DDN

Drink and Drugs News
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ALL TOGETHER NOW

DDN CONFERENCE SPECIAL

Posters and leaflets

for people at risk of overdose

EXCHANGE SUPPLIES

MAKING INJECTING SAFER

DDN

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CJ Wellings

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STAYING STRONG IN PARTNERSHIP

'We all share a great passion for helping people to change their lives for the better.'

Lydia Broom, Change Grow Live, at the *DDN* conference. More at **www.drinkanddrugsnews.com**

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'From the moment I arrived I was surrounded by energy'

We wondered if it would ever happen – and then there we were, with everyone pouring through the doors of our first conference for three years. Overwhelming and exhilarating. In this issue you'll find all kinds of impressions of the day, but for me the highlights, alongside inspiring speakers and our team of amazing volunteers, were the connections – reunions, introductions, endless possibilities for working together and sharing ideas. It reminded me that this event is shaped by each and every person who takes part. It's particularly inspiring to hear from people who haven't been before. Lydia said she wasn't quite sure what to expect, but 'from the moment I arrived, I felt like I was surrounded by people who were full of energy and determination...'

And this is what we need to take away from one day's event and pass on to colleagues. We have so many different viewpoints and perspectives between us and it's not always easy to align with others' beliefs and ways of doing things. But the common aim is to strive for better physical and mental health, safety and wellbeing and to challenge anything that limits our opportunities. A physical event is liberating and life-affirming in so many ways; let's keep that door open.

Claire Brown, editor
Keep in touch at www.drinkanddrugsnews.com and @DDNmagazine

Alcohol deaths five times higher in Scotland's deprived areas

Rates of alcohol-specific deaths are almost five times higher in the 10 per cent most deprived areas of Scotland, according to figures from Public Health Scotland (PHS), with rates of alcohol-related hospital stays eight times higher.

Population-level alcohol consumption – which is estimated from retail sales figures – was roughly the same in 2021 as the previous year, says the *MESAS monitoring report 2022*, which is part of the ongoing Monitoring and Evaluating Scotland's Alcohol Strategy (MESAS) programme. COVID-19 restrictions were still affecting on-trade premises such as pubs, clubs and restaurants in 2021, meaning that 85 per cent of all alcohol sold was through retail premises. Almost 1,200 people died of alcohol-related causes in Scotland in 2020, an average of 23 per week. Alcohol-specific death and hospital rates are at least twice as high among men, and highest in the 55-64 age range.

'Today's MESAS report shows that population-level alcohol consumption in Scotland has been maintained at a similar level to that seen in 2020, the lowest level observed in the available data,' said public health intelligence adviser at PHS, Vicki Ponce Hardy. 'However, it also clearly highlights that significant inequalities persist in both alcohol consumption and the harm it causes. The most recent survey data show that almost a quarter of adults in Scotland still drink more than the recommended low risk weekly drinking guideline. Among those exceeding the guideline, it's those in the lowest income group who are likely to consume the most. In the 10 per cent most deprived areas of Scotland, rates of alcohol-specific death were nearly five times higher, and alcohol-related hospital stays were nearly eight times higher, than in the 10 per cent least deprived areas. Like all harm caused by alcohol, this is preventable.'

The Scottish Government should introduce legislation to restrict alcohol marketing 'where it has powers to do so', says a report from Alcohol Focus Scotland, including outdoor and public spaces, print publications, merchandise branding, and sports and event promotions. The action is necessary to address a situation where people are being 'bombarded by booze ads' that normalise and encourage drinking at the expense of health, it states.

MESAS monitoring report 2022 at publichealthscotland.scot/publications/mesas-monitoring-report-2022

Realising our rights: how to protect people from alcohol marketing at www.alcohol-focus-scotland.org.uk/

In 2020, 1,190 people died in Scotland due to a cause wholly attributable to alcohol, an average of nearly 23 people per week. Alcohol-specific death rates increased between 2019 and 2020, an increase that was largely driven by deaths among males aged 45 years and over. Alcohol-specific death rates are consistently higher in Scotland than in England & Wales.

Rates of alcohol-specific death and alcohol-related hospital stays were at least twice as high for men as women and were highest in the 55–64 year age group.

