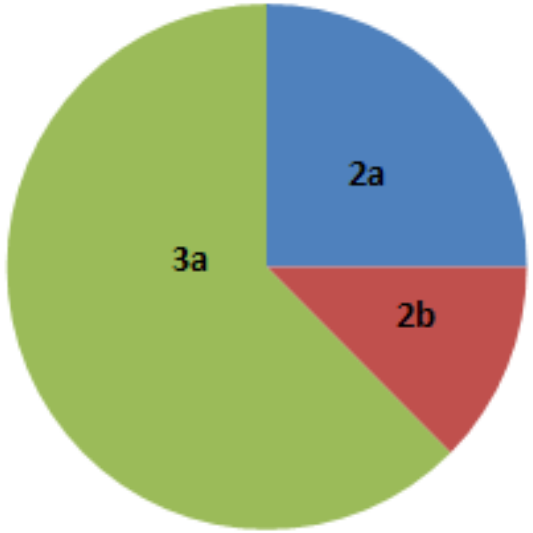
  He re-engaged, started treatment and now in Rehab in South West England
- x1 living with partner and on Methadone – engaged with drugs services, but not wanting to be treated there
- x4 living in Hostels (x2 significant mental health problems – CPN)
- **Other health issues: x2 cirrhosis; x1 sickle cell 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

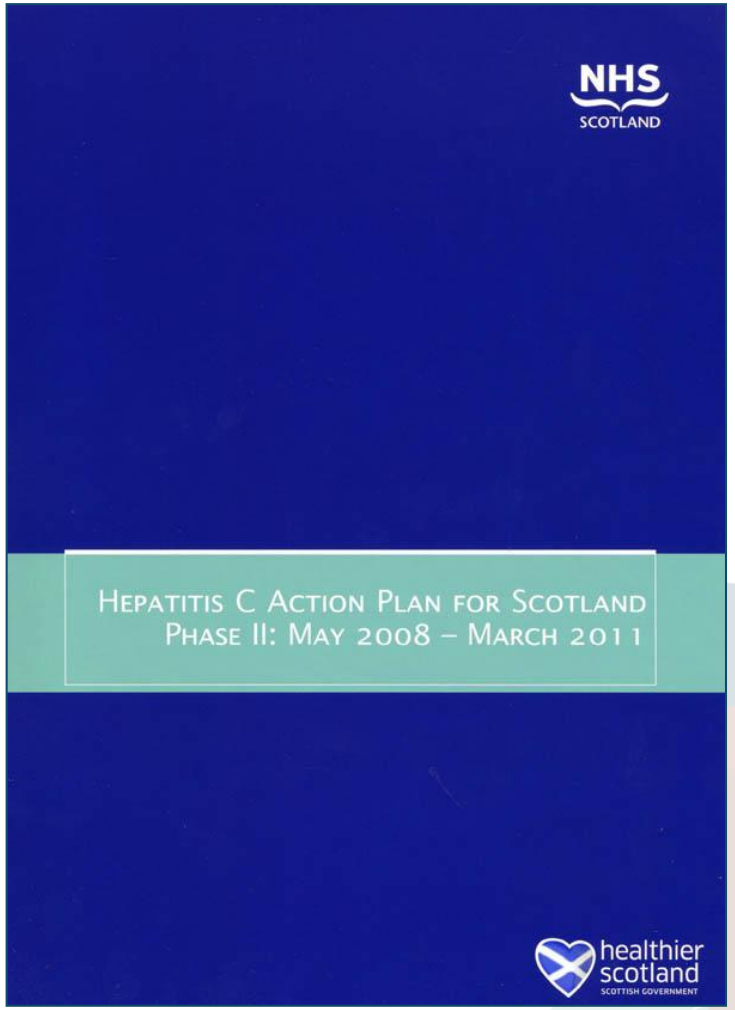
Scotland and Tayside HCV statistics

- 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

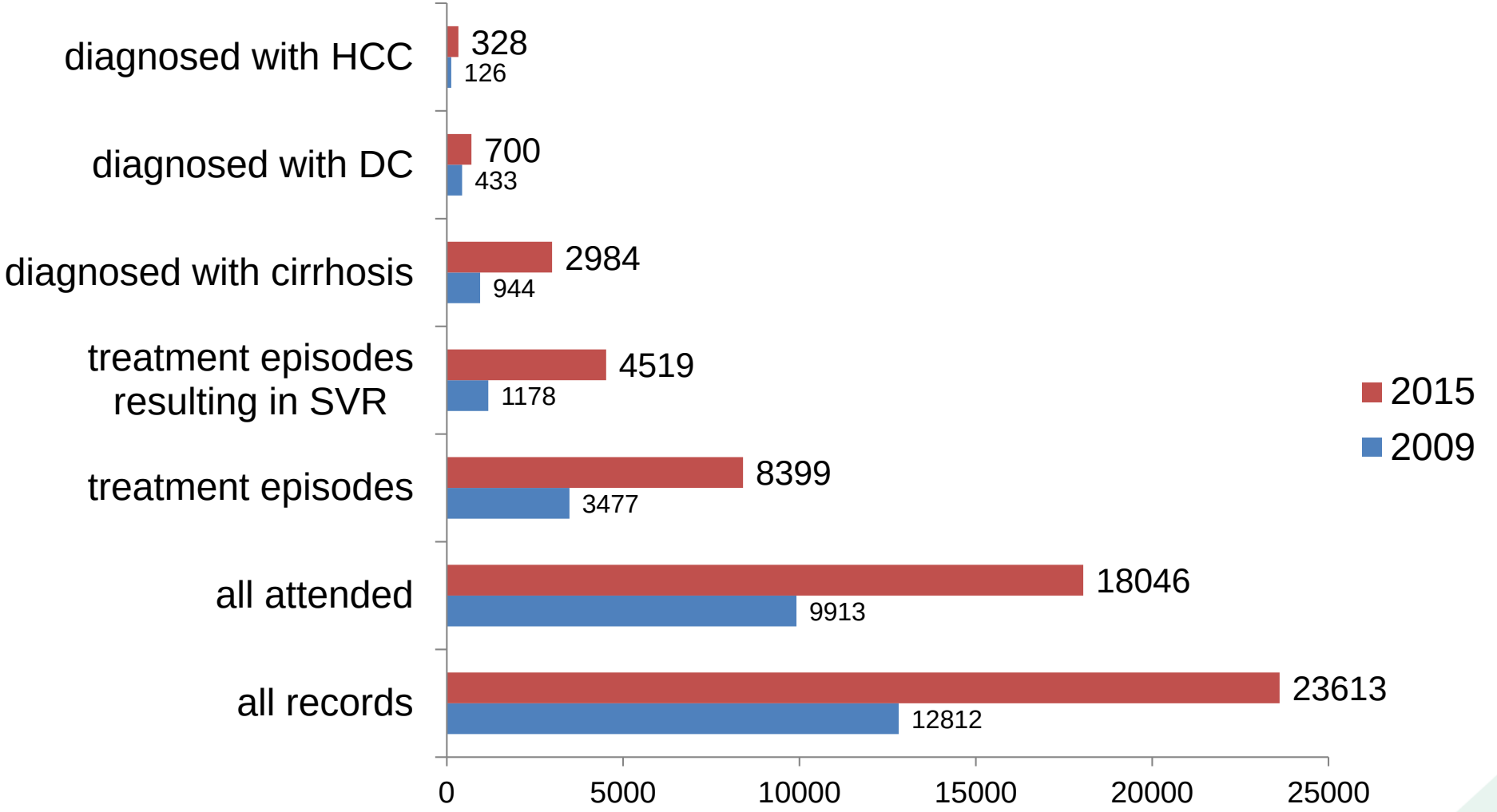
- Aims:
  - To prevent spread of hepatitis C, particularly among intravenous drug users
  - To diagnose hepatitis C infected people, particularly those who would most benefit from treatment.
  - To ensure that those infected receive optimal treatment, care and support
- 2006: Launch of Scotland's Hepatitis 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



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

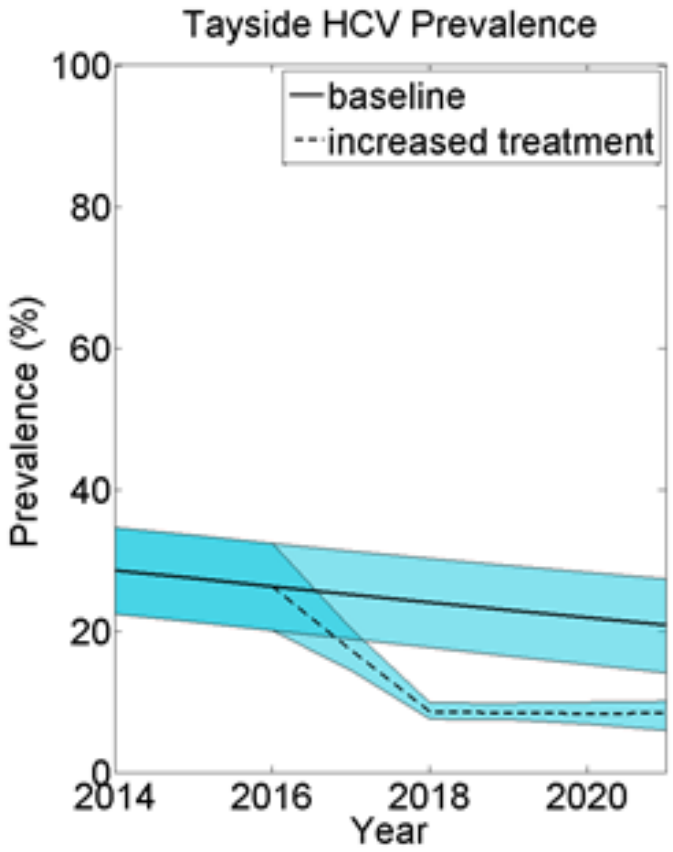
Purpose of current treatment and care pathways

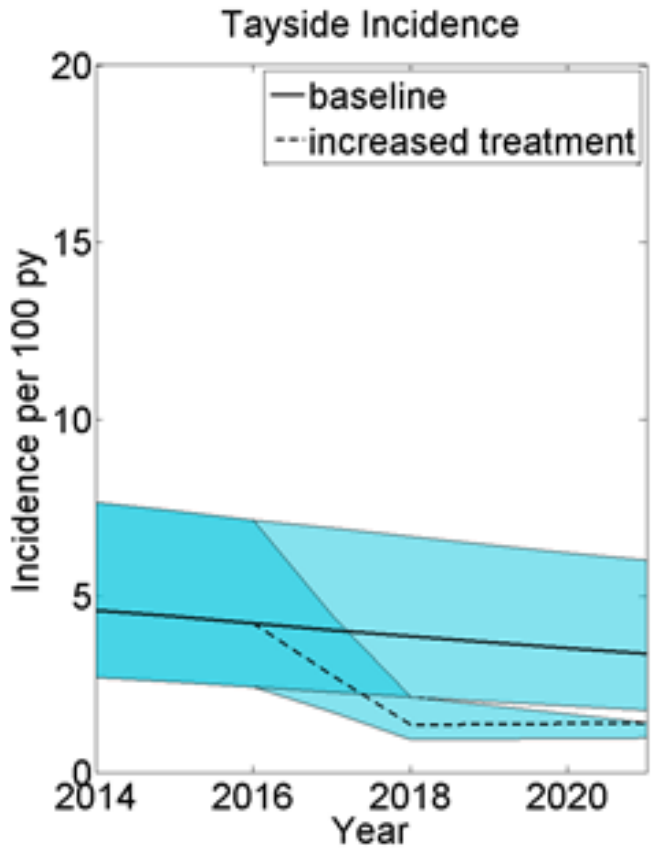
- Prevention of Liver failure and HCC
- Treatment of symptoms
- So a perpetual program of treatment

- ***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%

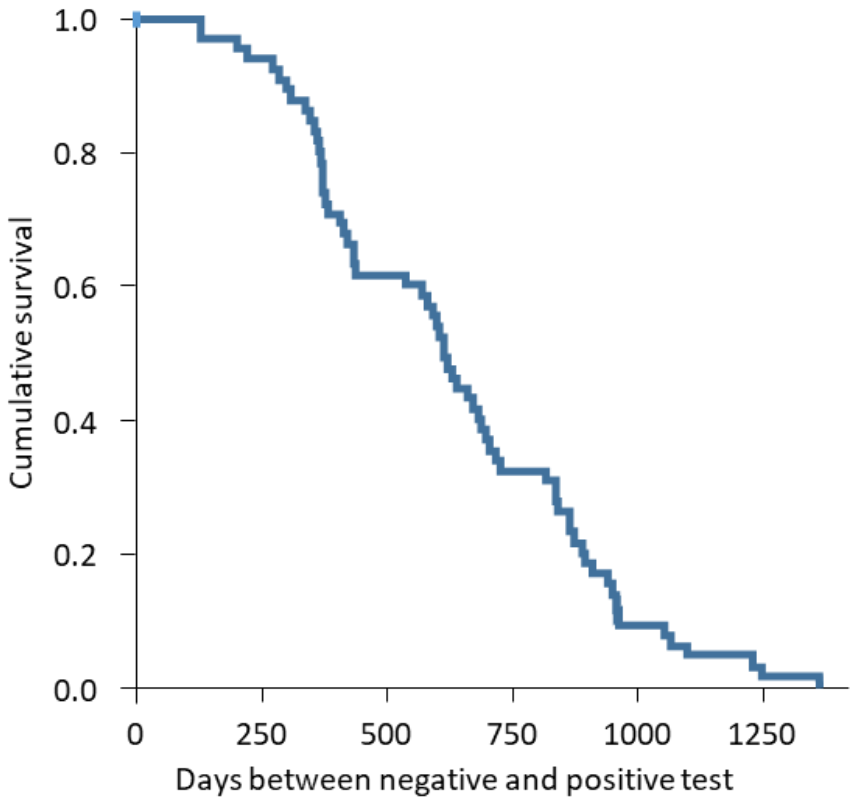




Unpublished data

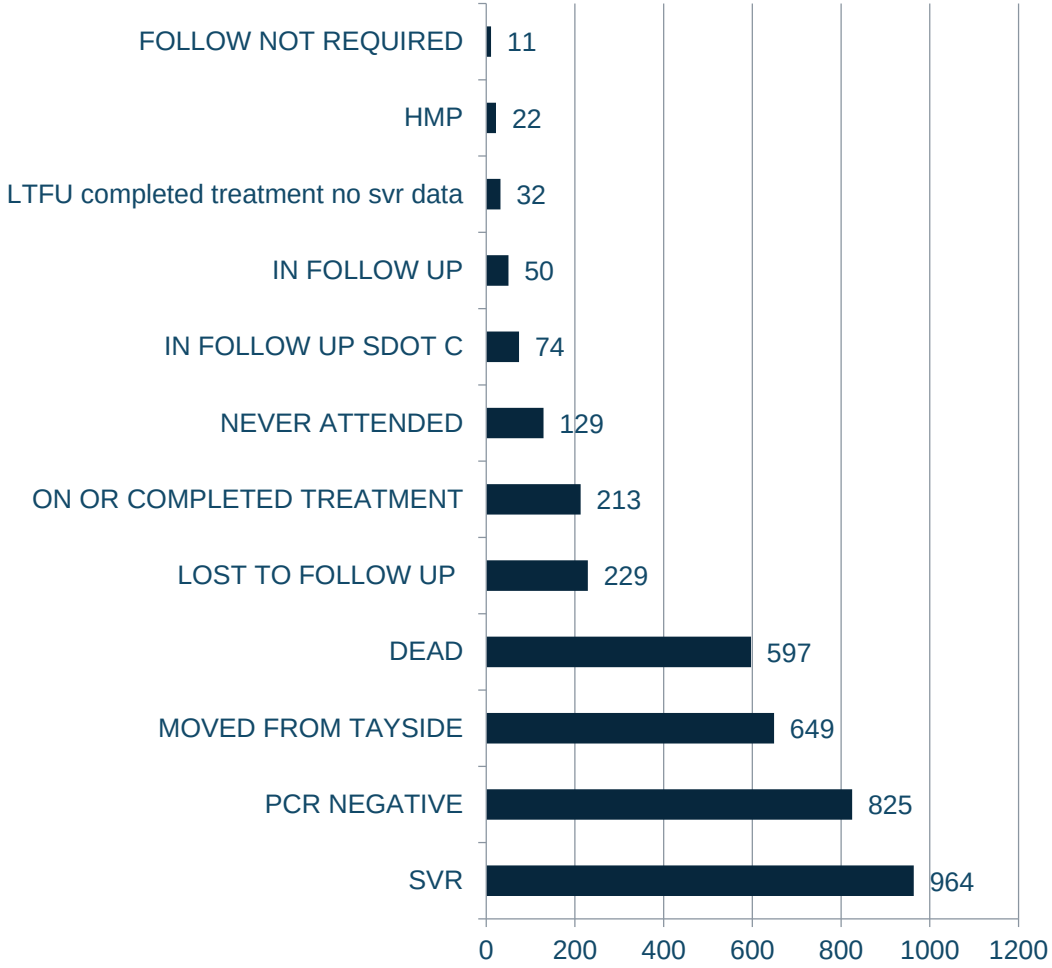
The first requirement of elimination

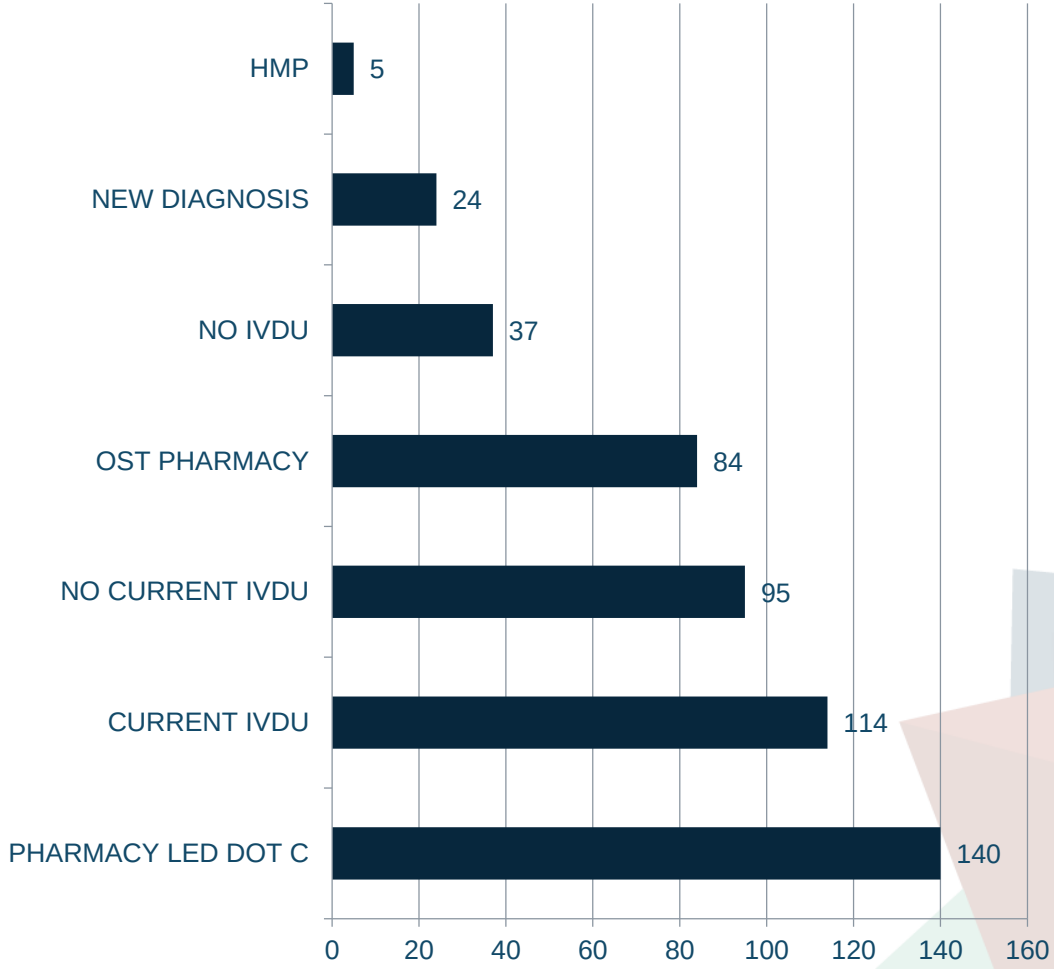
Survival HCV free in a needle exchange:
the unexpected benefits!



