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HCV ACTION & NHS ENGLAND
MIDLANDS & EAST HEPATITIS C ODN
EDUCATIONAL EVENT,
9 MARCH 2018
SUMMARY REPORT



Background

The second Midlands & East Hepatitis C ODN Educational Event took place on Friday 9th March 2018 at the De Vere East Midlands Conference Centre in Nottingham.

The event built on the success of the first Midlands & East Hepatitis C ODN Educational Event, which took place in February 2017. Hosted by HCV Action and NHS England, the event offered the chance for ODNs across the Midlands & East region to come together to share their experiences, highlight best practice and discuss challenges.

Overview of the discussions

ODN updates

West Midlands Hep C ODN

Sally Bufton (ODN Nurse Manager) provided an update on the West Midlands Hep C ODN. The presentation began with an overview of the area covered by the ODN, with the ODN now overseeing 14 Trusts, up from 13 a year ago.

An update was also provided on the ODN's treatment numbers in 2017/18. An underperformance against the run rate target in Q1 and Q2 led to a revised lower target for Q3 and Q4. The underperformance was ascribed to a lack of clinical capacity and staff shortages, in addition to difficulty finding undiagnosed patients to enrol into treatment. However, Q3 and Q4 have seen much better progress in treating patients, with an 'over-performance' against the revised run rate target.



There are 12 prisons in the ODN's area, with in-reach services established or due to start in eight of these. As part of the in-reach service, a consultant and a Clinical Nurse Specialist go into prisons, and a Fibroscan and treatments are available for prisoners.

Nine substance misuse service providers operate within the ODN area, with no integration, along with over a dozen Clinical Commissioning Groups (CCGs), making for a highly complex commissioning environment. There are various levels of engagement with substance misuse services by the ODN, with treatment provided in some.

An update was also provided on efforts to link patients into care. The ODN now receives a list generated monthly by laboratories of all hepatitis C-positive patients. The ODN writes to patients' GP to inform them of the diagnosis and, if there is no response after four weeks, the ODN contacts patients directly to offer treatment. Since February 2018, the ODN has also conducted a 'look-back' exercise to identify patients lost to follow-up. 197 patients have been identified, with two already due to start treatment, and eight booked into a follow-up outpatient appointment.

Increased testing and treatment outreach is taking place with services including the Health Exchange Clinic (a health clinic for homeless people in Birmingham), the Recovery Partnership rehab centre and the Umbrella sexual health service.

Updates were provided on new projects to find undiagnosed patients in the ODN area. A grant has been submitted for a pilot project offering blood-borne virus (BBV) dry blood spot (DBS) testing in community pharmacies in the West Midlands region, aimed at targeting people from high-prevalence countries. In addition, funding has been agreed for a project to provide point of care testing in eight community pharmacies with a high attendance rate by injecting drug users, with all relevant data to be shared with the ODN and a referral pathway established to enrol patients into care.

East Midlands Hep C ODN

Professor Martin Wiselka (ODN Clinical Lead) provided an update on the East Midlands Hep C ODN, which covers Leicestershire, Rutland and Northamptonshire, with the main urban centres being Leicester, Kettering and Northampton.



Prof Wiselka highlighted some of the ODN's achievements in the three years since it was established, including the appointment of additional staff, increased provision of equipment such as Fibroscans, and better structures within the ODN.

Three engagement meetings took place in 2016/17, with issues discussed including:

- ODN structure and organisation.
- Achieving run rates.
- Increasing testing and referral in different settings.
- Peer support and role of voluntary sector and patient representative in promoting testing and treatment.
- Treatment and referral protocols.

- Education and training.

It was reported that the ODN was on course to meet all CQUIN targets for 2017/18 but, as with the West Midlands ODN, reported a challenge in meeting its run rates in Q1 and Q2. Treatment outcomes for the ODN's patients were shared, showing that 91% of patients had achieved a sustained virological response (SVR) after 12 weeks.

Prof Wiselka also provided an update on outreach and community treatment by the ODN, including a screening programme for newly-arrived immigrants from high-prevalence countries and outreach clinics in substance misuse services and prisons. A fortnightly outreach clinic in the Turning Point substance misuse service achieved moderately improved patient referral rates.