Inequalities by area deprivation were stark. In the 10% most deprived areas of Scotland, rates of alcohol-specific death were nearly five times higher, and rates of alcohol-related hospital stays nearly eight times higher, than in the 10% least deprived areas.

Monitoring and Evaluating Scotland's Alcohol Strategy (MESAS)

Online casino spending highest in deprived areas

SPENDING ON ONLINE GAMING PRODUCTS like casino, slot and bingo games is disproportionately concentrated in the UK's most deprived areas, according to a report from the National Centre for Social Research (NatCen) and the University of Liverpool.

While betting on sports events like racing and football was the most popular overall in terms of numbers participating, gaming carries a higher probability of heavy losses, the document states.

The research, which was commissioned by GambleAware, analysed almost 140,000 online gambling accounts from seven major providers over the period of a year. It found that almost 30 per cent of gaming accounts came from the most deprived areas compared to 13 per cent in the least deprived. The top 20 per cent of accounts by amount staked generated more than 90 per cent of operator revenue, the report adds, meaning that 'a vital few customers are providing the lion's share of revenue for major gambling operators'.

Data for sports betting, meanwhile, showed 'more modest variations across the deprivation range' in terms of both participation and share of operator revenue. The research 'adds to the growing body of evidence showing that harms from gambling are falling disproportionately on the most deprived communities,' said GambleAware CEO Zoë Osmond. *Patterns of play at https://natcen.ac.uk/*

Half of festival MDMA fake

FORTY-FIVE PER CENT of the substances sold as MDMA at English music festivals last year contained no MDMA at all, according to research by The Loop. Two years previously just 7 per cent of the MDMA sold was fake, constituting 'a substantial shift in the UK drugs landscape between 2019 and 2021'.

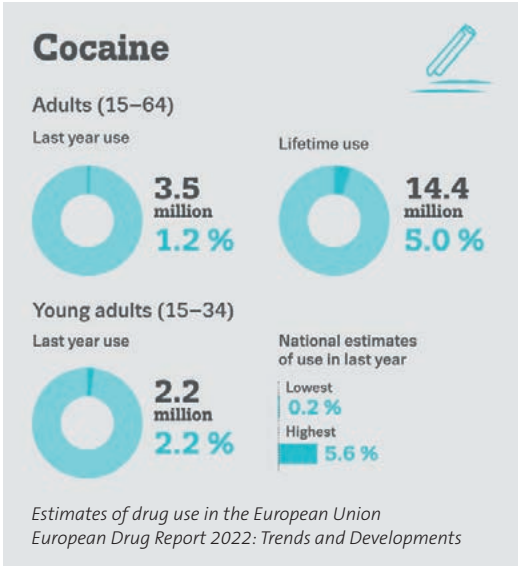
The rise in 'copycat' ecstasy was caused by lack of demand as a result of COVID lockdowns and compounded by Brexit-related supply chain issues, says the study, which was produced in association with Cardiff and Liverpool universities. Most of the substances sold as ecstasy instead contained drugs like cathinones or caffeine, with The Loop warning of the risks of similar unknown substances being sold during this summer's festival season.

'The sharp rise in synthetic cathinone prevalence in the UK in the summer of 2021 coincided with a unique combination of events including Brexit and the reopening of nightlife after 16 months of lockdowns, months ahead of other European nations,' said The Loop's director, Professor Fiona Measham. *Study at journals.sagepub.com/doi/full/10.1177/20503245221099209*

European cocaine supply exceeds pre-pandemic levels

The European drug market has seen a 'rapid bounce back' of supply and use following the disruption caused by COVID 19, according to EMCDDA's *European drug report 2022*, with cocaine availability now surpassing pre-pandemic levels. A record 213 tonnes of cocaine were seized in 2020, says the document, and more than 23 laboratories dismantled.

The ever-evolving European market is still seeing NPS appearing at a rate of one per week, the report states, 'posing a public health challenge'. Last year saw six new synthetic opioids, six synthetic cathinones and 15 synthetic cannabinoids reported for the first time, with the number of NPS being monitored by EMCDDA now close to 900. The war in Ukraine has added to the volatility of the market, with potential shifts in trafficking routes as criminal gangs exploit vulnerabilities or avoid affected areas. 'Darkweb' drug markets now seem to be in decline, however, as a result of law enforcement crackdowns and frequent scams, with people turning instead to instant messaging apps and social media to buy and sell drugs. Drug treatment has largely returned to 'business as usual' after the pandemic's restrictions, the report continues, although many services have retained some COVID-era innovations such as e-health provision. However, there is a need to scale up harm reduction services for people who inject drugs, with only four countries meeting WHO targets of providing 200 syringes per year per person and having 40 per cent of high-risk opioid users on substitute medication. There were an estimated 5,800 overdose deaths in the EU in 2020, mostly associated with 'polydrug toxicity'.