- 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

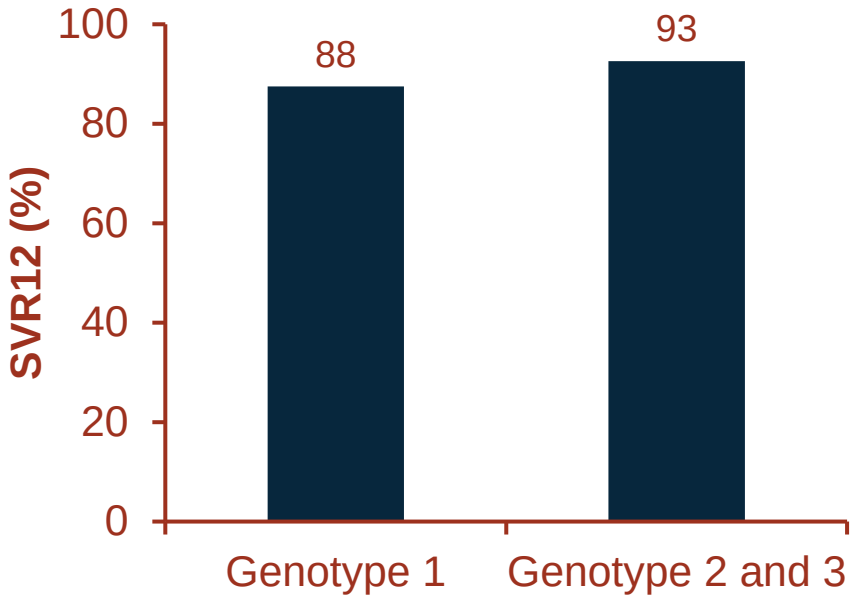
- Over 170 staff trained in Blood spot testing, mainly 3rd sector
- HCV testing embedded in
  - Drug problem centres
  - …ment Order
  - …s,
  - Criminal Justice, Prisons
  - Minor injury units
  - Needle exchanges
- 81% of tests are carried out by support workers, without clinical qualifications

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

Consented	105
Received treatment	94
Spontaneous resolver	3
Lost to follow-up	4
Stabilised drug use	2
Died prior to treatment	1
Prison prior to treatment	1



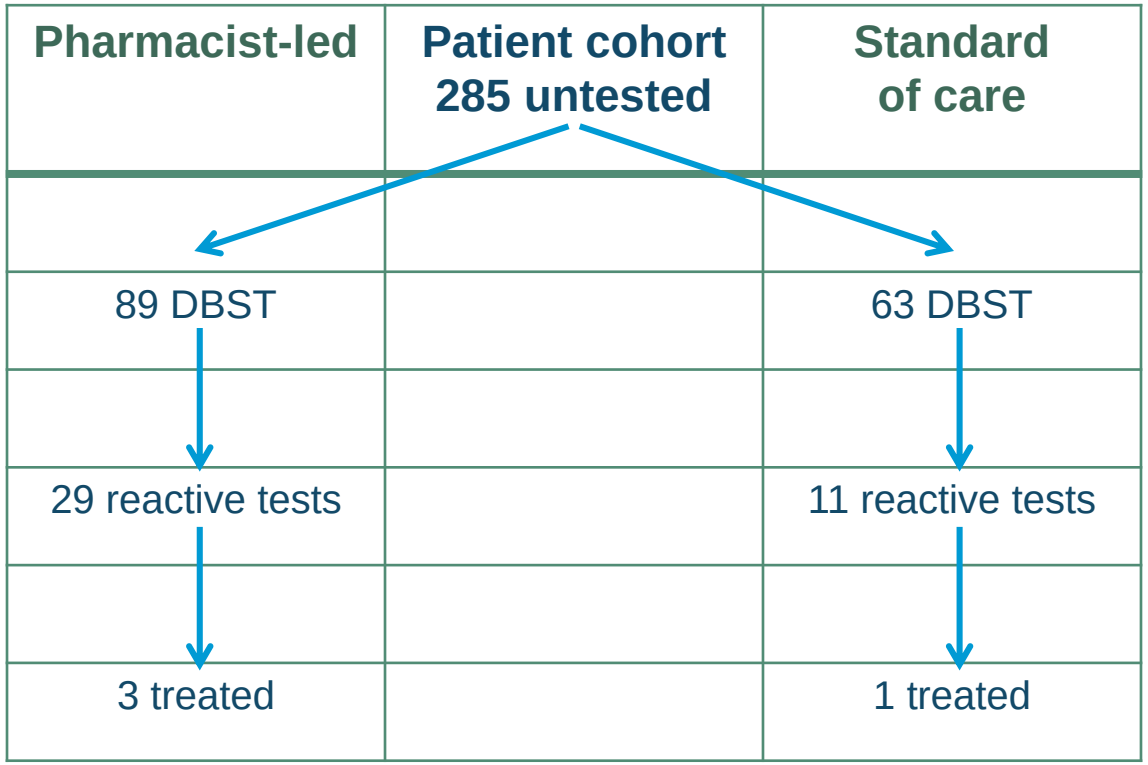
Dillon JF. Unpublished data

- SVR12: sustained virological response 12 weeks after the end of treatment

Make treatment easy

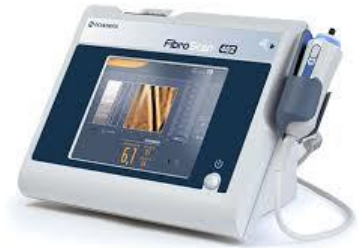
DOT-C: A pilot cluster randomised controlled trial

HCV testing and treatment in 8 community pharmacies

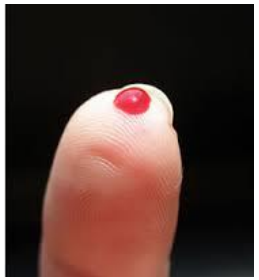


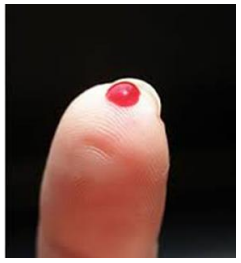
Radley A, et al. Unpublished data (manuscript under review)

What do we need for treatment?

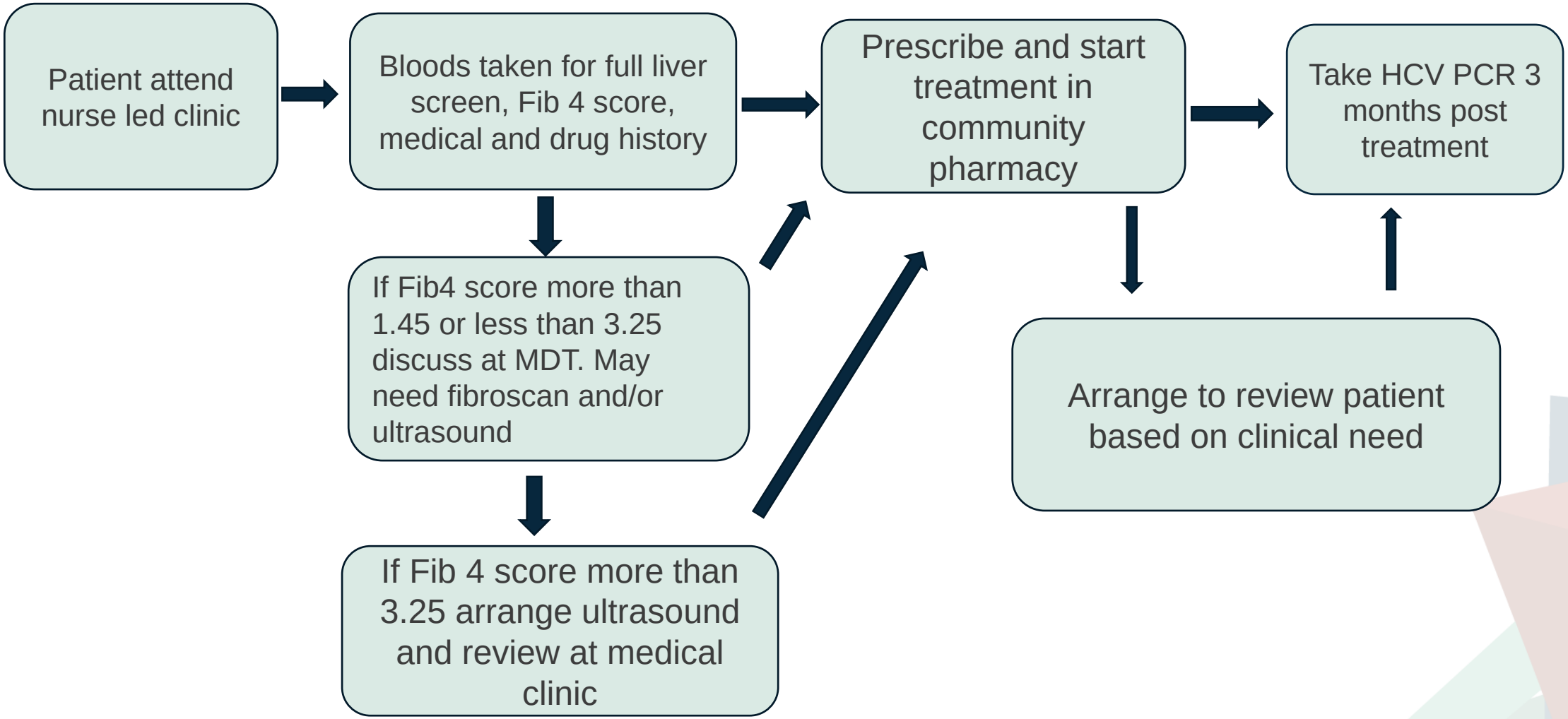


OR

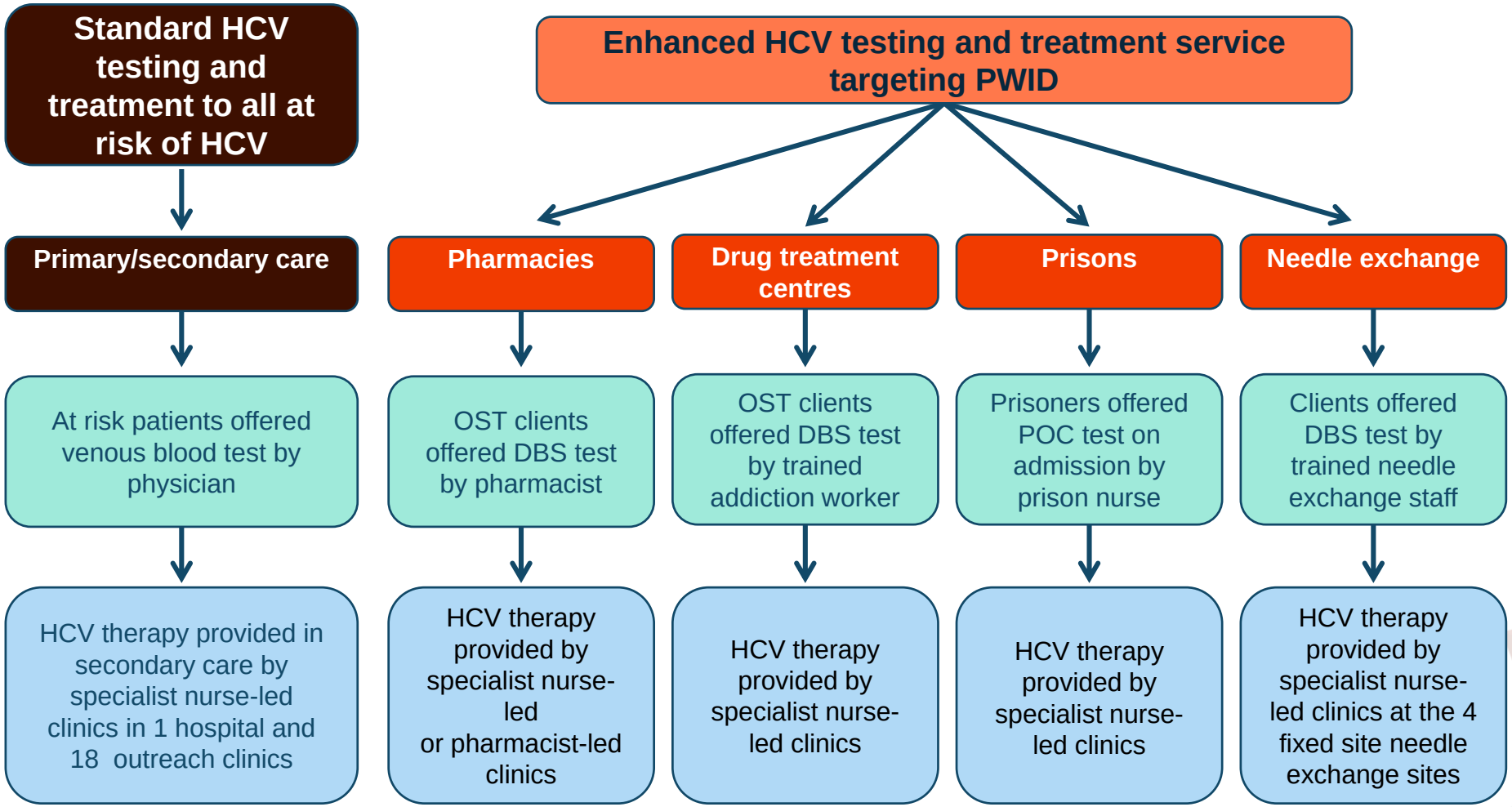




New nurse led prescribing pathway



HCV testing and treatment pathways for the PWID and OST populations



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

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Engaging the “lost” hepatitis C positives in treatment?