The East Midlands ODN has also conducted a look-back exercise, accessing data on positive hepatitis C cases from the local virology laboratory for the period from 2014 to 2017. Patients who had been diagnosed but not engaged with secondary care services were invited to attend an outpatient nurse-led clinic based at the Leicester Royal Infirmary for further assessment. As part of the exercise, 33 appointment letters were sent – 24 did not attend, nine attended clinic, of whom four had spontaneously cleared, one had been cured elsewhere, and two commenced treatment.

The ODN's future plans include increasing outreach clinics in all centres, better access to data on diagnosed patients, closer links with the local authority and public health, and increased use of novel initiatives, including 'bring a buddy' schemes, peer-to-peer support schemes, pharmacy testing, screening in emergency departments and engagement with offender health.

Eastern Hep C ODN

An update on the Eastern Hep C ODN was provided by Dr Will Gelson (Clinical Lead) and Kirsty McKibben (ODN Manager).

The ODN reported similar treatment outcomes to the East Midlands Hep C ODN, with 89% of patients achieving SVR after 12 weeks. The number of patients starting treatment has expanded each year, with 252 starting in 2015/16, 586 in 2016/17, and 640 (so far) in 2017/18. There are 838 patients in the ODN area known to services but still untreated. However, around 400 of these are not engaging with services and it is anticipated that the ODN will struggle to meet its run rate in 2018/19.

All 12 prisons in the ODN area have agreed to work with the ODN to



improve testing, referral and treatment rates. Between 75% and 100% of new arrivals to prison are offered a test (depending on the prison), and uptake is between 0% and 60%, with an average of 20-30%. Testing uptake is significantly higher at prisons using DBS testing.

There are ten substance misuse services in the area, with all commissioned for opt-out testing. Six have signed up to work with the ODN to improve testing, referral and treatment rates. Testing rates in substance misuse services across the region average 33%, with local variation of 17% to 56%.

The ODN has begun work to follow up positive diagnoses from laboratories and engage patients in treatment. By working with Public Health England, around 3,800 historical positive diagnoses were identified. A pilot of 600 letters to patients showed better response rates from more recent diagnoses and a further 700 letters have since been sent.

The ODN operates 24 outreach services, with four more due to open in the next two months. 10 of the outreach services are in prisons, two in primary care, three in secondary care and nine in substance misuse services. The number of patients being treated in secondary care has fallen by 20% as outreach has increased, taking treatment to patients in locations convenient to them.

In addition to the regular outreach services, the ODN has also carried out a number of testing events, in settings including gyms, homeless shelters, GP clinics and substance misuse services, with the highest proportion of positive cases being found in the latter. Of 211 people tested across all locations, 45 were found to be positive for hepatitis C. A number of other testing events are planned for the future, with an ambition to also secure funding for pharmacy testing.

Nottinghamshire, Lincolnshire and Derbyshire ODN

Kate Jack, Virology Nurse Specialist, provided an update on the Nottinghamshire, Lincolnshire and Derbyshire ODN, focusing on two aspects of the ODN's work.

Firstly, the ODN's offer of 'homecare' was highlighted. With direct acting antiviral (DAA) treatments safe for use in community environments, and a need to treat more patients in line with CQUIN targets, the ODN decided to explore efficient service delivery methods, including a pilot project of a novel home-based care pathway.

Patients who are interested in receiving treatment at home are discussed at MDT meetings and deemed to be eligible if they fit the following criteria:

1. Competence to adhere to therapy and blood testing without direct supervision
2. No current or documented evidence of decompensated liver disease
3. Contactable by telephone

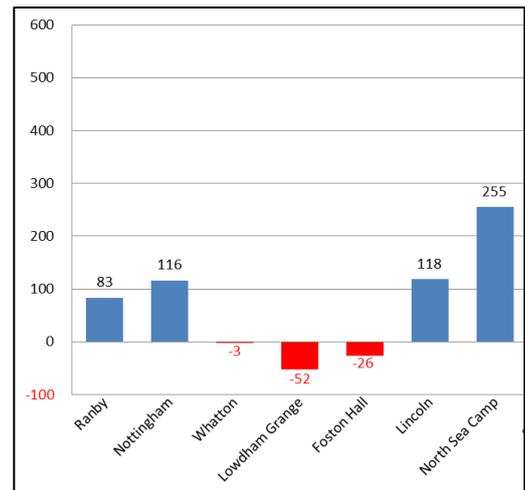
Following completion of administration, including agreement of a schedule for testing to be performed, medication is delivered by courier on a monthly basis at times

agreed with the patient. Blood forms are sent with the medication and results are retrieved for nurse/medical review.