Estimates of drug use in the European Union
European Drug Report 2022: Trends and Developments

Meanwhile, global cocaine manufacture grew by more than 10 per cent between 2019 and 2020 to more than 1,900 tons, according to UNODC's *World drug report 2022*. Cocaine trafficking also appears to be expanding to areas outside of the traditional markets of Europe and North America, say UNODC, with increased levels of trafficking to Africa and Asia. Around 11.2m people were injecting drugs, the document says, around half of whom were living with hepatitis C, compared to 1.4m living with HIV – 1.2m were living with both. 'We need to devote the necessary resources and attention to addressing every aspect of the world drug problem, including the provision of evidence-based care to all who need it,' said UNODC executive director Ghada Waly.

European drug report 2022 at www.emcdda.europa.eu

World drug report 2022 at www.unodc.org

More work needed to increase naloxone availability, says ACMD

MORE NEEDS TO BE DONE to increase the availability and use of naloxone, according to a report from ACMD. Community pharmacies should be able to deliver take-home naloxone as well as interventions in managing opioid overdose, says the document, while data quality also needs to be improved to allow commissioners to properly monitor how the drug is being provided.

The report cites examples of effective partnership working that it says should be used to model naloxone programmes across the UK, while prison services need to ensure people at high risk of overdose on release have easy access to the life-saving drug. 'Evidence suggests that the supply of take-home naloxone on release from prison is fragmented across the UK, with only a small proportion of opioid-dependent prison leavers currently being provided with naloxone, even though studies find that a high percentage of these people would willingly accept take-home naloxone upon prison release,' it says.

Ambulance services, hospitals and mental health trusts should also deliver take-home naloxone to those at risk, it adds, with additional training provided for police.

ACMD review of the UK naloxone implementation at www.gov.uk/

Local News

WALKING TALL
This year's Recovery Walk will be held in Newcastle on 17 September, starting at 12.30. For more information or to sign up visit *www.facesandvoicesofrecoveryuk.org/2022-recovery-walk*

NEW START
WDP has launched a refurbished Cobbold Road hub at its New Beginnings service in Brent. The new site provides a 'welcoming environment that will encourage people to access the excellent treatment offer' from New Beginnings and clinical leads CNWL, said WDP's executive director of services Tom Sackville.

HIGH ACHIEVERS
Greater Manchester's Achieve Drug and Alcohol Service provides a collaborative and holistic approach that is 'overwhelmingly positive' and could be rolled out to other areas, according to an independent external report. 'Partnership working is at the very heart of our approach and it is fantastic to see it praised so highly,' said GMMH head of operations for addictions services Kate Hall.

FEEL THE ENERGY!

When delegates gathered in Birmingham for *All Together Now*, the first *DDN* conference since the pandemic, the energy was tangible. Additional photography throughout by **nigelbrunsdon.com**

'Welcome to the *DDN* conference – I'm so pleased to be able to say that at last!' *DDN* editor Claire Brown told the opening session of *All Together Now*. 'A friend said to us last night, "Why do you have this event? You've had a hurricane one year, COVID stopping it for a couple of years and now you've been literally derailed by the train strike." I thought about that and realised that's exactly why we do have it – life's like that, and this is a gathering like no other event. You can feel the energy, and we just want to be here.'

A TIME FOR OPTIMISM

This was a time for optimism and big ambitions, said director of addictions and inclusion at OHID, Rosanna O'Connor. The drugs strategy meant there was a window over the next three years to 'show what a revitalised treatment and recovery system can deliver', and people with lived experience were going to be 'massively important', she stated. 'Your insight into what treatment and support a world-class system should have on offer can help shape that future.'

The significant new government investment was there to do two critical things, she said – to make sure 'we can offer treatment to all people who want and need it', which meant roughly 55,000 more people by the end of 2024, and to 'deepen the quality of that treatment offer'. This meant reinvesting in harm reduction, smaller caseloads for frontline workers, more medical specialists and more investment in recovery communities.