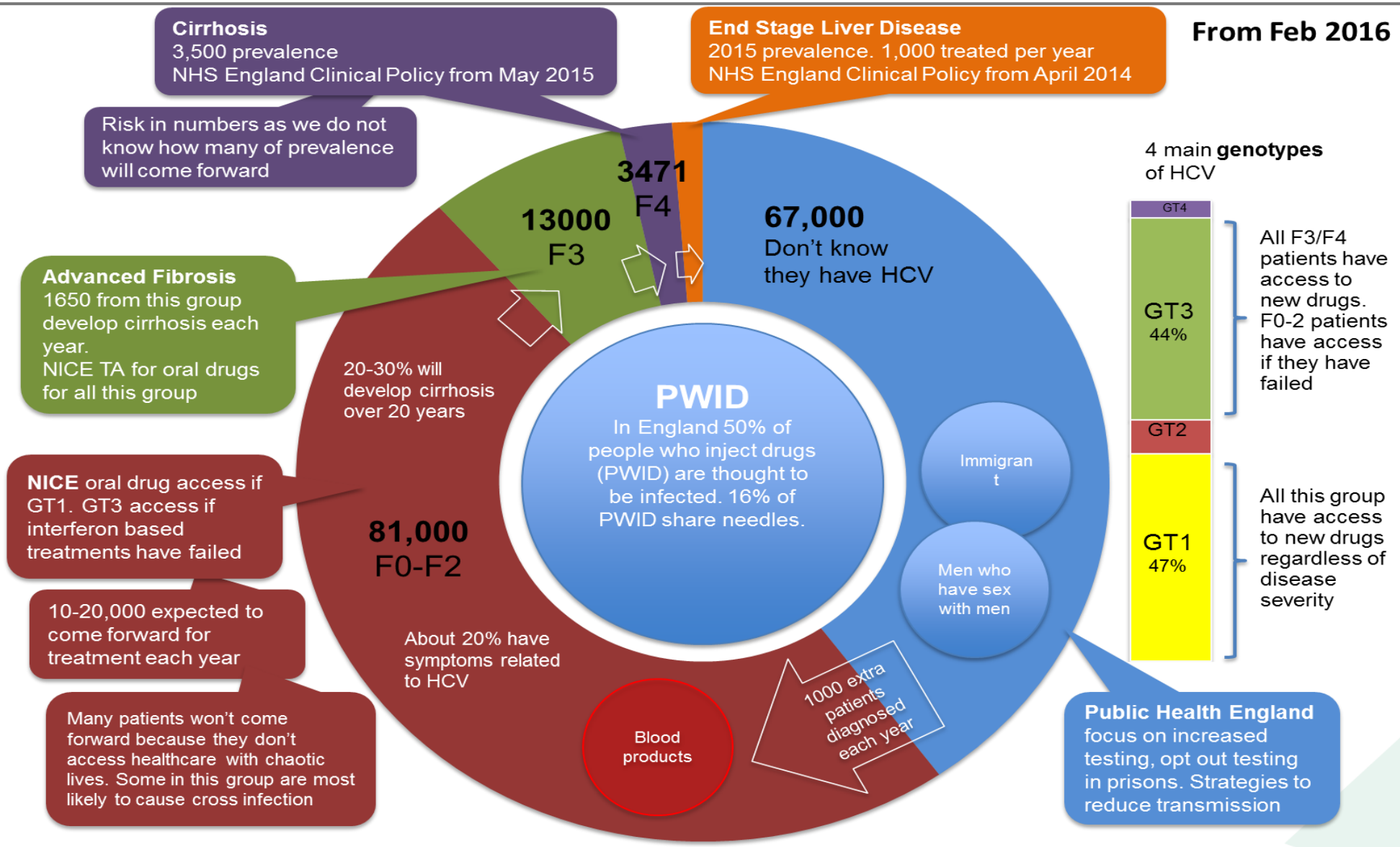
Dr Stuart McPherson

Consultant Hepatologist

Liver Unit, Freeman Hospital, Newcastle

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

Introduction



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

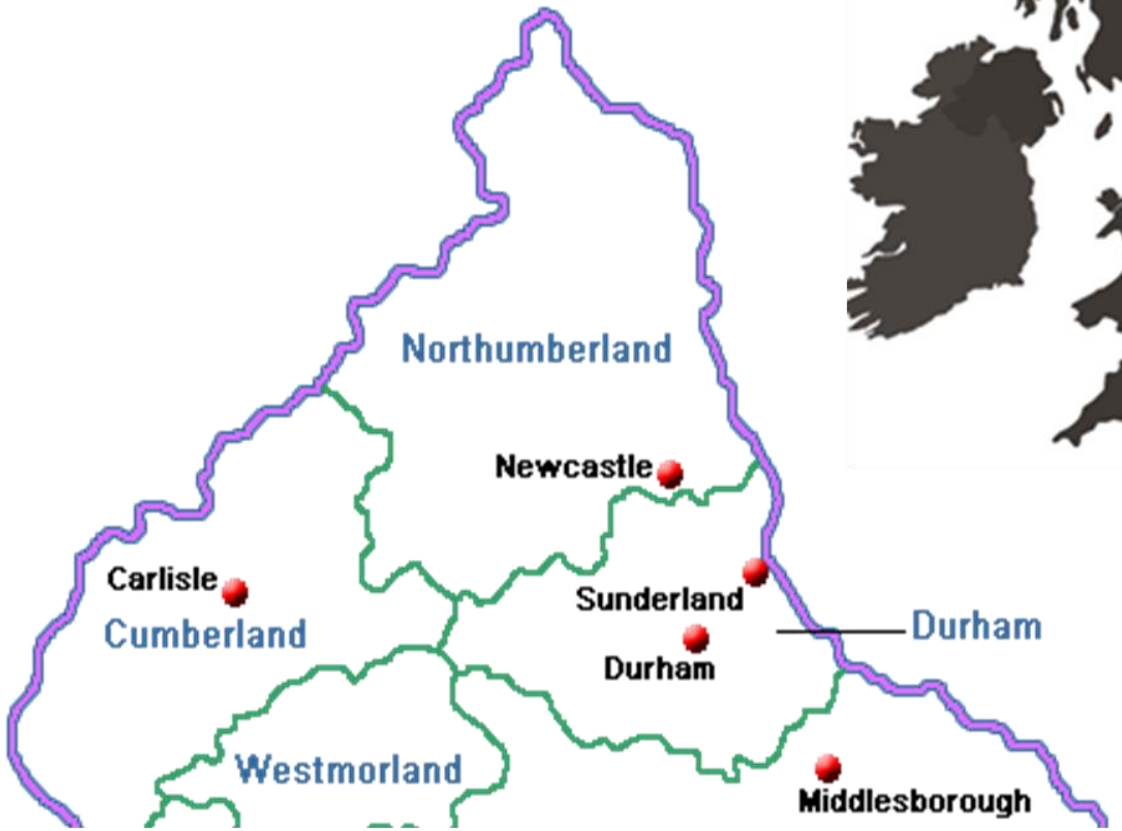
Sunderland Hospitals NHS trust

Queen Elizabeth Hospital, Gateshead

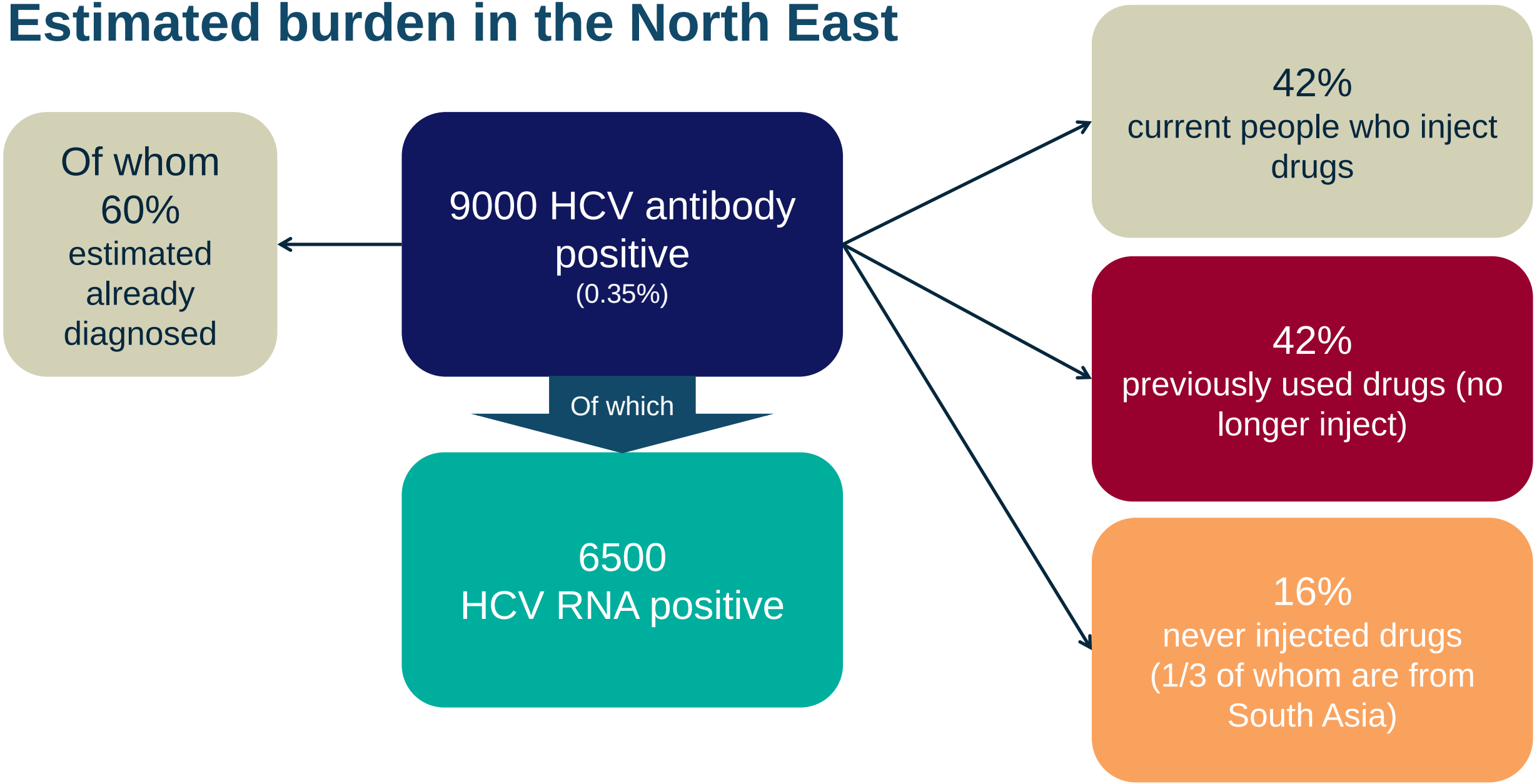
- Outreach

North Cumbria Hospitals

- Carlisle
- Whitehaven



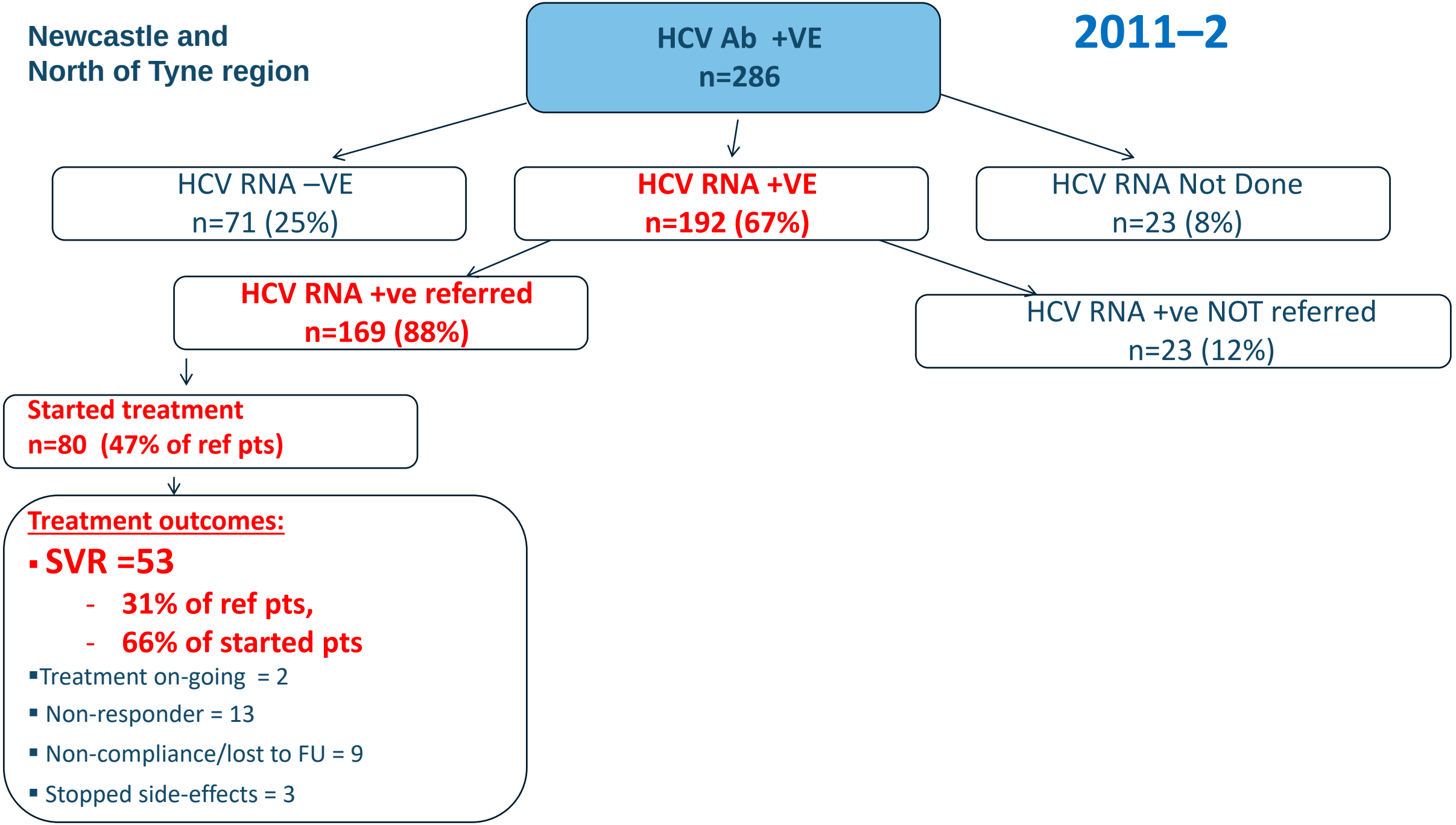
Estimated burden in the North East



Public Health England. PHE Commissioning Template for Estimating HCV Prevalence by PCT and Numbers Eligible for Treatment 2014.

Newcastle and North of Tyne region

2011–2



Newcastle and North of Tyne region

2011–2

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%)

HCV RNA +ve NOT referred
n=23 (12%)

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

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

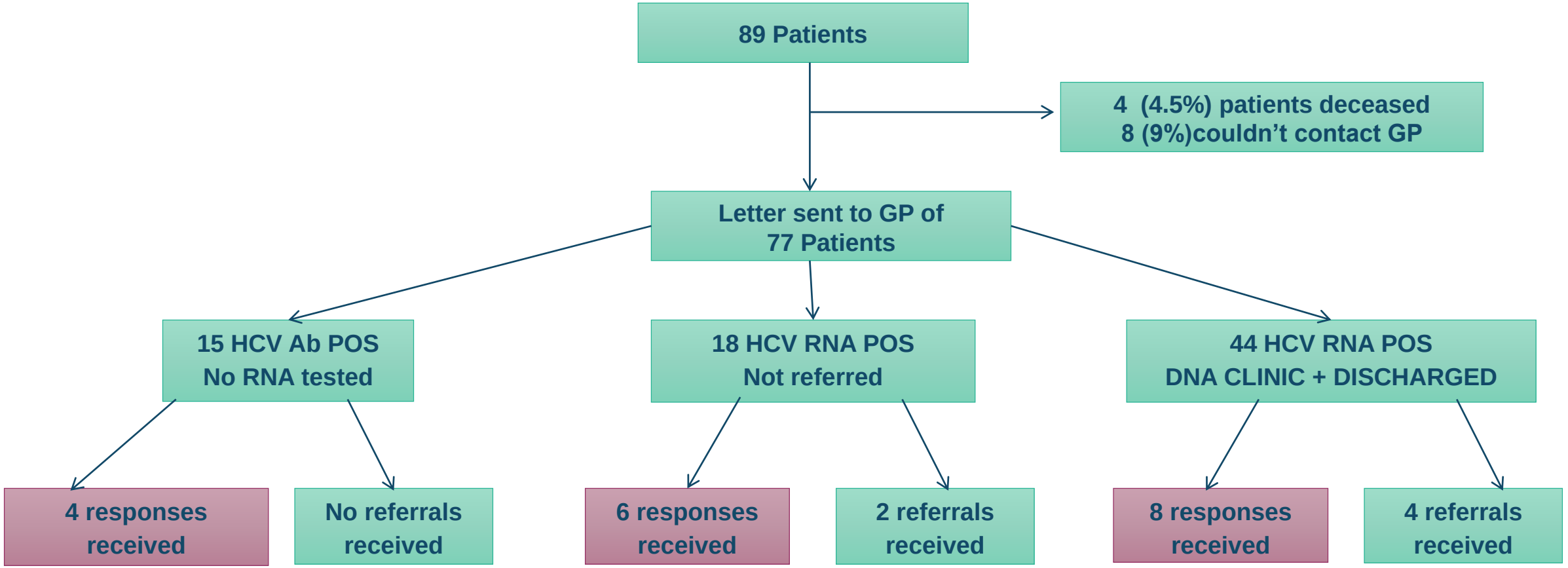
Treatment outcomes:

- 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**

Could we find the patients not attending the clinic?



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

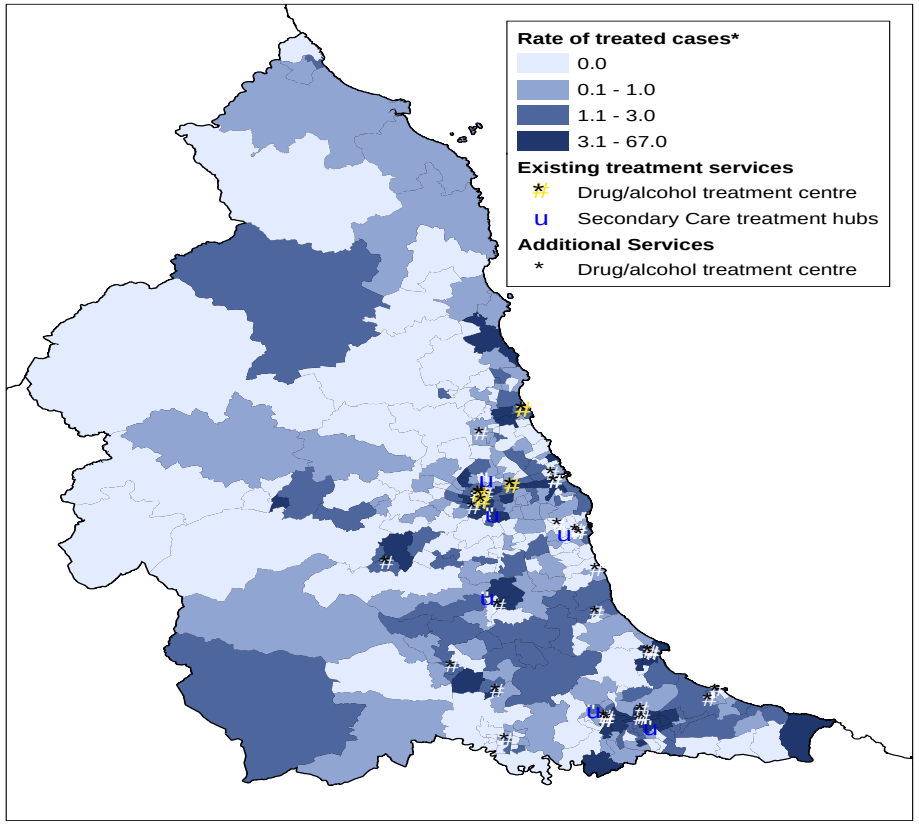
- To track down known cases of HCV to try and engage or re-engage them in treatment services

Methodology

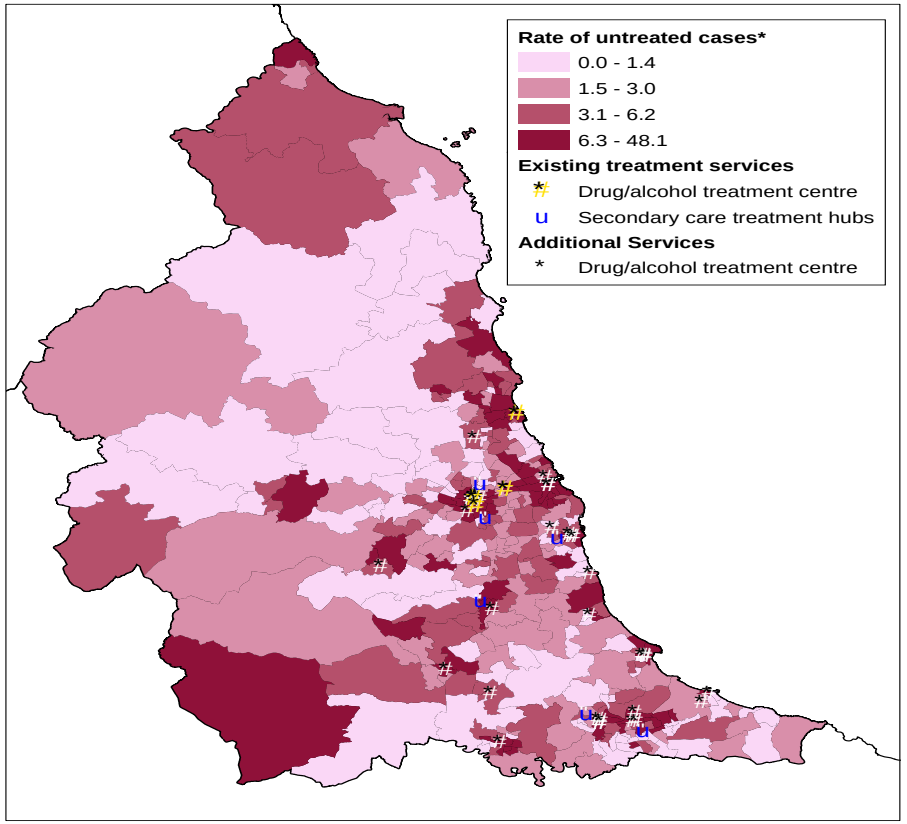
- All HCV infections reported from 1997-2016 in NEE were identified from PHE North East surveillance data (all reported HCV infections (Ab, Ag and PCR)
- Treatment outcome data was provided for patients treated at hospitals in the North East and Cumbria ODN from 2007-2016
- Epidemiologist “fuzzy matched” 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)

Mapping treated and untreated HCV cases

Rates of treated cases



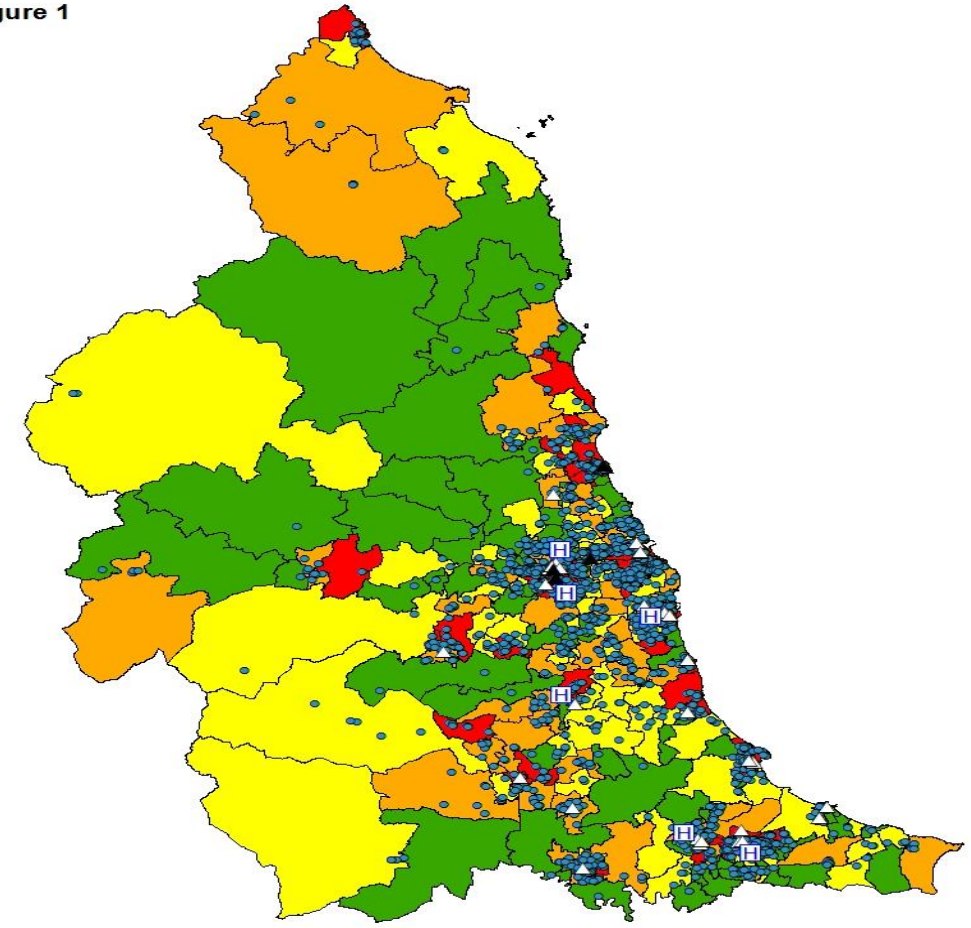
Rates of untreated cases



- 4243 reported HCV cases were identified.
- 858 (20%) were matched and had been treated,
- 3385 (80%) cases were untreated.