The project is run by Outpatient Pharmacy at Nottingham University Hospitals and the Homecare Technician attends weekly MDTs and works closely with the nursing team, the MDT Co-ordinator and ODN Lead to co-ordinate the service. Blood results are reviewed by the lead nurse and clinical problems are referred to the medical team if necessary. This integration facilitates good communication and the delivery of effective patient care.

The ODN has found that the average saving per patient compared with those receiving treatment in secondary care is £523. 80% (97/121) patients offered a choice of home- or hospital-based care between November 2016 and January 2018 elected to receive treatment at home. Of the 97 patients so far started on treatment, 57 have completed, 31 achieved SVR and treatment failed for four. Three patients withdrew from the study for reasons unrelated to homecare and one transferred back to hospital care. 18 feedback questionnaires have been received from 56 sent (32%) and all respondents stated that the service had lived up to or exceeded expectations and was particularly valued by patients living far from the hospital.

Following this, an update was provided on testing for hepatitis C in prisons in the Nottinghamshire, Lincolnshire and Derbyshire area. Uptake of testing in the seven prisons in the ODN area has been variable in the 12 months following the introduction of opt-out testing, with four prisons seeing increases in the number tested but three seeing a fall (see table). Between July 2016 and June 2017, 149 people were diagnosed as hepatitis C-positive following a test in prison, out of a total of 1,578 DBS samples collected (a positive rate of 9.44%).



National update

Following the four local ODN updates, Professor Graham Foster (National Clinical Chair for the Hepatitis C Operational Delivery Networks) provided a national hepatitis C update.

Prof Foster outlined NHS England's approach to rolling out the new DAA treatments, with therapy initially prioritised for those with decompensated cirrhosis and treatment numbers gradually expanded.

Regional networks were established with treatment numbers allocated for each network. Outreach treatments were incentivised and the use of 'lowest acquisition cost' medication was enforced.

The importance of the national data registry was highlighted, although it is not currently as comprehensive as hoped for, with data currently held on just 4,000 SVR patients.

Prof Foster stated that the price of hepatitis C treatments has fallen dramatically, with price reductions being reinvested into more treatments by NHS England and run rates for ODNs will increase substantially over the next six months.



Given NHS England's recently-announced ambition to eliminate hepatitis C by 2025, the biggest challenge now is to engage more patients into treatment. Schemes to re-engage previously diagnosed patients are under way and data on all historic diagnoses will be made available in April.

NHS England is supporting efforts to test and treat more patients in a number of ways:

- The 'HepFREE' trial of 90,000 immigrants in primary care has identified techniques to test and treat, and has shown success if targeted at older patients.
- Opt-out testing in prisons has resulted in testing rates varying from 0-85%, with efforts ongoing to increase testing and treatment in prisons.
- Large substance misuse services are being encouraged to offer testing and treatment, with those who do not engage facing the prospect of being 'named and shamed'.
- The new procurement deal being explored with the pharmaceutical industry will include a role for industry in funding case-finding.

With NHS England's strategy of treating patients with decompensated cirrhosis first having largely been achieved, Prof Foster said reductions in the price of treatments will offer the opportunity to make real progress towards elimination.

Other talks

How the global commitment to elimination was achieved

Charles Gore, Chief Executive of The Hepatitis C Trust and until recently President of the World Hepatitis Alliance, shared the story of how the global commitment to elimination was achieved. The commitment began with the establishment of the World Hepatitis Alliance in 2007, which used World Health Assembly meetings to convince member states to act on hepatitis C. This advocacy work secured victories including making World Hepatitis Day official, adopting a resolution on viral hepatitis, establishing the World Health Organization Global Hepatitis Programme and, eventually, the adoption of the global commitment to eliminate hepatitis B and C by 2030.

Development of the hepatitis C CQUIN aims and objectives

Claire Foreman, National Programme of Care Senior Manager at NHS England, presented on the development of the aims and objectives of the hepatitis C CQUIN, aimed at improving treatment pathways through the ODNs. The five 'strands' of the CQUIN were shared and were said to have acted as an effective lever, with a 10% fall in mortality and a 50% fall in hepatitis C-related transplants and huge increases in treatment numbers in recent years.