The government was determined that the voices of people in treatment and recovery – and those not yet engaged – would help shape its work, she said. 'More than that, you are a full part of the system – supporting each other and making treatment more meaningful, real and more effective. Keep talking to us, keep challenging us.'

RELEVANT SYSTEMS

'People are messy, people are unique, people are individuals and they all have unique needs,' said executive director of Change Grow Live, Nic Adamson. 'I think we all want to see treatment systems that are attractive and relevant to everybody.' However, women – who represented 51 per cent of the population – were still being let down by homogenised treatment models developed for, and by, men. 'As a woman you're less likely to have your voice heard and your needs met,' she said. 'We've seen an almost 80 per cent increase in the number of women dying a drug-related death, but the numbers in treatment remain largely unchanged. Services for women have not improved significantly in design or sophistication over the last 20 years.'

However, this was something we now had a chance to do something about, she stressed.

SPECIALIST PROVISION

The recently launched Women's Treatment Group (*DDN*, April, page 5) would be advocating specifically for the needs of women, she said, and making tangible improvements across the system, including a gender-specific evidence base, specialist women's provision, new contracting arrangements – and for women's lived experience to be 'valued and sought after'.

The group was committed

'People are messy, people are unique, people are individuals and they all have unique needs.'

NIC ADAMSON

and had real energy, she told the conference. 'While these improvements will benefit women, they'll also benefit their families, their partners, their children. So I would argue this is not a women-only issue. It's a core part of strengthening our ability to make a difference.' The broader health world was waking up to the importance of women's health and acknowledging the inequalities, 'so we have to ask ourselves what have we done to address that gap in treatment systems, and what do we need to do to ensure we're playing our part?' While more and more women were now using web-chat services, roughly only a third of the people attending structured treatment were women, she pointed out.

Women reported using substances for a shorter period when entering treatment, with their drug use escalating faster – they were also more likely to relapse, she said. 'Their withdrawal symptoms may be more intense, and they may experience more physical effects on their heart and blood vessels – do we do enough to consider those things?' Change Grow Live's national lived experience group had been working to understand women's experience of treatment, with one emerging headline finding that the majority of women accessing services had done so not through choice but necessity. When asked why, the reason was either to respond to a health need or through their role as a mother – because social care services required them to.

TRADITIONAL VIEWS

'I'd also add the criminal justice route to that,' she said. 'So why are women reluctant?' Reasons included denial, stigma, fear of judgment, and exposure to men in treatment settings, she stressed. 'Society still holds very traditional views of women. Men's drinking and women's drinking are seen very differently – we still have the "mother's ruin" hanging over us from the 18th century.' Women had a fear of what treatment would be like – and its consequences – with an overriding sense of responsibility to their families and the perceived risks around that, plus the added feeling of pressure as the primary provider of emotional support.

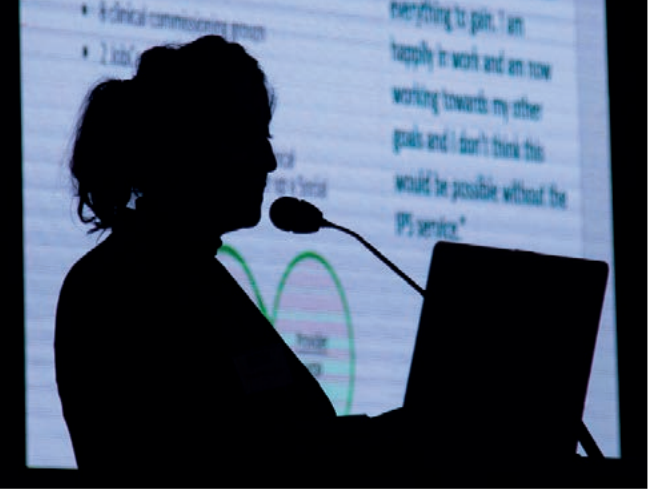
> 'How many black and brown faces do we see in our services? We all need to ask why that is.'
>
> SOHAN SAHOTA

All of this meant that the next steps needed to be around challenging stigma and ingrained societal attitudes, and finding the 'quiet' voices – women who haven't historically come forward or were not in treatment. 'The need to change how women see themselves, and how society sees women runs deep. What I'm championing is the messiness of humans and the need to identify and explore our uniqueness and our differences, and what they mean in terms of how we experience support and help and care. And if that includes my difference as a woman, and then exploring all our other differences, I think we'd all be much better for it.'