Map of untreated cases

Figure 1



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

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

If all drug services used this can increase to 70%

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

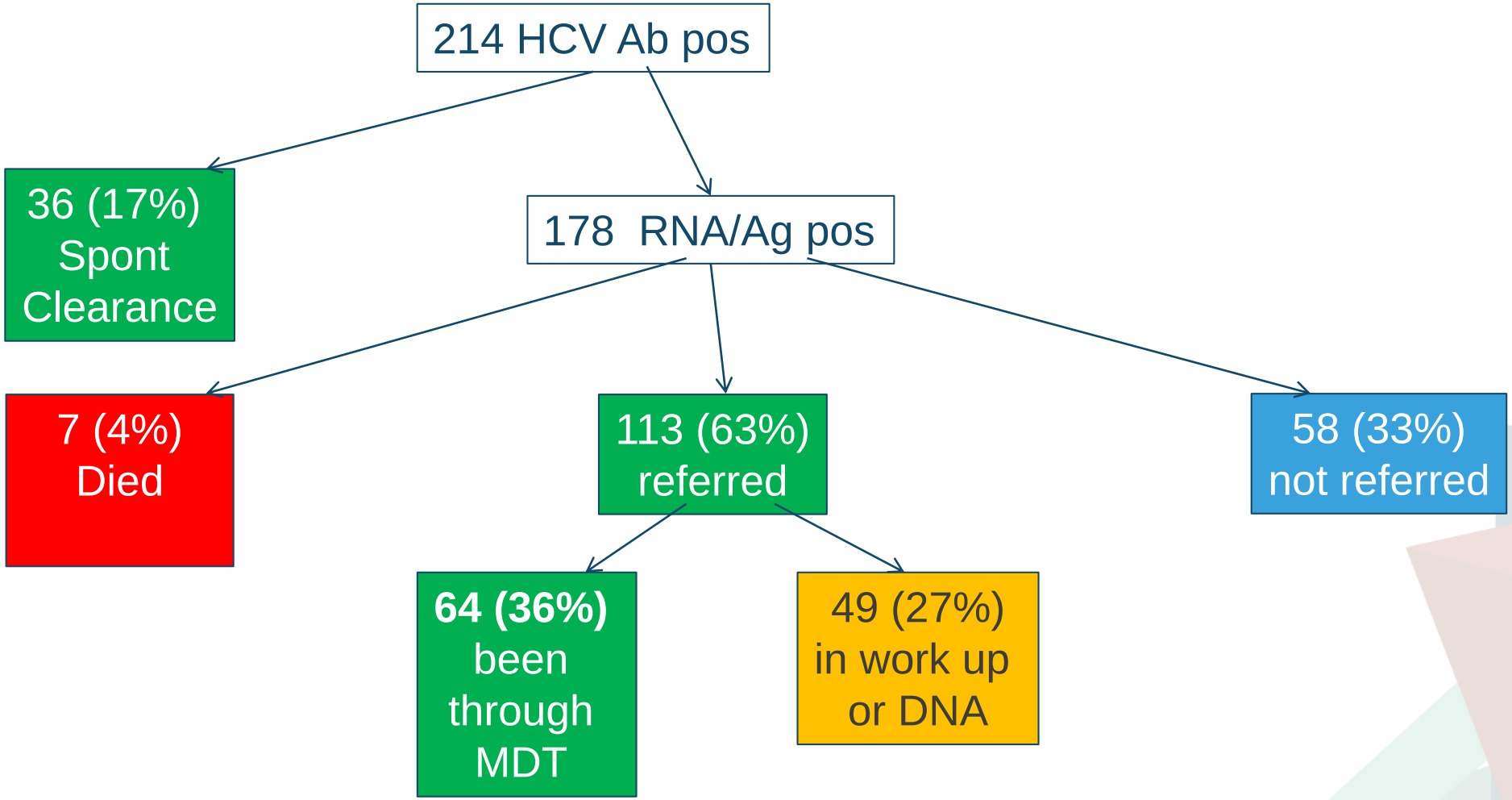
Use Summary care/Mermaid, E-record to filter out the deceased patients, treatment responders and those on treatment

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.

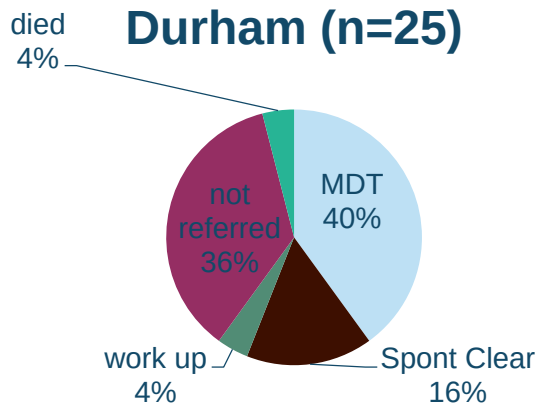
Patients who are unaware of their diagnosis should NOT be contacted directly. Contact should be made with their GP/DTC for discussion with the patient – follow up after duration of time and then if diagnosis awareness is confirmed the patient can be contacted and appt slot reserved and confirmed when referral received

What happened to the 2016 new HCV diagnoses in NE England?

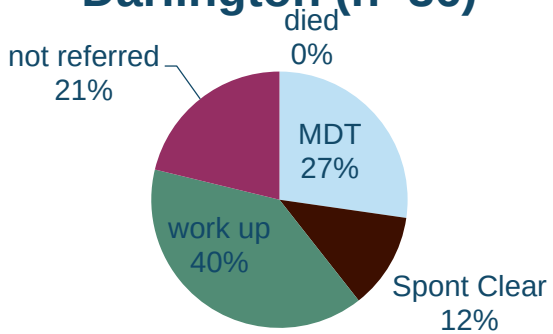


Treatment rates by postcode

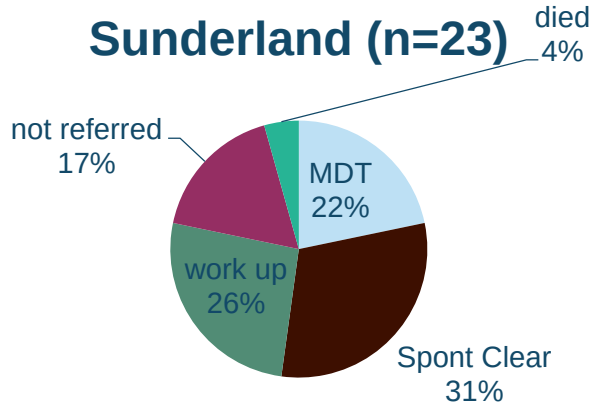
Durham (n=25)



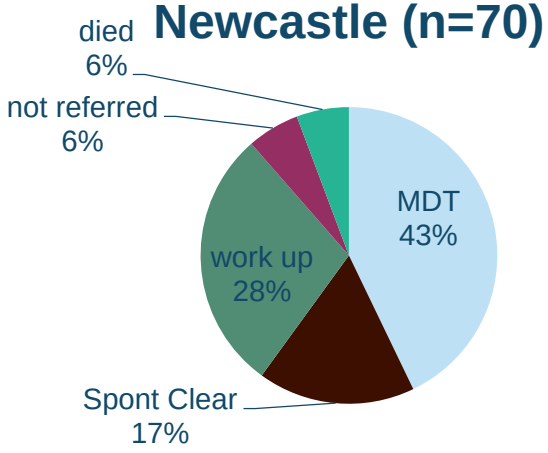
Darlington (n=36)



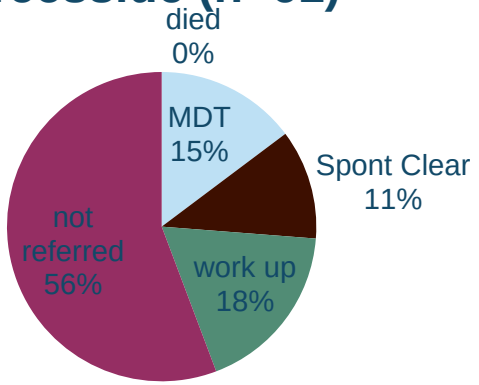
Sunderland (n=23)



Newcastle (n=70)



Teesside (n=61)



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

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Jane Knowles

Margaret Hewett

Harriet Mitchison

Julie Walker

The Newcastle upon Tyne Hospitals NHS Foundation Trust

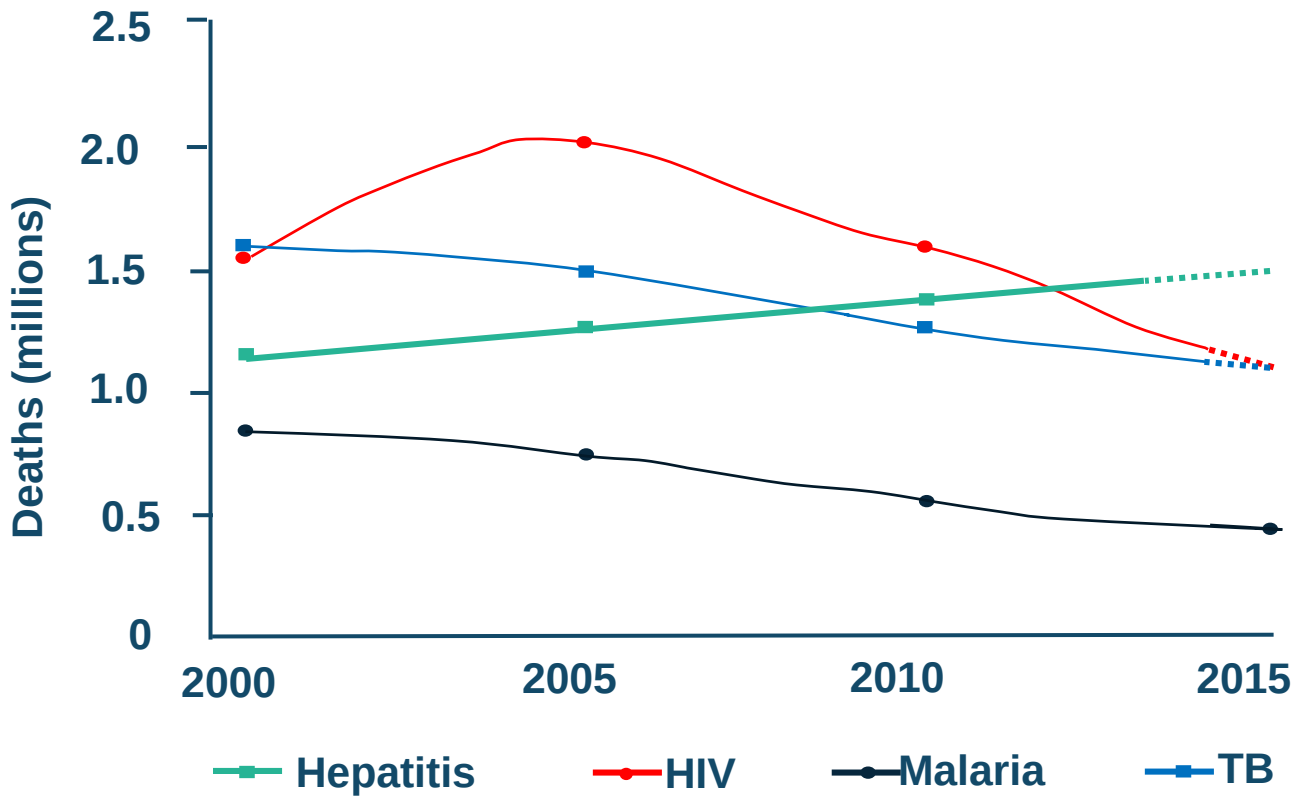
Community HCV models: Engaging the Disengaged

Sumita Verma

Reader in Medicine, BSMS

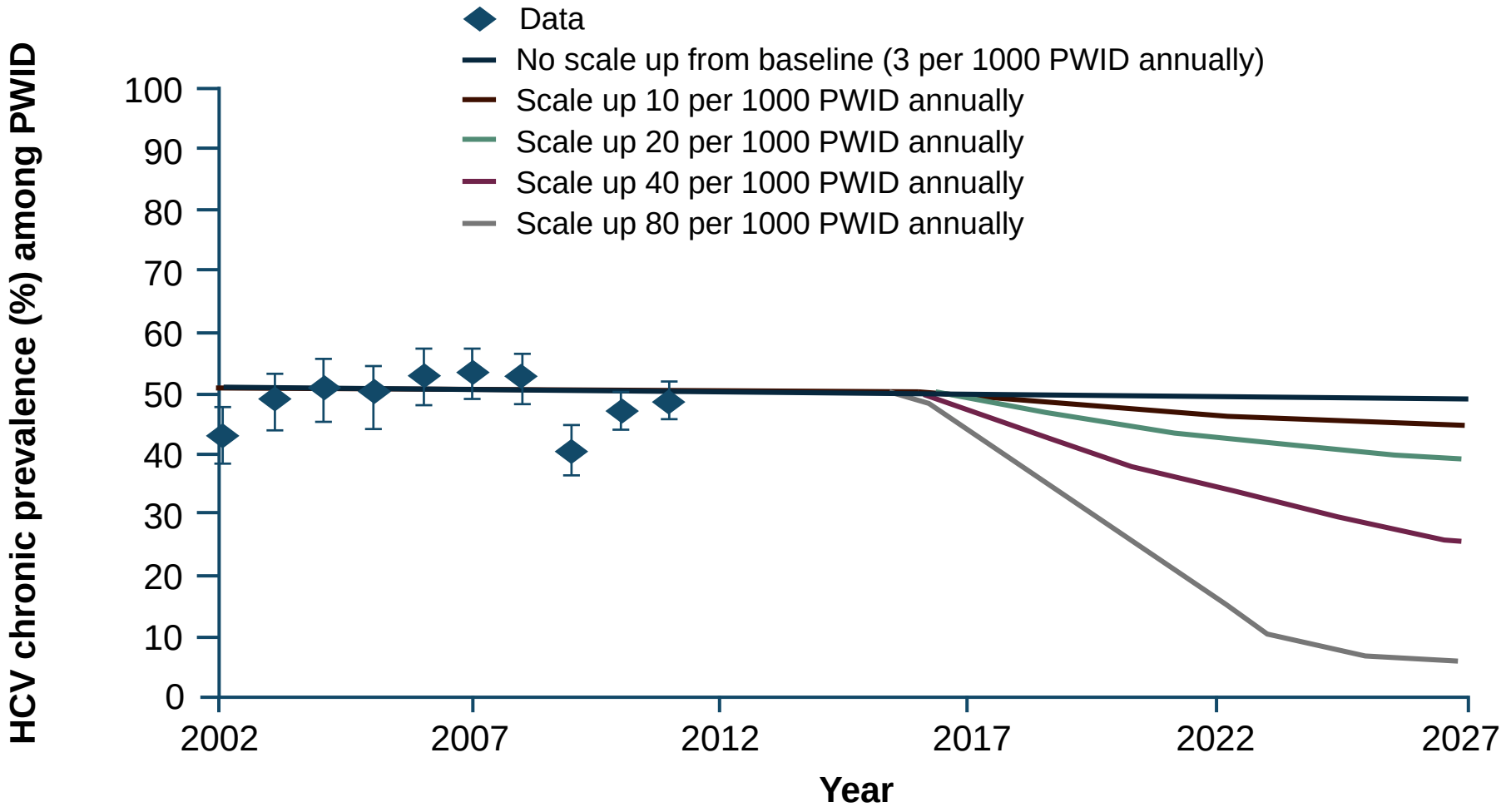
Hon Consultant Hepatology, BSUH

Estimated Global Number of Deaths Due to Viral Hepatitis, HIV, Malaria and TB (2000–2015)



Draft global health sector strategies. Viral hepatitis, 2016–2021: Available at: http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_32-en.pdf (Accessed April 2017)

HCV Treatment in People who Inject Drugs (PWID)



Martin NK, et al, Hepatol 2013;58:1598–609; Unlinked Anonymous Monitoring Survey of PWID Summary 2005-2015, Brighton

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. Olafsson[1,2], T. Tyrfingsson[3], V. Runarsdottir[3], O.M. Bergmann[1], E.S. Björnsson[1,2], B. Johannsson[4], B. Sigurdardottir[4], R.H. Fridriksdottir[1], A. Löve[2,5], T.J. Löve[2,6], G. Sigmundsdottir[7], M. Heimisdottir[2,8], M. Gottfredsson[2,4,6] and the TRAP HEP C Working Group. [1]*Gastroenterology and Hepatology, Landspitali University Hospital;* [2]*Faculty of Medicine, School of Health Sciences, University of Iceland;* [3]*Vogur Addiction Treatment Center;* [4]*Infectious Diseases;* [5]*Virology;* [6]*Department of Science, Landspitali University Hospital;* [7]*State Epidemiologist, Directorate of Health;* [8]*Department of Finance, Landspitali University Hospital, Reykavik, Iceland*
E-mail: sigurdol@landspitali.is

- More cost
- Moderate
- Mild fibros

CV prevalence

Martin NK, et al. J Hepatol 2016;65:17–25

Trying to Engage PWID

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

- Mar–Sept 2011
- 73 with positive BBV screen
  - 14 (19%) known to Hepatology services – 2 (3%) treated
- 40 eligible for HCV treatment
  - 8 (20%) accepted referral
  - **2 (5%) attended, none treated !!**

Marufu M, et al. J Med Virol 2012;84:1737–43

BBV: blood-borne virus

Stages in Developing a Community HCV Service

Establish unmet need for Community HCV service (2011)

↓

Engage with stakeholders: Commissioners, Hepatitis C Trust, British Liver Trust, Substance Misuse Service (SMS), Pharma (2011–2013)

↓

Develop team: Hepatologist, Hepatitis nurse, Psychiatrist, Qualitative researcher, Health economist, Statistician (2011–2013)

↓

Successful 2-yr funding BH Commissioners and National Gilead Fellowship (2013)
Two years additional funding Gilead ISR and BH Commissioners (2015)

↓

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)

Care Pathway

Participant attends drop-in liver clinic based at SMS/hostel, undergoes BBV screening (DBST/PCR). Engagement with key worker, provided mobile phone number for community hepatitis nurse/Research Fellow

HCV Ab -ve
Follow up as SOC

HCV Ab +ve
PCR test

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 fulfils national/exceptional criteria

Community nurse/Research Fellow monitor and assesses for SVR12, provide additional support

Encourage yearly HCV PCR test

ITTREAT and VALID: Interim Clinical Outcomes

No recruited	659 (80% men)
Age (yrs)	
ITTREAT	41 ± 9.9
VALID	49 ± 8.5

Updated data from ASSLD 2017

ITTREAT and VALID: Interim Clinical Outcomes

No recruited Age (yrs) ITTREAT VALID	659 (80% men) 41 ± 9.9 49 ± 8.5
IDU Alcohol Psychiatric illness	475 (72%) 552 (84%) 332 (50%)
Unstable housing	345 (52%)