Addressing the unmet needs of patients, to work towards the elimination of hepatitis C by 2030

David Rowlands, a patient representative for the East Midlands ODN, shared his perspective as a former patient. Potential barriers to patients engaging with care were shared, including lack of knowledge of hepatitis C, fear of stigma and concerns about treatment. A number of recommendations were made for increasing patient engagement, including:

- Training and awareness-raising for healthcare staff.
- Educational events for patients.
- Increased testing in non-clinical settings.
- Tailoring care to meet patients' needs.
- Peer support, mentoring and education.
- Improved harm reduction.
- Support for patients after treatment has finished.
- More opportunities for patient advocacy.
- Data collection to understand the patient experience.



Hepatitis C elimination, global strategies and how England is progressing

Dr Andrew Ustianowski, Research Lead and Consultant in Infectious Diseases & Tropical Medicine at Pennine Acute Hospitals NHS Trust, provided an overview of how England is progressing towards hepatitis C elimination, including in comparison with other countries. Australia was presented as an example of best practice, with Government buy-in for the elimination agenda in countries such as Portugal, Spain, Slovenia, Iceland, Egypt and Mongolia also highlighted.



Data was shared showing that the UK is failing to make as significant inroads into treating its prevalent population as countries such as Belgium, Germany and Portugal. In order for England to make progress towards elimination, more diagnosed patients need to be re-engaged, and undiagnosed patients found and enrolled into treatment.

The key components of the Greater Manchester hepatitis C elimination plan, being led by Dr Ustianowski, were shared:

- Engaging with risk groups at locations they are more likely to access – for example, current or former injecting drug users accessing needle and syringe programmes or opioid substitution therapy at community pharmacies.
- Treating ‘networks’ of injecting drug users at the same time to prevent onward transmission and reinfection.
- Interrogation of records to find those previously diagnosed but not treated.
- Rapid prison diagnosis and treatment.
- Testing in primary care and Accident & Emergency departments.

Hepatitis C – Assessment to Treatment Trial (HepCATT)

Dr Kirsty Roberts of Bristol Medical School presented on the HepCATT project, beginning with an overview of the HepCATT drug treatment pilot study. The study took place in three cities (Liverpool, Lincoln and Walsall) over the course of one year, with a Hepatitis C Nurse Facilitator working with the main drug treatment centres to increase uptake of hepatitis C testing, referral and engagement, provide awareness-raising initiatives, enhance peer support and buddy systems, and link to hepatitis C specialist care.

The study saw an increase in testing, referral and engagement with treatment across all three sites. The intervention was found to be highly cost-effective when compared to the NICE threshold and, if scaled up to all drug treatment services (70% coverage of PWID), then intervention could reduce prevalence of hepatitis C in PWID by 44% (25%-62%) by 2030.

Dr Roberts then presented on the HepCATT Primary Care trial, with practices receiving interventions which included HepCATT training, a hepatitis C test algorithm that searches GP records for high-risk patients, posters/leaflets in waiting rooms and encouraging ongoing educational hepatitis C training for practice staff.

The trial resulted in increased self-reported general awareness of hepatitis C among practice staff, although interim results have not indicated a significant increase in testing in primary care services taking part in the trial compared with control practices.

Ipswich NHS Trust prison treatment in-reach

Dr Abdul Mohsen (Consultant Gastroenterologist) and Paula Roberts (Viral Hepatitis Nurse Specialist) presented on Ipswich NHS Trust’s prison treatment in-reach work. The Trust engages with four prisons, with a total population of 2,755 inmates.

To date, Ipswich NHS Trust has received 144 referrals, with 41 treated, 11 having cleared naturally and nine being assessed. The number of patients treated in prison has increased substantially each year.

Challenges in setting up the service were outlined, included logistical challenges (dealing with security, IT issues, tracking patients etc.), challenges engaging patients (motivation, attending appointments, treatment worries, release before treatment) and organisational challenges (management blockage, difficulties engaging other staff).

Despite these challenges, there is now an in-reach service twice-monthly across four sites, ensuring effective treatment delivery, quicker access to treatment, linkage to outside services for those untreated upon release, and improving patient and team awareness of the service.