UNMET NEEDS

Nottingham's BAME-led, peer-led BAC-IN organisation (*DDN*, September 2021, page 6) also came about in response to an unmet need in mainstream services, said its managing director Sohan Sahota – and 'very little' had changed since then. 'I must say this, UK drug and alcohol treatment has betrayed, abandoned and rejected ethnic minority communities in their search for recovery and wellness,' he told the conference.

'How many black and brown faces do we see in our services? We all need to ask why that is. Nic was talking about women – let me say something about ethnic minority women. Black women, south Asian women – the stigma they get in their communities, the pain they go through. Where are the services to address their addiction, but also the cultural issues of stigma and shame, and the racial trauma, cultural and religious abuse? Where can they go and take that as part of



> 'Getting people into work is what it's all about. It makes a huge difference in people's lives.'
> REBECCA ODEDRA

their recovery?'

UK drug policy had let down generations of families and young people, he stated. 'If we truly want visible recovery for all then we all need to speak about the gaps in services and this under-representation.' His organisation had been involved in research with Cardiff, Sheffield Hallam and Middlesex universities to highlight these issues, he said, and was asking for 'change in policy and how we commission, how we design services. What we don't want is to be an afterthought, a tokenistic gesture. We want to be an integral part of the system, right at the heart of it. Because we're part of this society, and our communities are suffering beyond measure.'

RECOVERY FOR LIFE

BAC-IN was about 'recovery for life', he said. 'We have a programme that's culturally responsive, culturally competent, culturally sensitive, a visible reflection of the community it serves. BAC-IN is an expression of the community, an energy of change inspired by the community.' Culturally responsive provision embraced race, identity, ethnicity, language and cultural heritage, he said. 'It provides an alternative route into treatment and recovery, and speaks to and embodies the values and beliefs of the whole person. It's holistic, adaptable, culturally sensitive and inclusive.'

While the government's new money would go a long way to filling some of the gaps in provision, the challenge was how to ensure the new system worked for everyone, said his colleague, senior recovery worker David Thomas. 'That includes women, those on the margins of society and BAME communities.' While people understandably spoke passionately about these issues there was also a business case, he stressed. 'We all want to live in a society in which we're safe, and we all want to live in inclusive communities. It's incumbent on us all not just to look at system change but to look at individual change – what more could I do to understand more about the people we're here to serve? The challenge of the new drug strategy is how do we get this system working for all.'

PAYING DIVIDENDS

When it came to the vital issue of getting people into paid employment, WDP's individual placement and support (IPS) model (*DDN*, April, page 9) was paying real dividends, said WDP's head of reintegration, Rebecca Odedra. 'I genuinely feel passionate about this – I think getting people into work is what it's all about. It makes a huge difference in people's lives.'

In the UK there were around 300,000 adults in treatment for drugs or alcohol, with the majority still failing to find work. 'We all know the current market is difficult, but it's even more difficult with those additional barriers.' IPS had originally started around 20 years ago in the mental health sector in the US, with extremely positive outcomes. It had been recommended to be trialled in drug and alcohol settings, with funding for a pilot in west London.

'As the Dame Carol Black report highlighted, getting and keeping a job is one of the most important things,' she said. Paid employment could boost confidence, motivation and ensure financial independence – but it was 'so much more than that as well.' WDP's partners in the project included eight local authorities and eight local commissioning groups, as well as two Jobcentre Plus. 'For us it's really important to make this sustainable and make this last. We know that this works.'

SERVICE USER SUCCESS

Working closely with service users was vital to the success of the project, she stressed – 'we focus on people's readiness to get into work. It's not about what the keyworker says. If the client says they want to get into work, then they come on our programme.'

IPS was an intensive model that worked closely with employers and there had now been more than 250 job outcomes in the project since 2019, with more than 4,000 hours of support provided and 100 per cent of participants stating that they'd recommend the project. 'The team work really creatively to try to help people get into work, and they really believe in our service users – that makes a huge difference. Pre-COVID we were achieving a 36 per cent job start rate and 38 per cent sustainment rate', with people entering work in a wide range of fields. 'It could be anything from entry level to high executive level, across all sorts of different industries.