Updated data from ASSLD 2017

ITTREAT and VALID: Interim Clinical Outcomes

No recruited Age (yrs) ITTREAT VALID	659 (80% men) 41 ± 9.9 49 ± 8.5
IDU Alcohol Psychiatric illness	475 (72%) 552 (84%) 332 (50%)
Unstable housing	345 (52%)
BBV uptake Positive HCV Ab Positive PCR GT 1/3 Prior HCV treatment	647/661 (98%) 354/659 (54%) 287/353 (81%) 51%/42% 14

Updated data from ASSLD 2017

ITTREAT and VALID: Interim Clinical Outcomes

No recruited Age (yrs) ITTREAT VALID	659 (80% men) 41 ± 9.9 49 ± 8.5
IDU Alcohol Psychiatric illness	475 (72%) 552 (84%) 332 (50%)
Unstable housing	345 (52%)
BBV uptake Positive HCV Ab Positive PCR GT 1/3 Prior HCV treatment	647/661 (98%) 354/659 (54%) 287/353 (81%) 51%/42% 14
Underwent fibroscan LSM > 7.5 kPa LSM > 12 kPa	312 115 (37%) 67 (21%)

Updated data from ASSLD 2017

ITTREAT and VALID: Interim Clinical Outcomes

Suitable for HCV treatment	216/287 (75%)
Commenced treatment	130/216 (60%)

Updated data from ASSLD 2017

ITTREAT and VALID: Interim Clinical Outcomes

Suitable for HCV treatment Commenced treatment	216/287 (75%) 130/216 (60%)
Ongoing IDU Ongoing non injecting drug use On going alcohol Unstable housing	18 (12%) 37 (28%) 40 (31%) 55 (42%)
Cirrhosis	42 (32%) 5 decompensated
GT 1/3	62/60

Updated data from ASSLD 2017

ITTREAT and VALID: Interim Clinical Outcomes

Suitable for HCV treatment Commenced treatment	216/287 (75%) 130/216 (60%)
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Cirrhosis	42 (32%) 5 decompensated
GT 1/3	62/60
P/R P/R/DAA DAA	16 (12%) 18 (14%) 96 (74%)

Updated data from ASSLD 2017

ITTREAT and VALID: Interim Clinical Outcomes

Suitable for HCV treatment Commenced treatment	216/287 (75%) 130/216 (60%)
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Cirrhosis	42 (32%) 5 decompensated
GT 1/3	62/60
P/R P/R/DAA DAA	16 (12%) 18 (14%) 96 (74%)
SVR EOTR On going Other outcomes	**85/96 (88%)** 18 (14%) 16 (12%) 11 (8%): 5RR, 1PR, 3D/C, 2 RIP, 1 lost FU

Updated data from ASSLD 2017

ITTREAT and VALID: Interim Clinical Outcomes

Suitable for HCV treatment Commenced treatment	216/287 (75%) 130/216 (60%)
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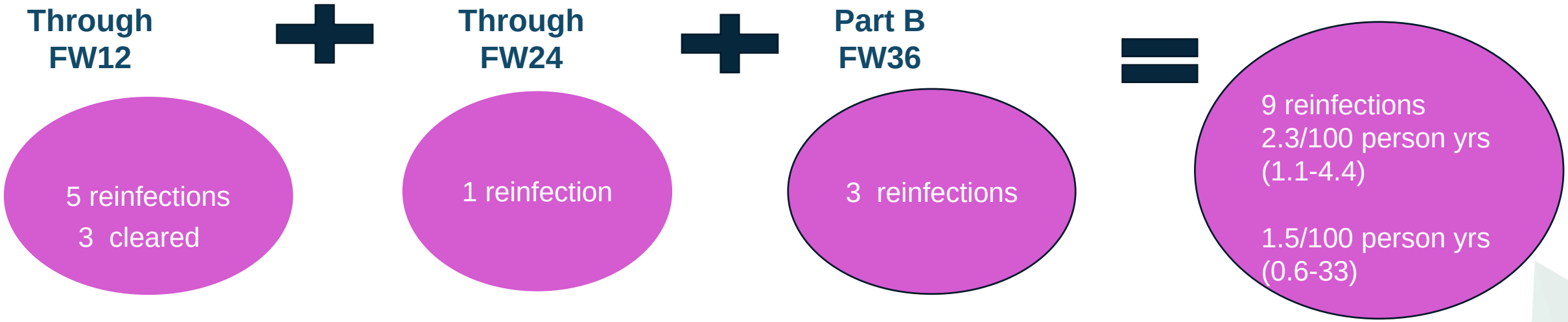
Cirrhosis	42 (32%) 5 decompensated
GT 1/3	62/60
P/R P/R/DAA DAA	16 (12%) 18 (14%) 96 (74%)
SVR EOTR On going Other outcomes	**85/96 (88%)** 18 (14%) 16 (12%) 11 (8%): 5RR, 1PR, 3D/C, 2 RIP, 1 lost FU
Compliance with clinic visit	**97%**
Reinfection till date	1/41

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)

Dore G, AASLD 2016 Oral #871; Dore G, AASLD 2017 oral #195; Johnston L, EASL 2017 # 278

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

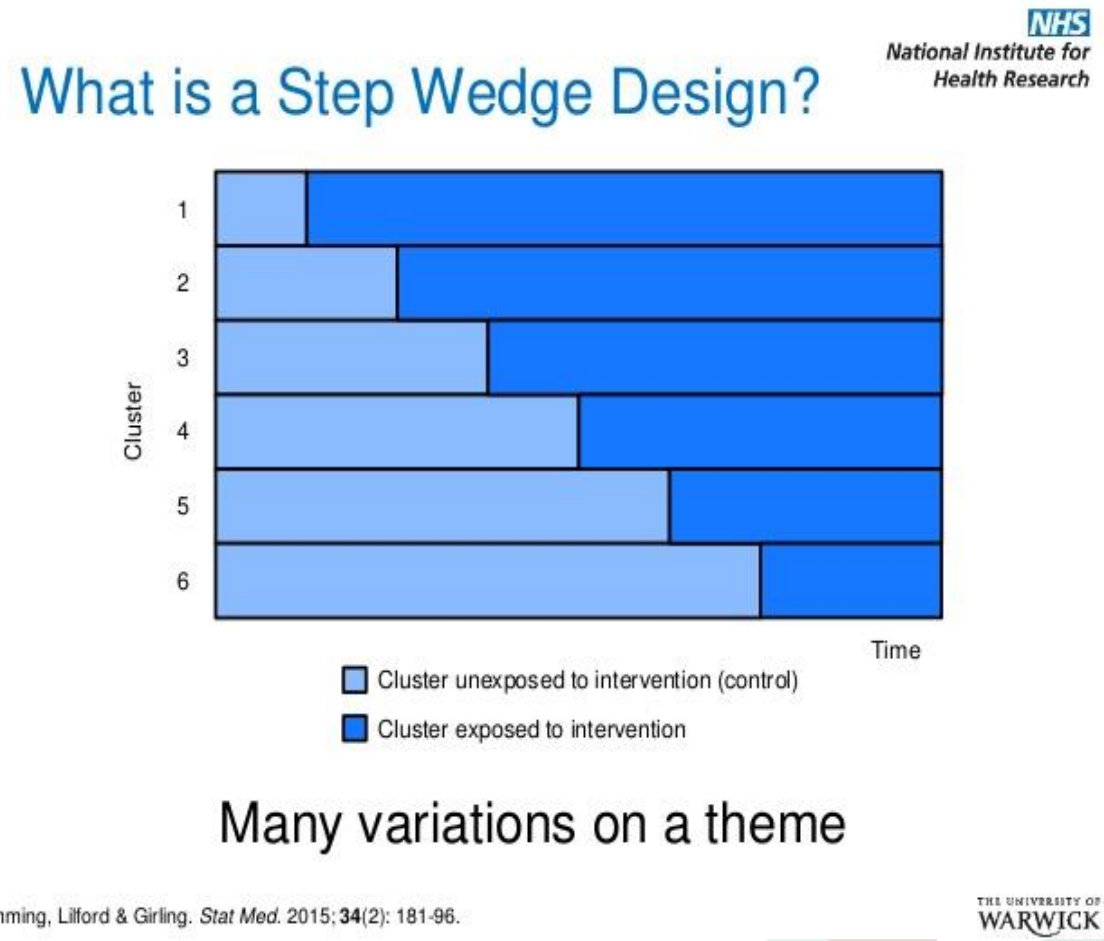
Ryder S et al , HSJ May 2014

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



Click here to visit the website:

Gilead UK and Ireland Fellowship Programme

www.ukifellowshipprogramme.com

NHS Brighton and Hove Clinical Commissioning Group

Brighton and Sussex University Hospitals NHS Trust

PAVILIONS

brighton and sussex medical school

Sussex Partnership NHS Foundation Trust

Anna-Marie Jones

Chrissie Jones

Margaret O'Sullivan

Hugh Williams

Heather Gage

brighton and sussex medical school

NDDC BRU
Nottingham Digestive Diseases Centre
Biomedical Research Unit

Brighton and Sussex University Hospitals NHS Trust

NHS

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www.ukifellowshipprogramme.com

KSS NHS Postgraduate Deanery for Kent, Surrey and Sussex
remote.kssdeanery.ac.uk

The Dunhill Medical Trust

Tim Worthley

Stephen Bremner

Ahmed Hashim

Guru Aithal

BHWC community
Sharing knowledge, to help each other achieve a healthy lifestyle & overall wellbeing.
Brighton Health & Wellbeing Centre UK (wellbeing-centre.org)

NHS
Brighton Homeless Healthcare

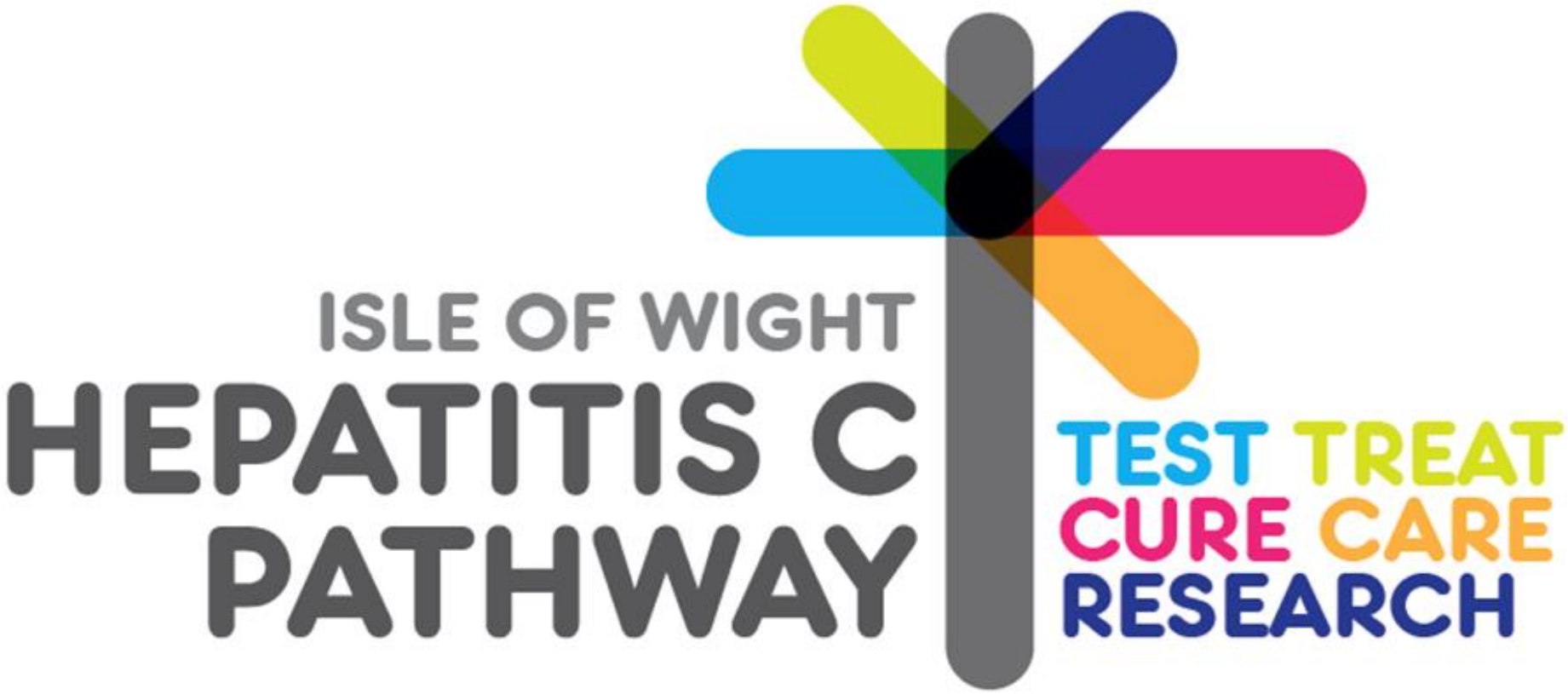
Brighton & Hove City Council

Riverside

Towards the elimination of Hepatitis C on the Isle of Wight

Ryan Buchanan


Gurnard Bay
Cowes
East Cowes
Osborne Bay
Thorness Bay
Newtown Bay
Gurnard
Whippingham
Northwood
Fishbourne
Ryde
Puckpool Point
Spring Vale
Seaview
Binstead
Wootton Bridge
River Medina
Hamstead
Porchfield
Newtown
Parkhurst
Haven Street
Nettlestone
Nodes Point
St Helens
Bembridge
Yarmouth
Sconce Point
Cranmore
Shalfleet
Thorley
Ningwood
Carisbrooke
Newport
Shide
Downend
Arreton Down
Brading Down
Brading
Whitecliff Bay
Colwell Bay
River Yar
Wellow
Newbridge
Totland Bay
Freshwater
Totland
Alum Bay
Afton
Calbourne
Bowcombe
Blackwater
Arreton
Langbridge
Adgestone
Morton
Yaverland
Tennyson Down
Freshwater Bay
Chessell
Newbarn Down
Westover Down
Brighstone Down
Gatcombe
Merstone
Newchurch
Alverstone
Whitecliff Point
Culver Cliff
The Needles
Freshwater Bay
Compton Bay
Mottistone
Brook
Rookley
Sandown
Chillerton
Apse Heath
Brighstone
Shorwell
Godshill
Sandford
Sandown Bay
Brook Bay
Yafford
Whiteley Bank
Shanklin
St Martins Down
Wroxall
Atherfield Green
Chale Green
Brighstone Bay
Week Down
Wroxall Down
Bonchurch
Atherfield Point
Whitwell
Chale
Niton Down
Ventnor
Chale Bay
Blackgang
Niton
St. Lawrence
Ventnor Bay
Rocken End
Binnel Bay
St Catherine's Point


ISLE OF WIGHT
HEPATITIS C
PATHWAY
TEST TREAT
CURE CARE
RESEARCH

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

... NONE

KATIE SHOWS ALL THE SIGNS THAT SHE HAS HEPATITIS C...