VirA+EmiC project

Sam Douthwaite, Consultant in Infectious Diseases at St. Thomas' Hospital, presented on the VirA+EmiC project, which aimed to assess the effectiveness of opt-out hepatitis C testing for adult patients at St. Thomas' A&E department. Notifications were automatically generated for any bloods ordered via A&E to also be tested for HIV, hepatitis B and hepatitis C.

As a result, 74% of those who had a blood test after attending A&E were tested for hepatitis C – a total of 6,679 tests in 10 weeks. Hepatitis C prevalence was highest among those who were:

- Male (1.5%)
- Aged 30-69 years (>1.2%)
- White British or White Other ethnicity (>1.2%)
- Attending during the weekend (1.2%) or at night (1.4%)
- Had no fixed abode (13.4%)

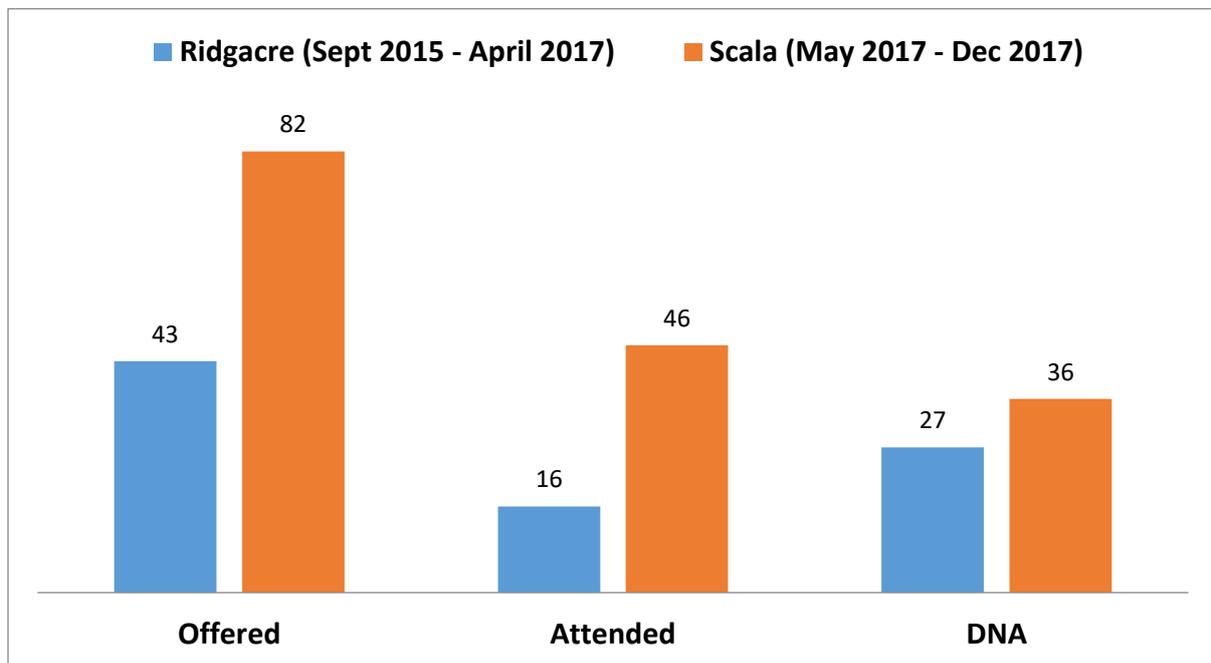
Overall, the project found testing in A&E to be a low-impact process for staff with high uptake rates and led to large-scale testing at a single site.

Outreach in Birmingham

The final talk of the day was delivered by Dr Ahmed Elsharkawy, Consultant Transplant Hepatologist at University Hospitals Birmingham NHS Foundation Trust, and Danny Morris, Peer Support Lead for Birmingham at The Hepatitis C Trust, on outreach work in Birmingham.

With an outreach clinic having previously been held at Ridgacre Medical Centre, with low engagement, a new clinic was established in substance misuse services at Scala House in May 2017. A nurse attends for a day a week, carrying out DBS testing, and The Hepatitis C Trust provide peer support alongside the clinic. There have been much greater numbers of referrals and better attendance at appointments

following the venue-change, as demonstrated in the table below.



Other work to increase diagnoses is also taking place, including in-reach work in HMP Birmingham which started in July 2017, a new outreach clinic in the Health Exchange Clinic for homeless people which started in February 2018, and opportunistic community DBS testing in Changes UK substance misuse services.