'This sort of work is something that's been needed in the sector for so long and we need to keep advocating, keep growing and keep reaching more and more people to get them into paid work,' she said. 'It's more than just a job for people. We've seen improved health outcomes, increased confidence and motivation – it gives so much more meaning to life. It gives hope.' **DDN**

2022 RECOVERY STREET FILM FESTIVAL

OPEN FOR 'ENTRIES'

SUBMIT A FILM

We are inviting anyone who is directly or indirectly affected by drug and alcohol use to submit a film of between one to three minutes in length, themed around the question: **WHO AM I?** We want to know how your identity and place in the world has shaped your recovery, or the recovery of those in your life. **THE DEADLINE FOR ENTRIES IS MONDAY 15TH AUGUST 2022**

FIND OUT MORE ABOUT ENTERING THE FESTIVAL HERE

HOST A SCREENING

Film has the power to bring people together to create a shared understanding. Making connections through real life experiences and creative story telling is a powerful means of reducing stigma. That is why we encourage as many people as possible to hold screenings of the festival in services, community centres, cafés, restaurants, events, workplaces or even homes up and down the country throughout September

FIND OUT MORE ABOUT HOSTING A SCREENING HERE

FIND OUT MORE NOW AT WWW.RSFF.CO.UK

RECOVERY STREET FILM FESTIVAL

WE ARE A VOLUNTARY PROJECT AND WE NEED YOUR HELP

Help us promote the festival by liking, sharing and following us

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PEOPLE HAVE THE POWER

The second *All Together Now* session focused on the power of community

'We're at an exciting point and you guys are a key part of this journey,' the government's recovery champion Ed Day told *All Together Now* delegates. People's relationships with substances – or other behaviours like gambling – occurred across a spectrum, he said. 'Many people don't use substances at all, many people use substances without any problem – but other people run into very severe problems. We have to think about this whole spectrum of issues, and a wide range of different responses.'

Treatment had above all to be flexible and to 'meet people where they're at', he said. Good treatment 'to be honest, doesn't look like a lot of the things that appear in government documents', he acknowledged. 'The key thing is engagement – if you only offer one service, and they don't want that service, they're not going to take you up on it. But when people turn up and start building a therapeutic alliance with you, then you can start changing their behaviour.'

INDIVIDUALLY TAILORED

It had to be tailored to the individual and be evidence-based, he stated. 'It's a journey, a process. It doesn't happen overnight, and it requires quite a bit of aspiration and hope, which is what our services need to bring to people. I'm a strong believer that the opposite of addiction is connection – people who are deep into addiction are isolated from the people they love, friends, family, work, all those things.'

The journey to recovery required building a system that catered to everyone, whatever level they were at, he said. Research had shown that on average it took people five years to even seek any form of help, and once there it took around eight years to reach a stable period of recovery. 'And once you hit recovery it then takes another five years on average to be really confident that you're not going back to where you were before.'

The positive message, however, was that well over half of the people with the most serious addiction issues did reach recovery, he stressed. 'People are recovering every day in huge numbers, in the UK and all over the world. So we have to have that hope and aspiration to give people.'

While the 2000s had seen money being spent 'hand over fist' on treatment services, the financial crash and change of government in 2010 had seen services 'relentlessly' cut over the next ten years. 'I'm sure I'm not alone in feeling worn out by that,' he said. However, things were looking up, he told the conference, and LEROs were crucial to the creation of the optimum model of a recovery-orientated system of care. Services shouldn't be time-limited, and had to include peer-based recovery support, peer-based harm reduction initiatives, recovery community centres, housing, employment services and more, he stated.

> 'If I want to engage someone in my service I don't send one of my treatment staff – I send someone with lived experience.'
>
> ED DAY

THE EVIDENCE IS THERE

'The evidence is there – what we need is all of this, and people with lived experience are absolutely crucial, so don't let anyone tell you otherwise. The mission I have now is to ensure that this gets

enshrined in whatever comes out of the new money coming into the system. If I want to engage someone in my service I don't send one of my treatment staff – I send someone with lived experience. Because that conversation they have with them cuts through far more often than someone who's a professional.'