For more information on risks visit **www.hepctrust.org.uk**

THE HEPATITIS C TRUST

ISLE OF WIGHT HEPATITIS C PATHWAY TEST TREAT CURE CARE RESEARCH

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

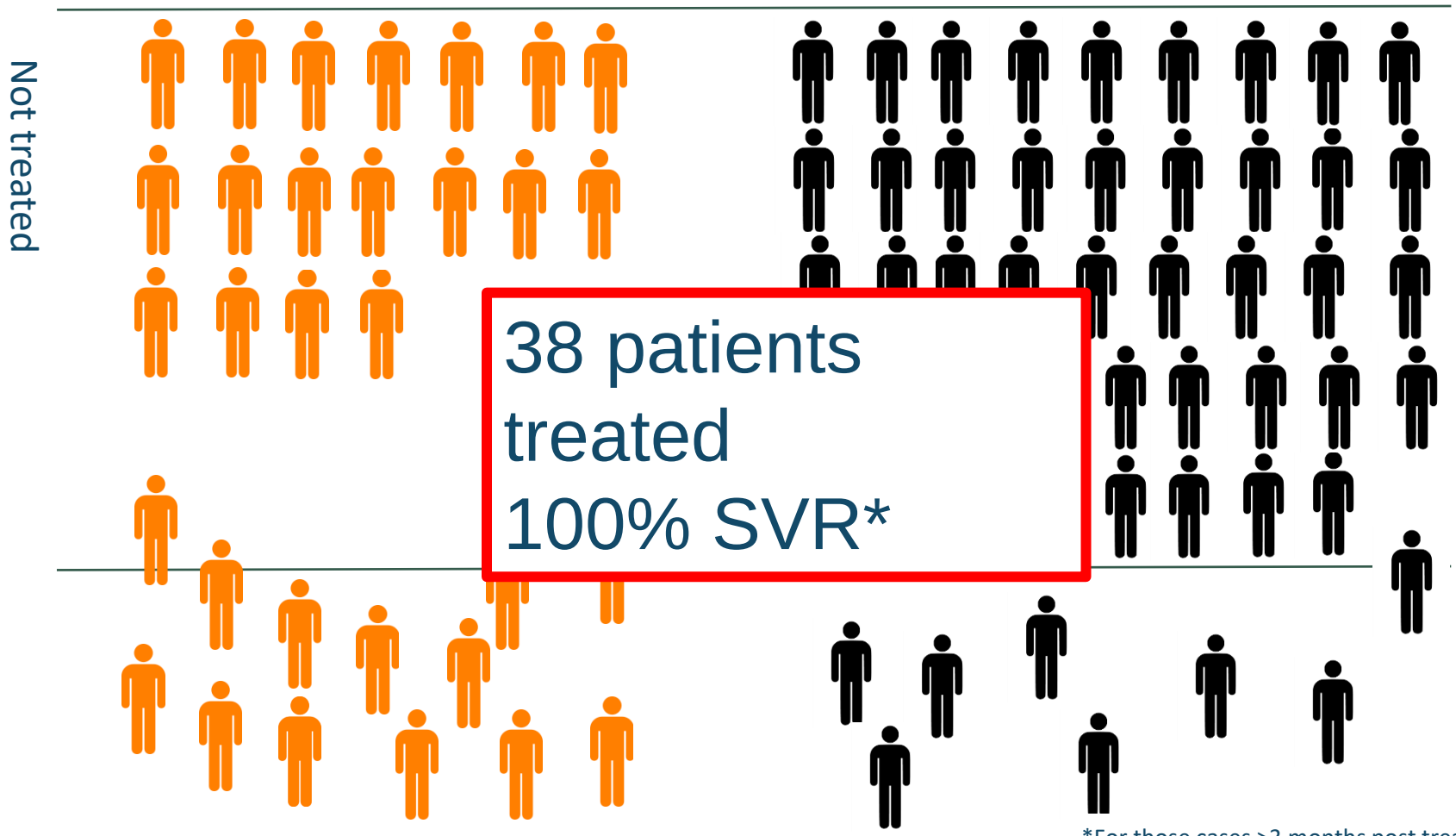
3 on waiting list for treatment

2 treated with SVR12

Pharmacist

PharmOutcomes® Delivering Evidence

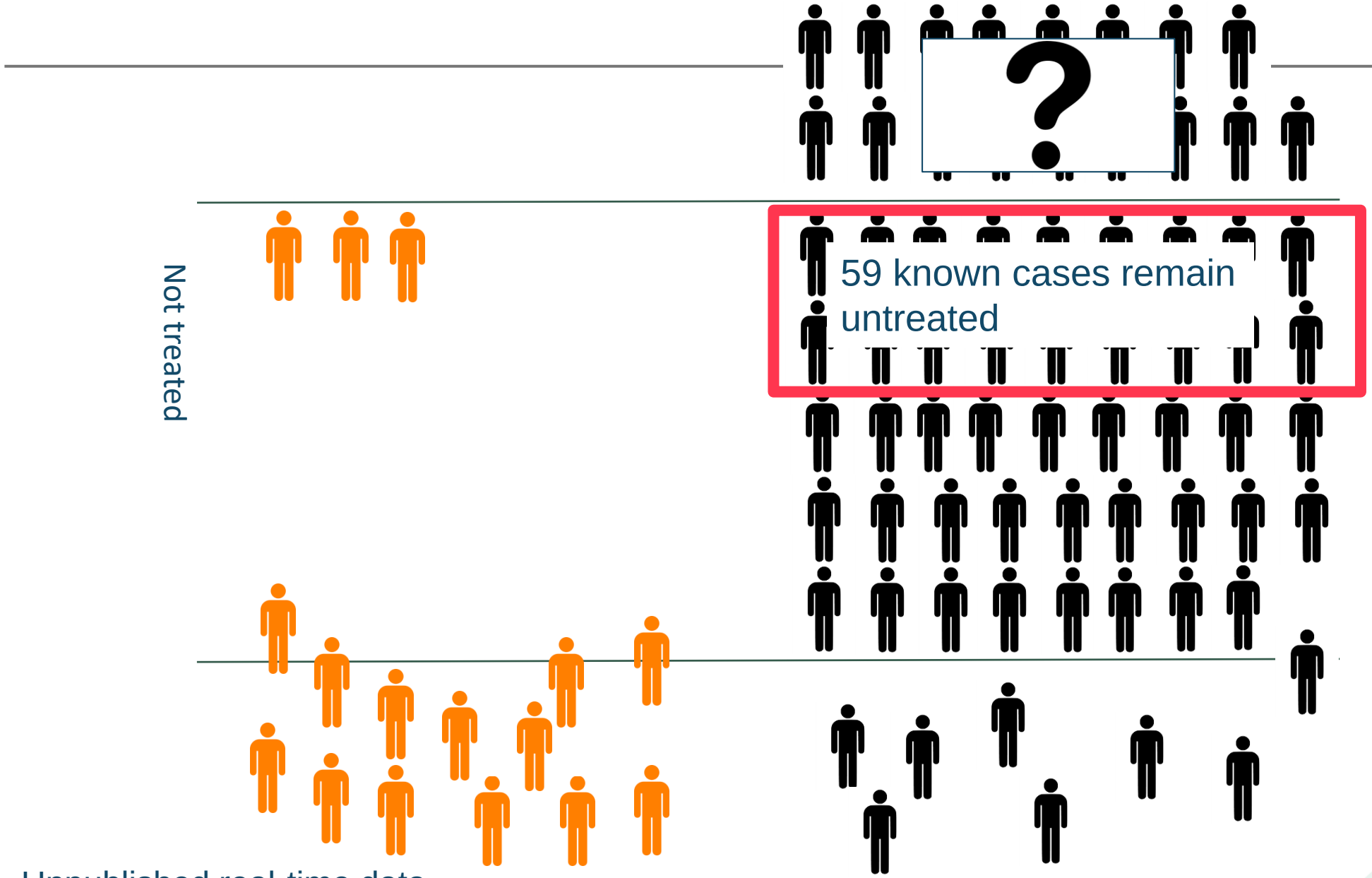
Locally available treatment



*For those cases >3 months post treatment

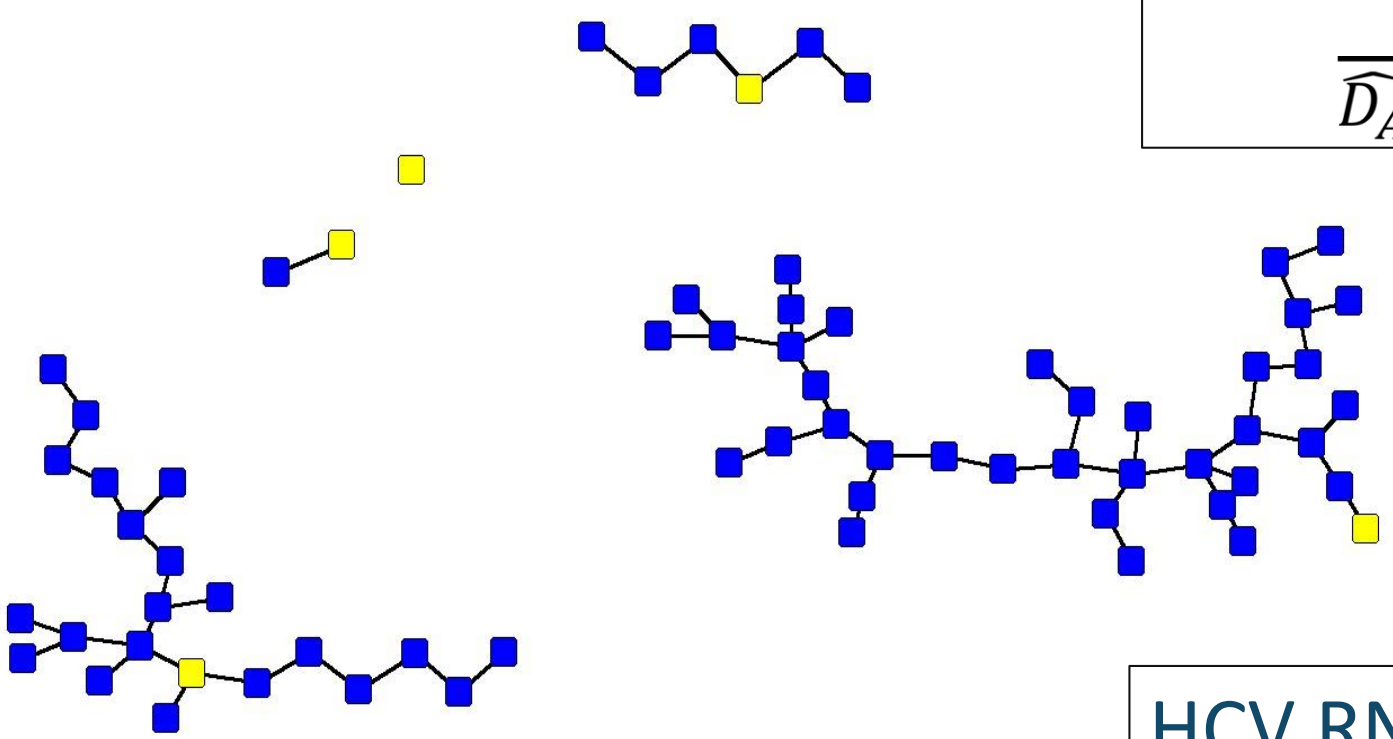
Unpublished data Sept ‘17

Challenges to meet elimination



Unpublished real-time data

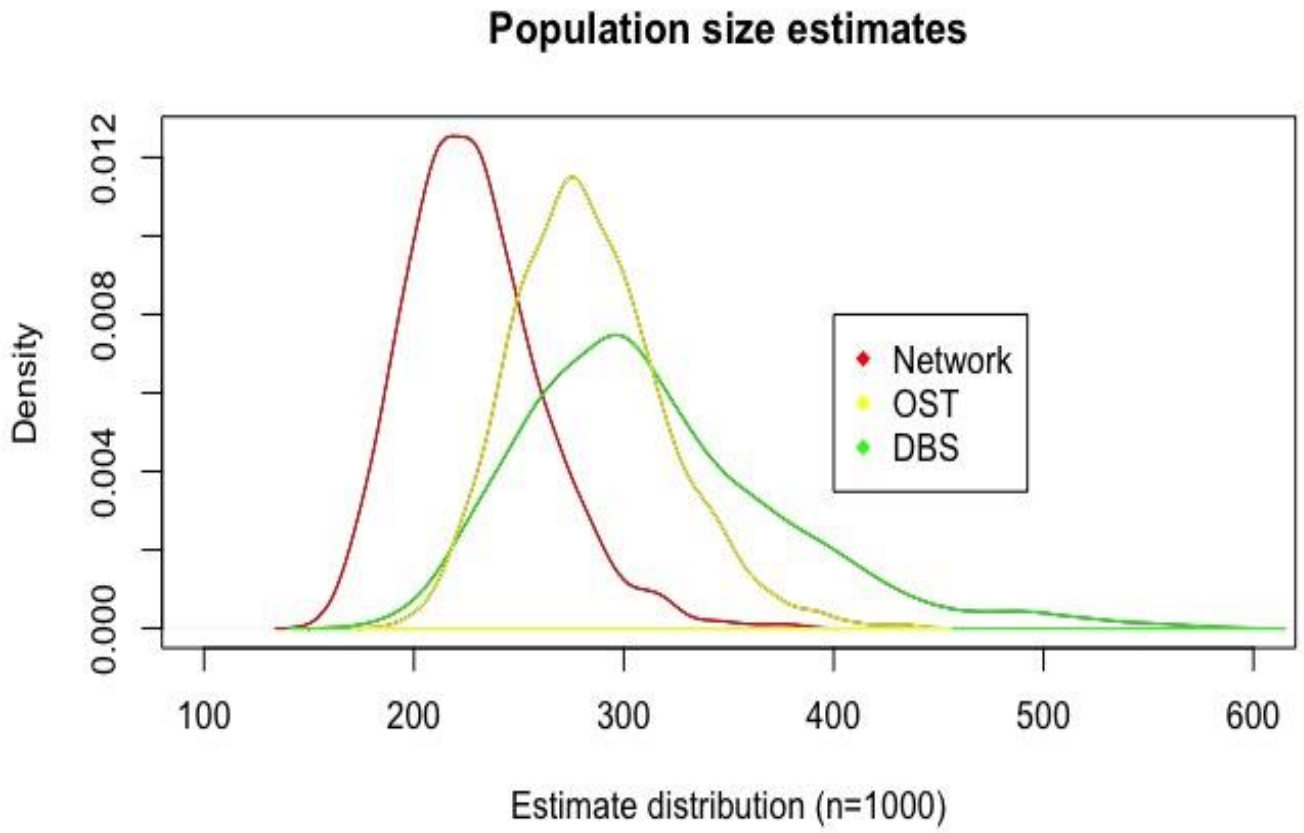
Redefining the Hepatitis C disease burden



$$\frac{\widehat{D_B} \cdot \widehat{C_{B,A}}}{\widehat{D_A} \cdot \widehat{C_{A,B}} + \widehat{D_B} \cdot \widehat{C_{B,A}}} = \widehat{PP_A}$$

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

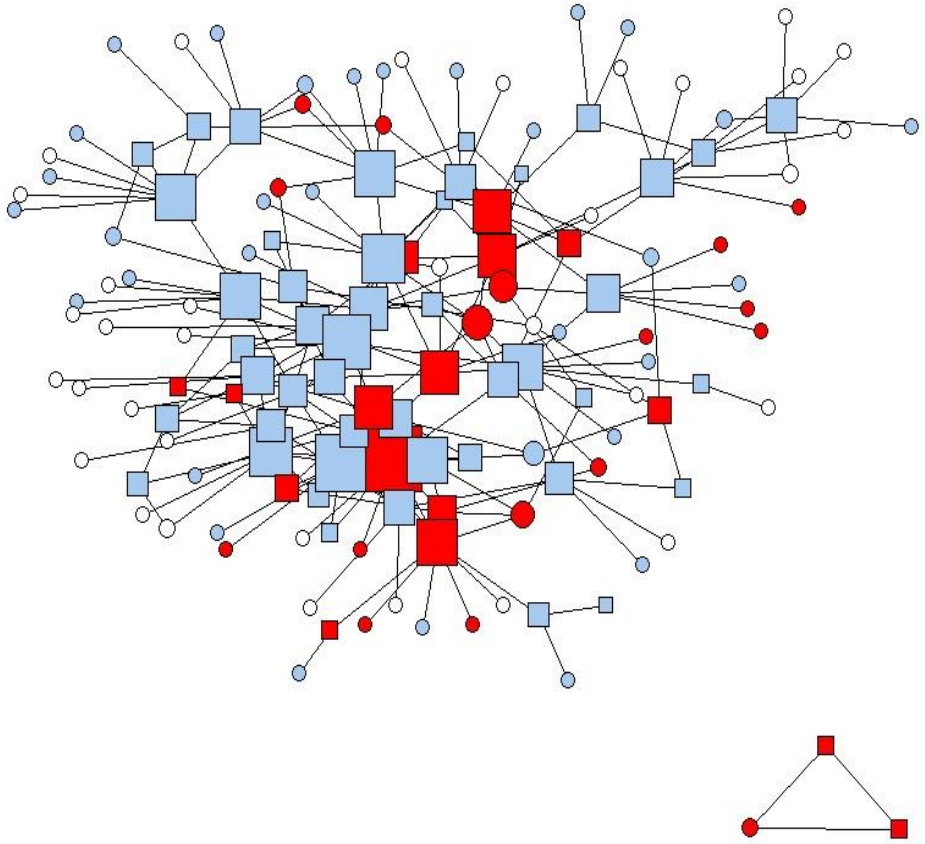
Redefining the Hepatitis C disease burden

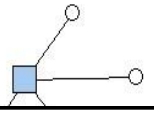
Risk Group	Number in group	HCV Prevalence in group (%)	Cases
PWID	~~474~~ *262*	~~39~~ *29*	~~181~~ *76*
Ex-PWID	311	24	75
General pop.	130,000	0.006	65
Non-white ethnic.	400	0.01	2
		Total	~~323~~ **218**

Unpublished data

Health Protection Agency – Hepatitis C in South-East England. 2011.

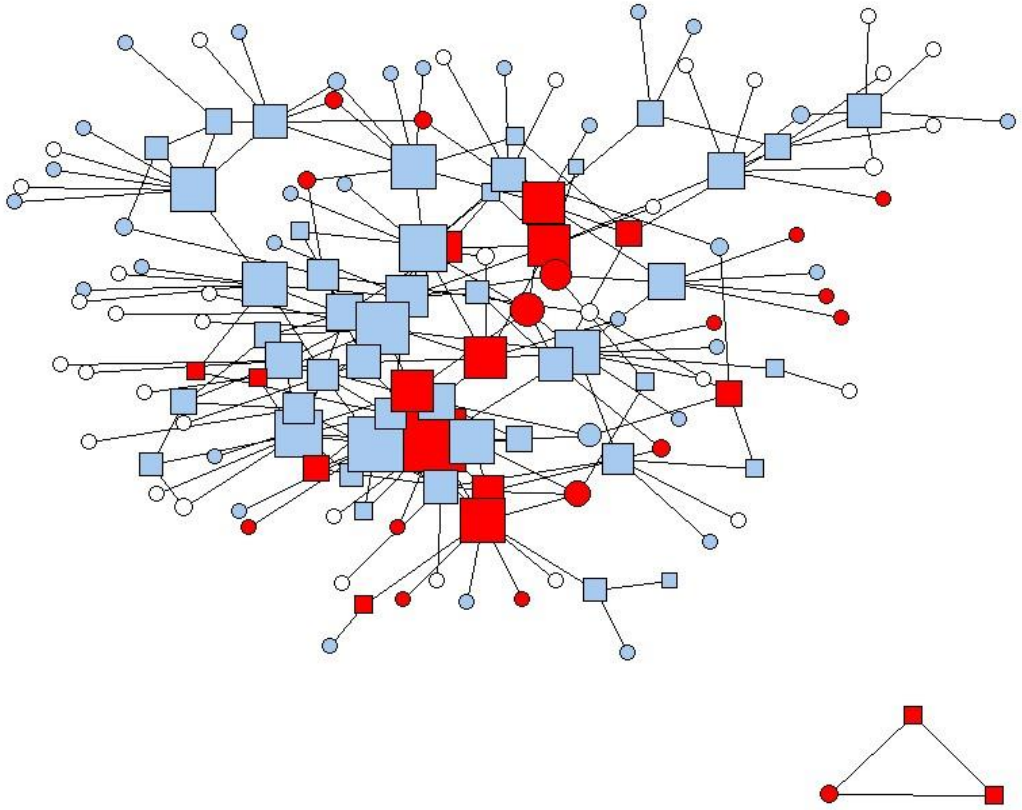
Engaging the disengaged

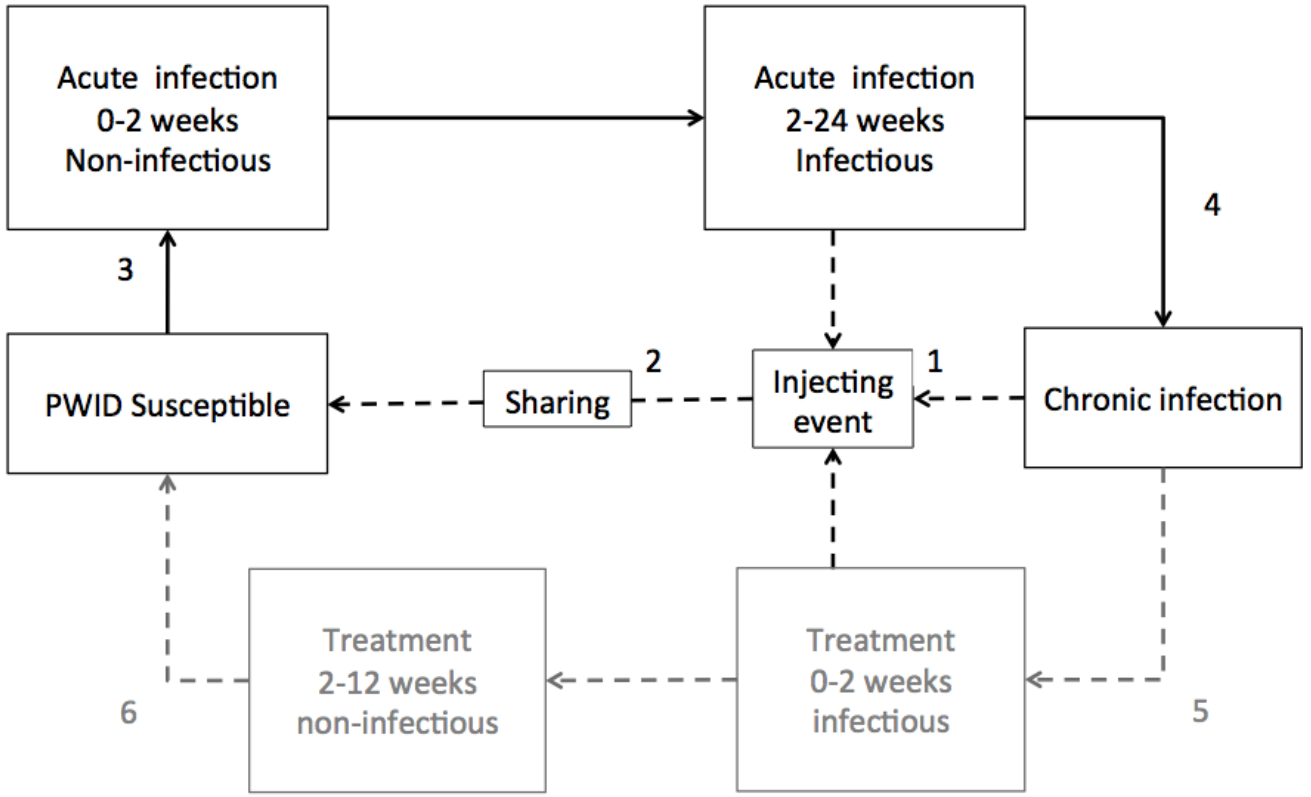




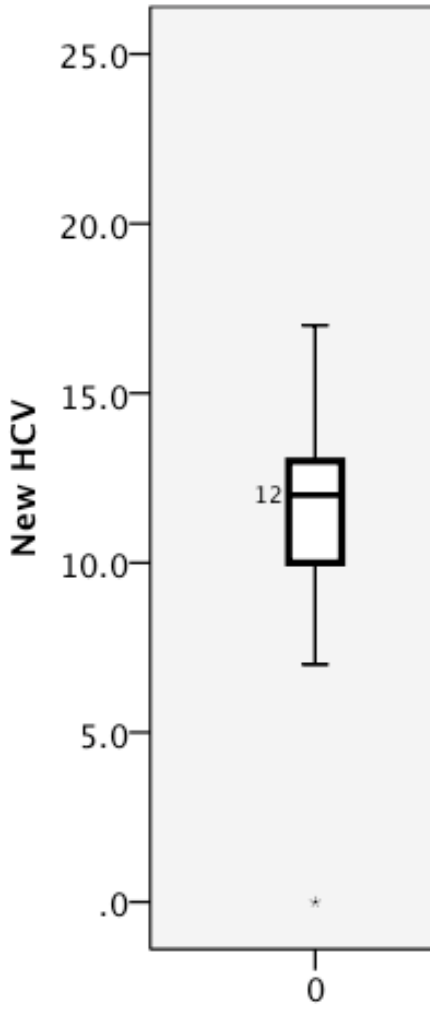
	Specificity	Sensitivity	PPV	NPV
Ego-alter HCV status report accuracy	0.81	0.82	0.84	0.79
Network-nodal report accurately	0.90	0.78	0.74	0.92

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

Ryan Youde (medical student, University of Southampton)

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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

NIHR CLAHRC Wessex in partnership with:

UNIVERSITY OF Southampton

GILEAD
Advancing Therapeutics.
Improving Lives.