This was now a genuinely exciting time, he said, with initiatives like diamorphine-assisted treatment, consumption rooms – 'why not, if they work?' – naloxone, psychosocial interventions and Buvidal, which would be a 'game changer' for many people. 'And of course the pandemic has taught us that we can all use telemedicine,' allowing us to provide more treatment to more people over a longer period of time.

> 'We want to build cohesion, trust, credibility and consensus for recovery groups and communities... Community is everything.'
>
> DOT SMITH

ESSENTIAL INITIATIVES

Other essentials included recovery check-ups, ensuring that people don't spend 'six months in the wilderness' if they relapse, recovery housing – which still didn't get proper recognition, funding or support – 'life-changing' collegiate recovery programmes, and recovery coach roles. 'And of course lived experience is crucial here. We need to carve out clear roles to get recognition and funding in this area.

'Whatever your route to recovery, the key things are connecting with people and helping others – 24/7 community support is there,' he said. 'Why aren't statutory services grabbing this and working with it? Respecting it, funding it, supporting it?'

There was now a nationally recognised group of lived experience recovery organisations in the shape of the CLERO, he said. 'It's in both Dame Carol Black's report and the drug strategy, so they can't get out of this. We urge you to join with us. People with lived experience need a voice to get this into the system, and once it's in there it won't leave. But while we're divided, the politicians won't listen to us. United we're a powerful force – this is our window of opportunity. Let's take it.'

AUTONOMY IS KEY

CLERO member organisations met every month to share good practice and 'cheer each other on', said CEO of Recovery Connections, Dot Smith, as 'it can be a difficult landscape out there, especially if you're a small organisation trying to work alongside the treatment system'. But what was key was autonomy, she stressed. 'We want to build cohesion, trust, credibility and consensus for recovery groups and communities, based on an evidence-based approach predicated on lived experience with human rights at its heart. Community is everything.'

More than 20 peer researchers had already been trained by CLERO, said Dave Higham, CEO of The Well Communities, and the college had also been working on a set of national standards for recovery organisations. 'We should be seen as equal stakeholders in this recovery field,' he stated. 'We should not be getting the crumbs off the table. We should be getting a fair share of the pie, because the impact we have on our communities is phenomenal.'

> ‘Everybody who comes to our project starts as members... We like to treat everybody as if they’re a member of the family.’
>
> SAMANTHA SMITH

WE’RE JUST PEOPLE

The hugely successful Red Rose Recovery group had come out of the Lancashire User Forum, Peter Yarwood told the conference, and didn’t focus on ‘labels like harm reduction or abstinence – we’re just people. We want to create a space where we can have a little bit of autonomy and make a difference in our communities.’ This year it had celebrated its tenth anniversary and now had one hundred staff – 95 of whom had lived experience. ‘That might make us the biggest LERO in the United Kingdom,’ he said.

‘I’m one of those people who’s a lived experience worker,’ said Red Rose Recovery team leader Sarah O’Mara. ‘I destroyed my life with drink and drugs, and during that time I was given many labels – a failure, irresponsible, a drunk, an addict, and I had no confidence in myself. But a year into my recovery and looking to give back to those people who’d held me up when I couldn’t hold myself up, I found Red Rose Recovery – people who believed in me. And very quickly I was brought into that community, that family.’

The organisation’s community support took many forms, including online and face-to-face groups, and some that were ‘just about connection’, she said. ‘We have a lot of fun. We didn’t get clean and sober to spend our lives miserable. We did it to create the best lives we possibly could, and that’s what we try to help people to do. We’re there to give that continuity of care.’

BACK TO OUR ROOTS

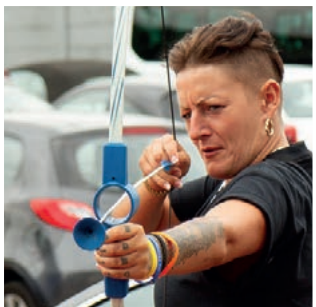
Penrose Roots, the Social Interest Group’s (SIG) garden-based project had started in 2013, said service manager Samantha Smith, beginning with a small allotment space. ‘We had this vision that we could do something much bigger so we went to the council and harassed them until they gave us a one-acre site in Luton.’ In 2016 the project began taking on volunteers as members of staff, and the project ‘just grew and grew’, adding a bicycle recycling scheme and much more. ‘In 2021, after being one of the only projects in Luton and Bedfordshire to be able to continue through COVID, we finally became fully funded.’