NHS
Isle of Wight

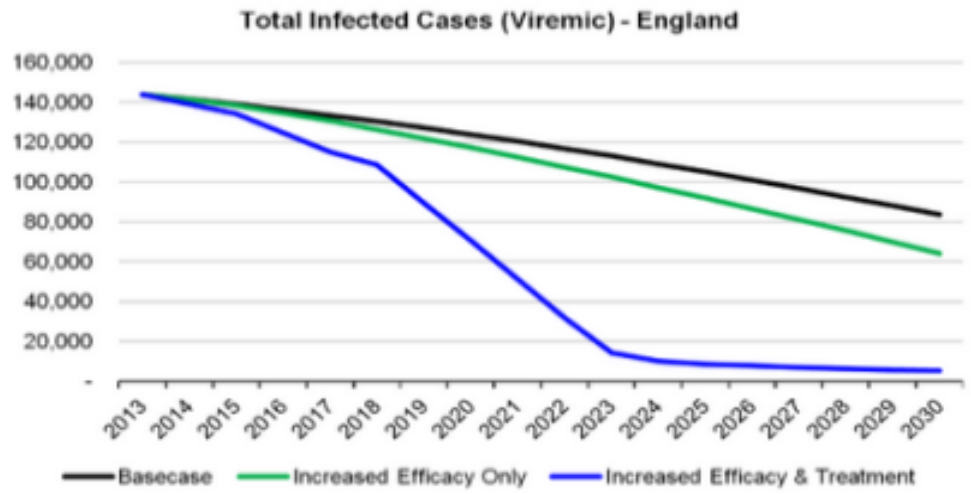
Pinnacle
HEALTH PARTNERSHIP

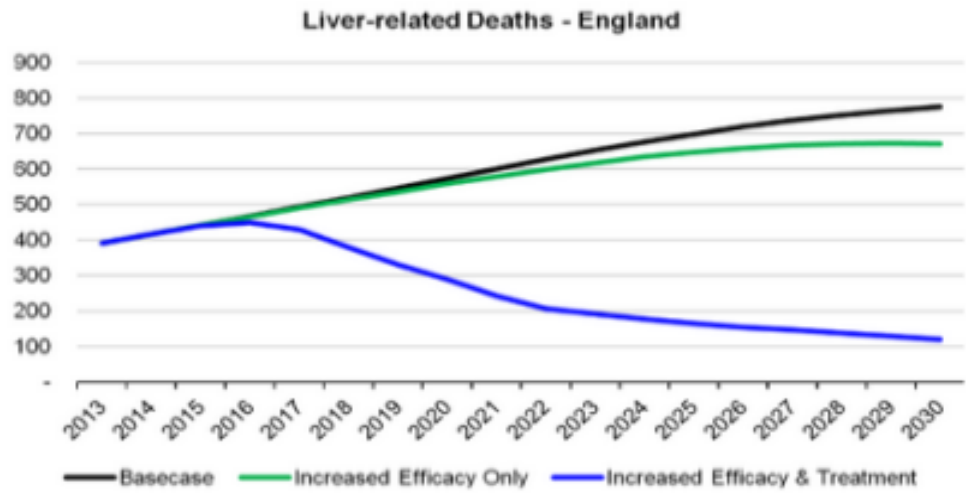
Thank you for listening

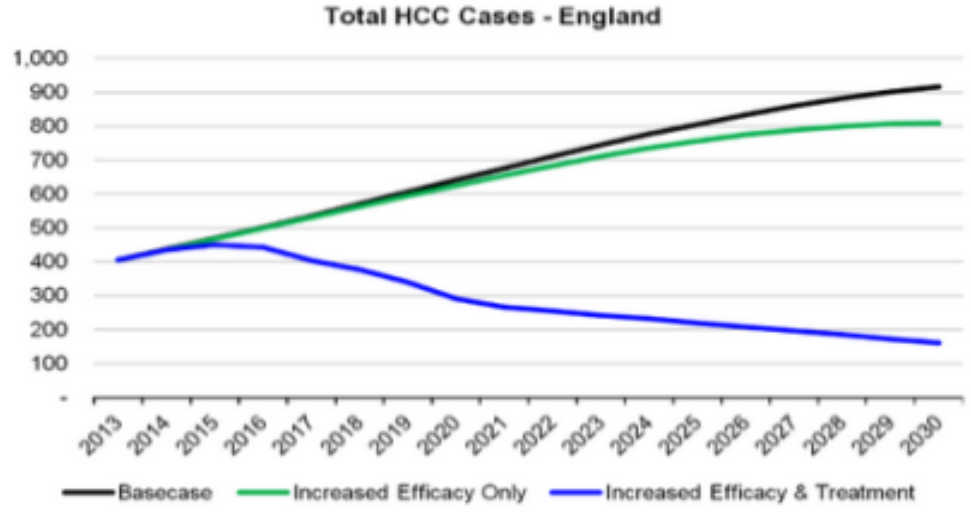
Greater Manchester Elimination Plans

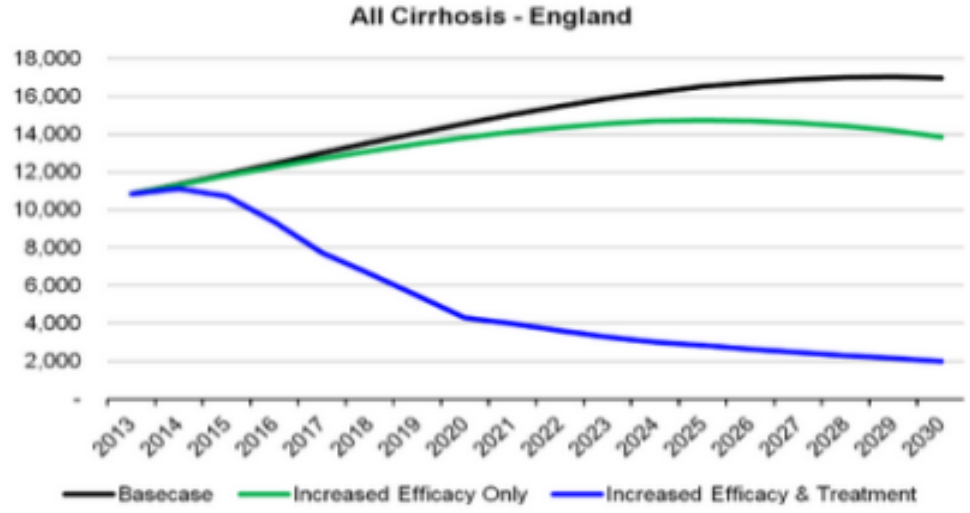
Andy Ustianowski

Elimination is possible



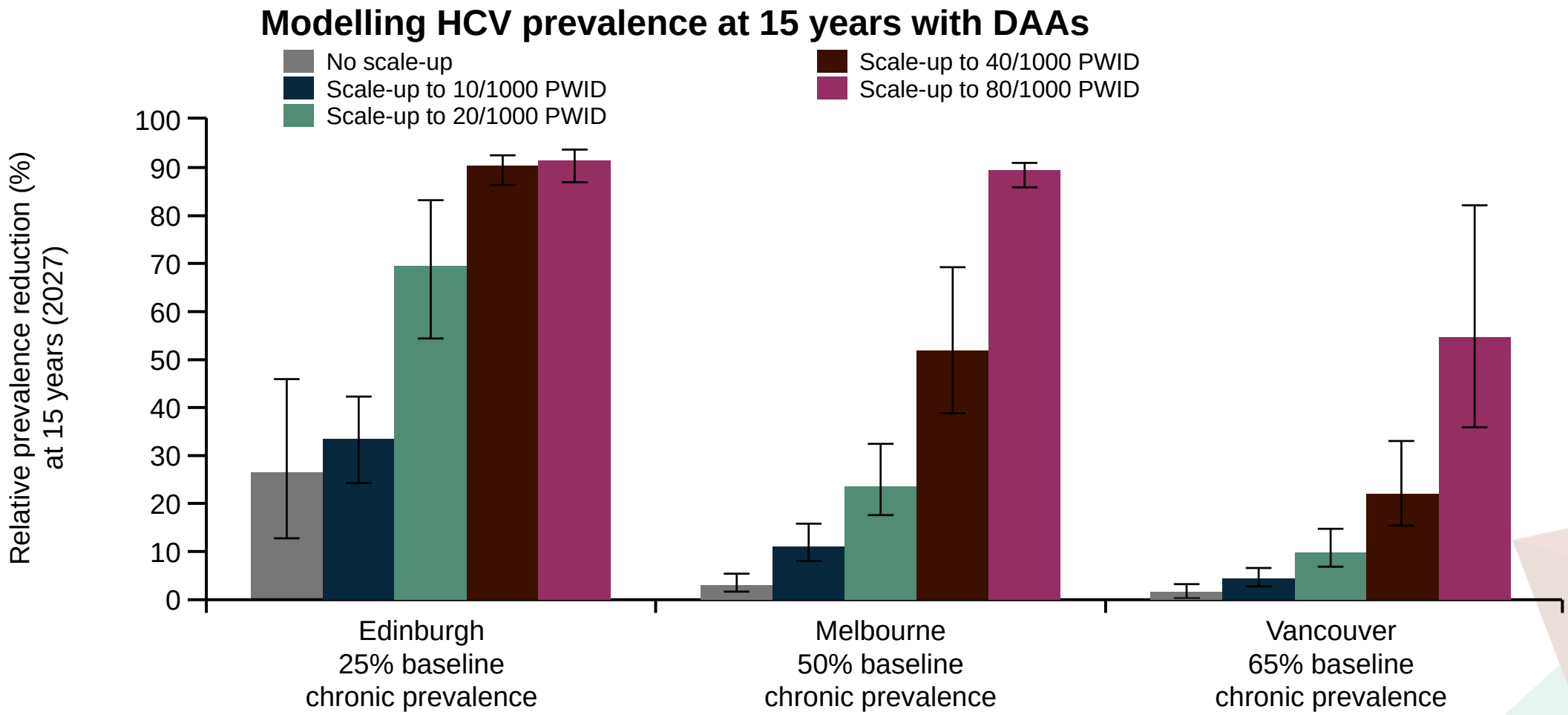






Wedemeyer et al, JVH April 2014

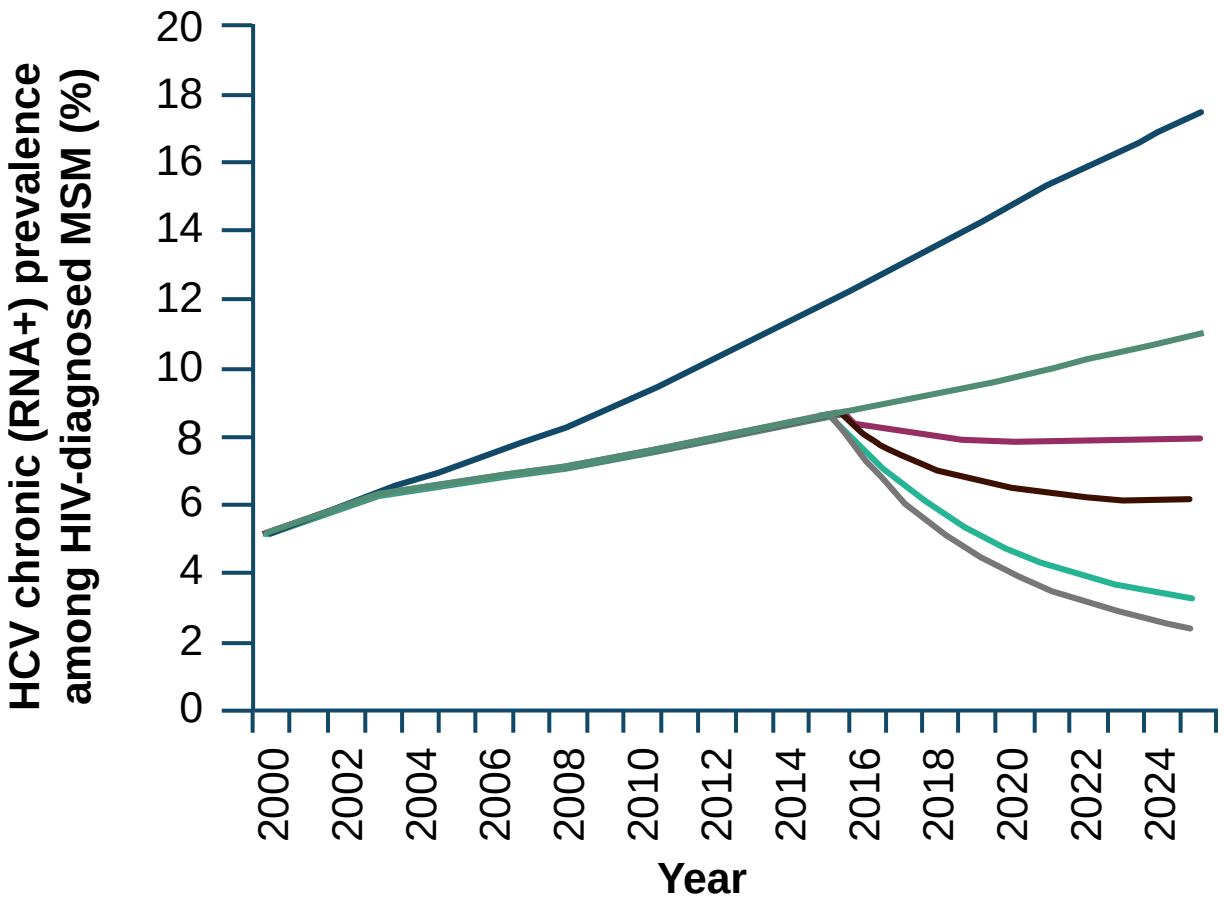
There is modelling – People Who Inject Drugs



*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

Martin NK, et al. Hepatology 2013;58:1598–609

There is modelling – Men who have Sex with Men

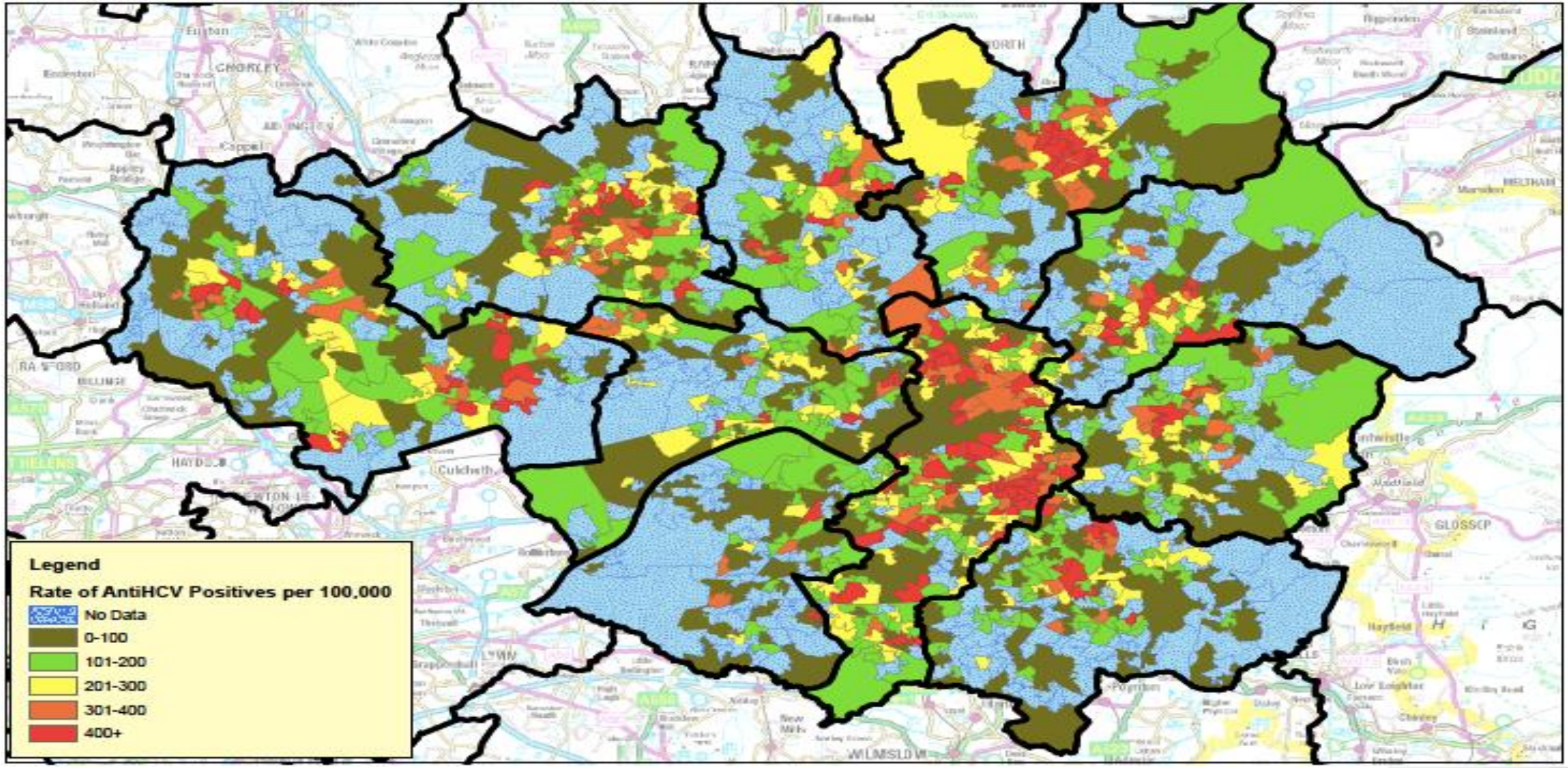


- No treatment
- PEG-IFN + RBV
  Current treatment rate
- DAAs from 2015 (SVR 90%)
  Current treatment rate
- DAAs from 2015 (SVR 90%)
  Scale-up treatment for recent diagnoses (<1 year) to **80%**
- DAAs from 2015 (SVR 90%)
  Scale-up treatment for recent diagnoses to **80%** AND non-recent diagnoses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

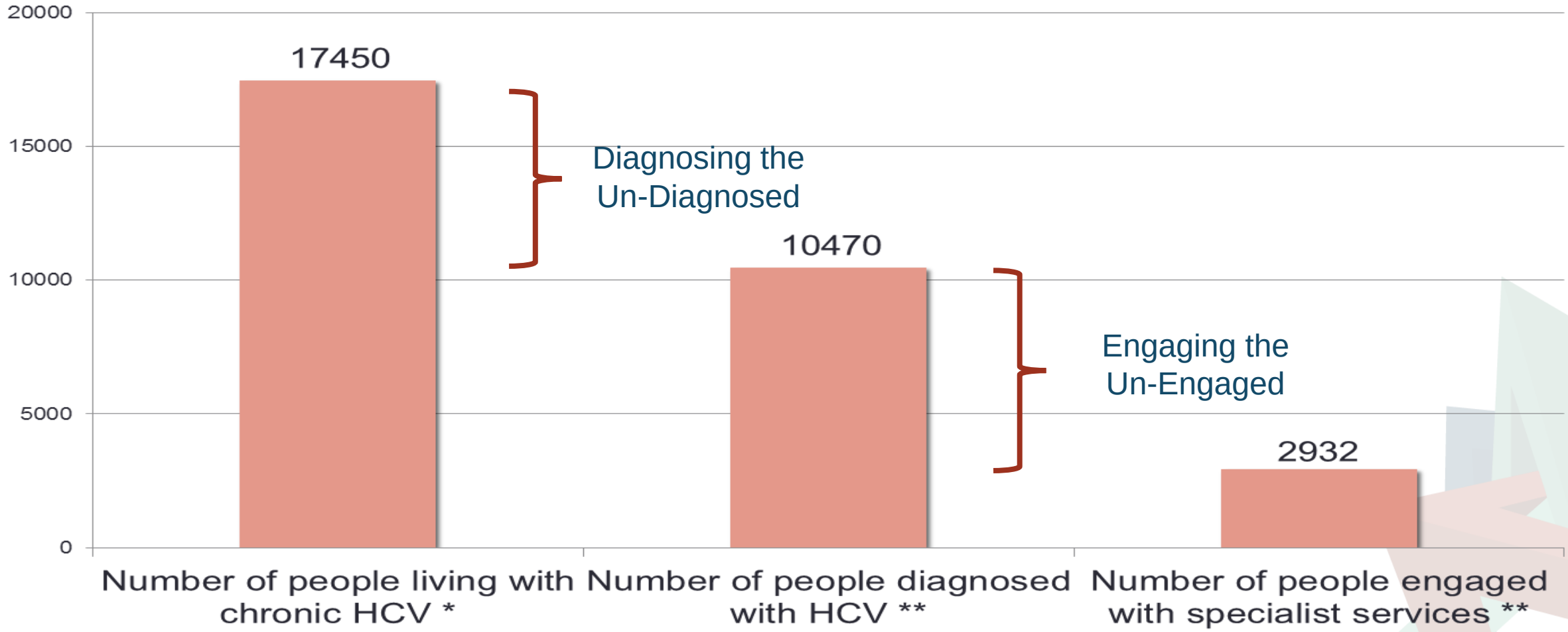
DAA: direct-acting antiviral; MSM: men who have sex with men; PEG-IFN: pegylated interferon; SVR: sustained virological response

Martin N, et al. Clin Infect Dis 2016; 62:1072–80

GM HCV Elimination



Attrition Tree… Greater Manchester



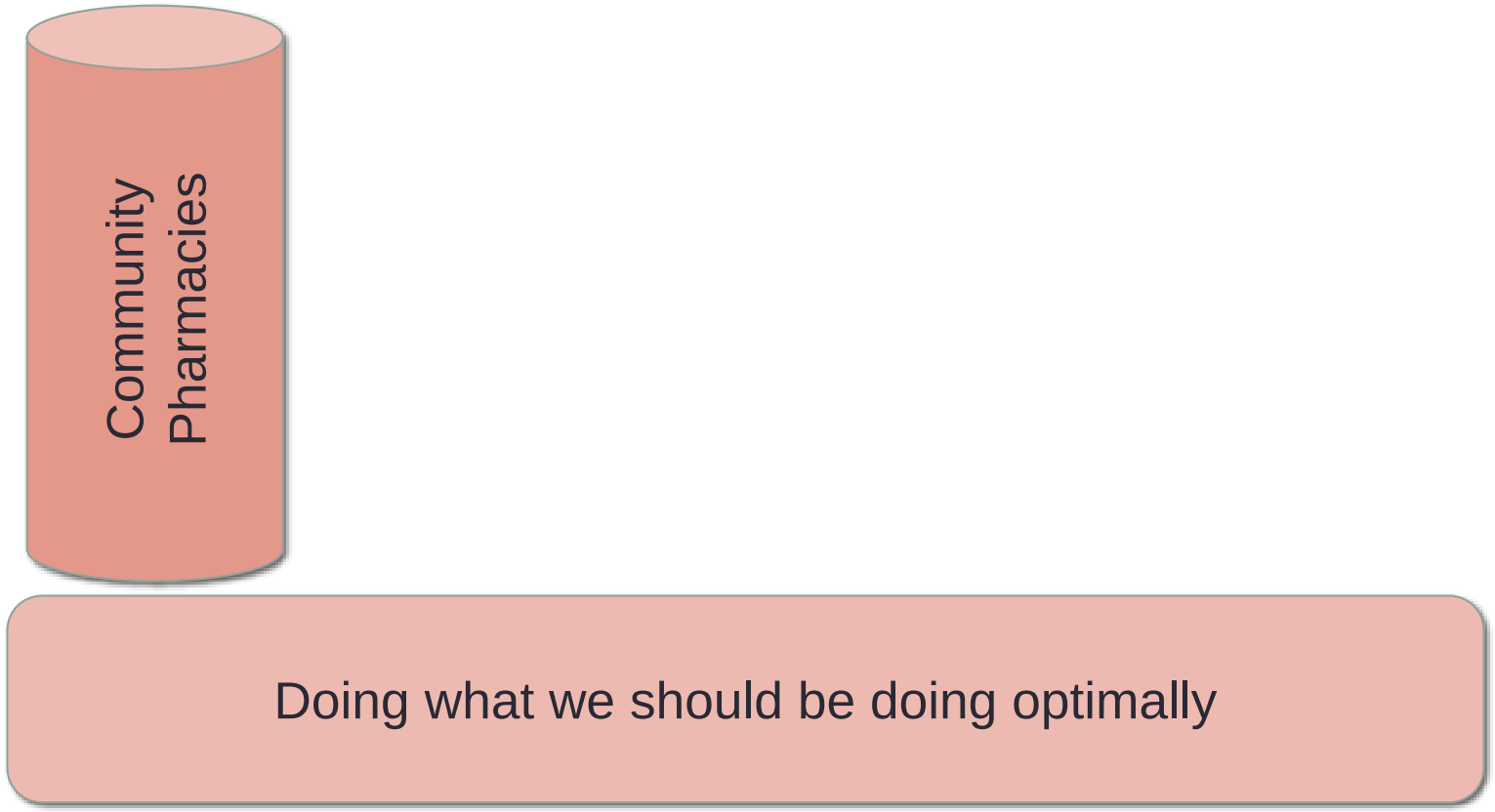
*Based on data from https://www.gov.uk/government/publications/hepatitis-c-commissioning-template-for-estimating-disease-prevalence

** 60% aware of diagnosis, based on data from Health Protection reported in (1)

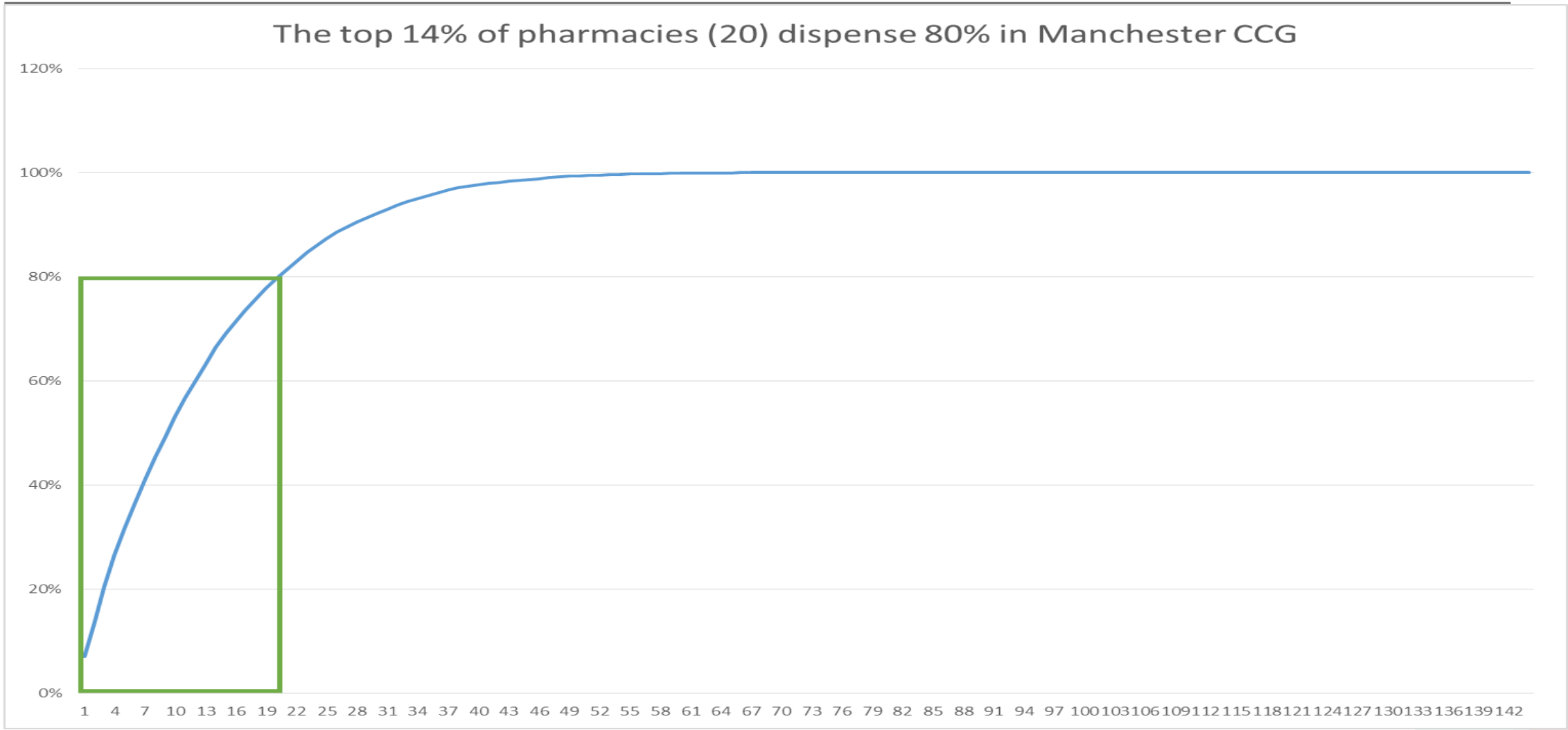
***28% patients diagnosed with chronic HCV in 2014 seen by specialist in 2014 reported in (1)

Hepatitis C in the UK 2015 report – Public Health England, Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/448710/NEW_FINAL_HCV_2015_IN_THE_UK_REPORT_28072015_v2.pdf

GM HCV Elimination Strategic Pillars

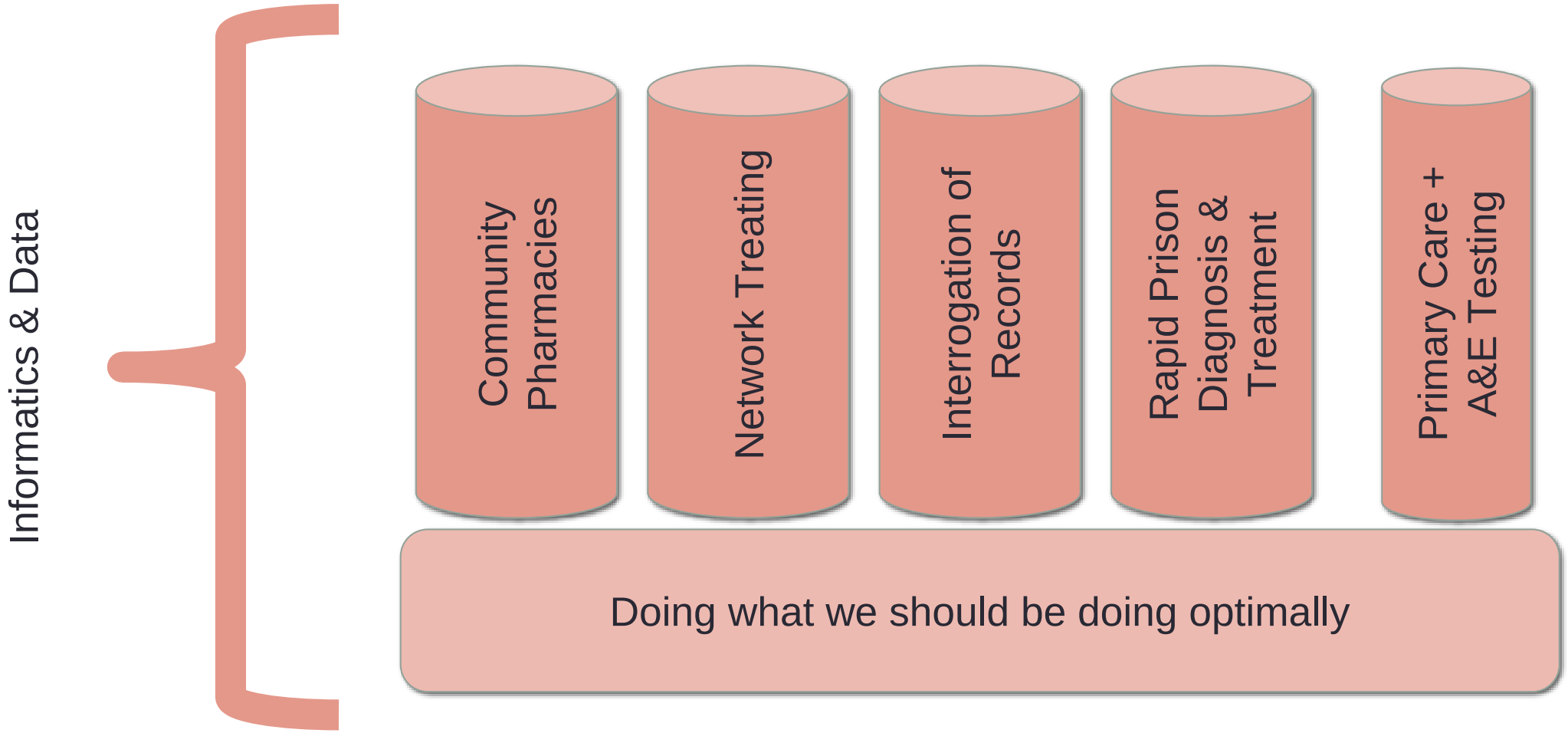


Analysis of pharmacies who dispense heroin substitutes identifies concentration within CCG's (hotspots)



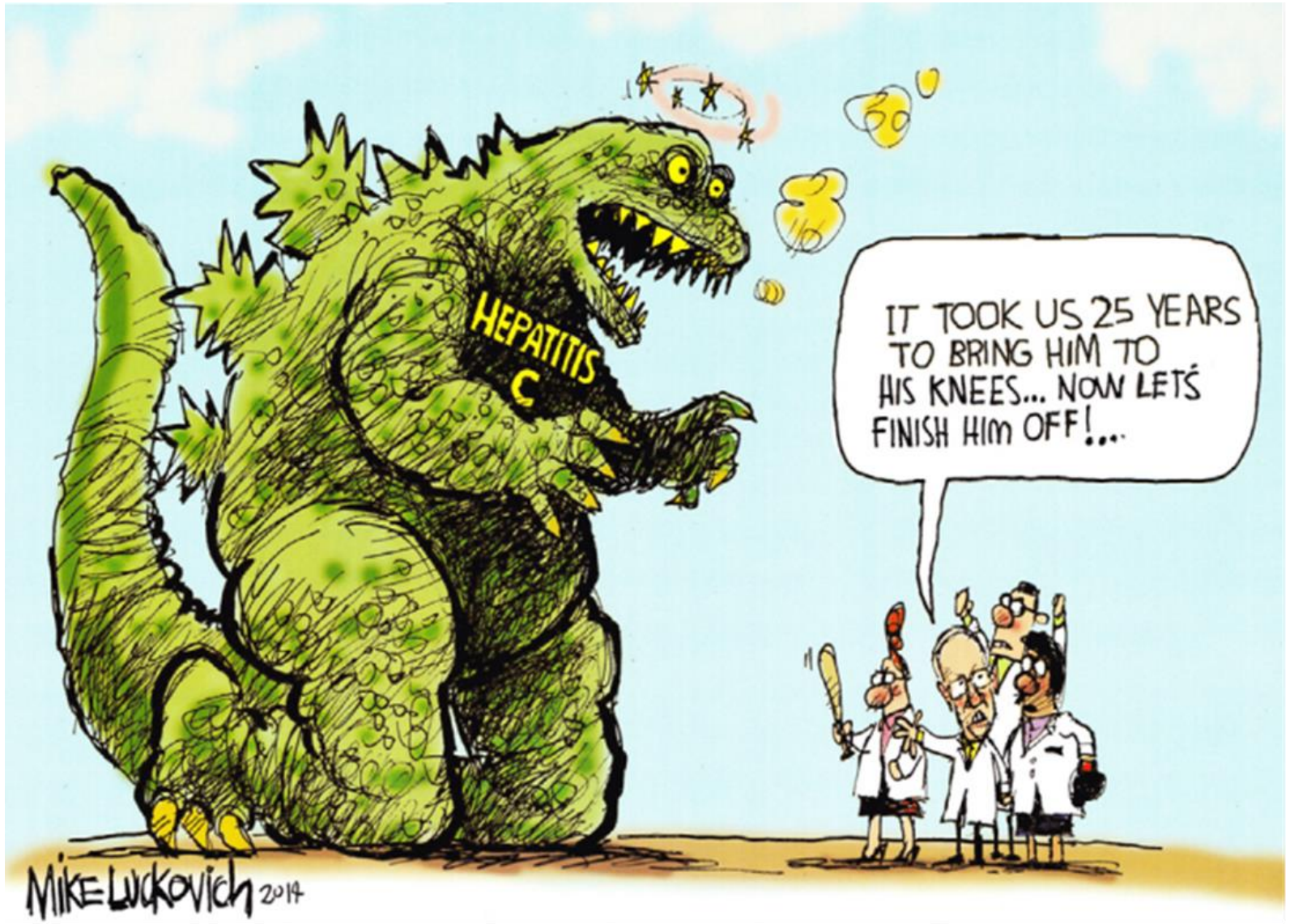
Source: QuintilesIMS PBS Qtr to July '17. Dispensed buprenorphine; buprenorphine+naloxone; methadone

GM HCV Elimination Plan



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


HEPATITIS C
IT TOOK US 25 YEARS TO BRING HIM TO HIS KNEES... NOW LETS FINISH HIM OFF!...
MIKE LUCKOVICH 2014

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

	Yes definitely	Yes to some extent	Not really	Definitely not	Does not apply
1. Was the doctor/nurse polite and considerate?					
2. Did the doctor/nurse listen to what you had to say?					
3. Did the doctor/nurse give you enough opportunity to ask questions?					
4. Did the doctor/nurse answer all your questions?					
5. Did the doctor/nurse explain things in a way you could understand?					
6. Are you involved as much as you want to be in the decisions about your care and treatment?					
7. Did you have confidence in the doctor/nurse?					
8. Did the doctor/nurse respect your views?					
9. Did the doctor/nurse respect your privacy and dignity?					
10. By the end of the consultation did you feel better able to understand and/or manage your condition and your care?					

11. Overall, how satisfied were you with the doctor/nurse that you saw?

Very satisfied Fairly satisfied Not really satisfied Not at all satisfied

12. About you

Gender Age What transport did you use to get here today

13. Please tell us what would help you in getting to future appointments?

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?