The project is part of the ‘green prescription’ implementation across Luton and Milton Keynes – ‘getting people out of their social isolation’ – and also works with the NHS and public health to share best practice to maximise engagement. ‘We also work alongside the local authority to improve deprived areas and create new green spaces on unused pieces of land’, she said, as well as supporting churches and communities to ‘clean up their local unloved areas’.

‘I work in a beautiful public gardens in a 150-foot greenhouse,’ said the project’s horticultural trainer, Sally Waller. ‘During mental health awareness week we planted loads of lettuces and people loved it. We work with local schools, the NHS recovery college, and some of our people worked in local food banks during the pandemic. We harvested around 600 kilos of vegetables, and were working with local community kitchens.’

‘Everybody who comes to our project starts as members – we don’t use the term “service user” – but they can move on to become a support volunteer or a lead volunteer’ said Smith. Ninety-five per cent of staff were people with lived experience, and ‘we like to treat everybody as if they’re a member of the family’, she said. According to a member survey, 94 per cent of members had learned a new skill, 100 per cent stated that their mood had improved, and 100 per cent had made new friends, with more than half now meeting those friends outside of the project.

Members had a sense of ownership and were consulted on every aspect of the project, with great care taken to avoid barriers, she stated. ‘We don’t have any hefty paperwork, and if someone doesn’t come along then we’ll do a weekly welfare check – not to say, “you’re not coming back if you don’t turn up” but purely to let them know what’s happening. So if they do come back – whether that’s the following week, or month, or year – they’ll have been kept up to date with what’s going on.’ **DDN**



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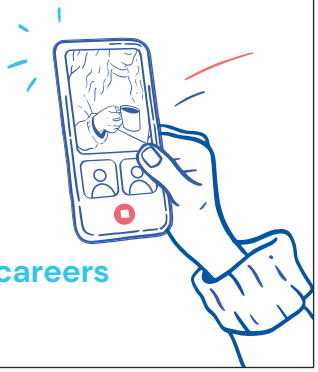

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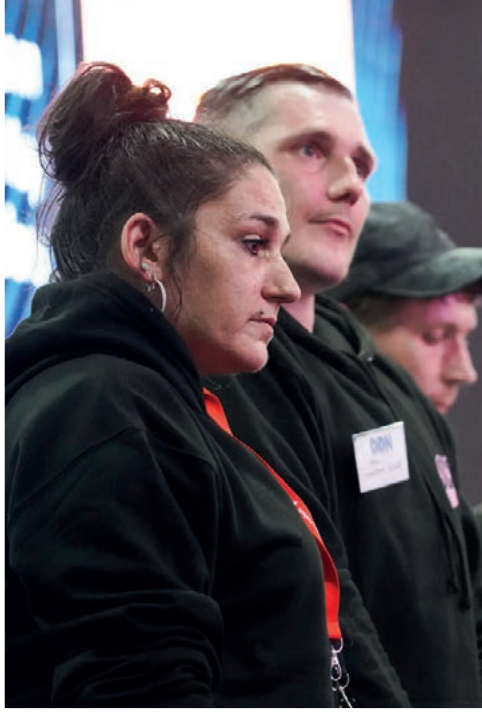


TOGETHER WE CAN DO ANYTHING

All Together Now's vibrant afternoon session celebrated the many facets of peer power

'I'm a drug war veteran,' George Charlton of the peer-led Medway Hope outreach project told the conference. 'I was let down by a system that called me a junkie and a smackhead and a piece of shit, and said I wasn't worth anything. I didn't believe I was worth anything. I was written off, stigmatised, demonised, vilified. But with love and compassion and support and hope, we do recover.'

Medway Hope's focus was on reducing drug-related harms across the Medway district, facilitated by people with lived experience. 'Peer-led everything,' he said. 'We don't need more professionals. We need more lived experience and living experience. We need it embedded in every fucking part of the treatment system.'

The project had 'given me a new lease of life,' said Julia. 'I've found confidence, self-esteem and direction. Life's good today – I live in the light, I don't live in the dark.' Whereas some of the bigger treatment agencies 'just hand out' naloxone, Medway Hope trained people in how to use it properly, she said. 'Mine came through the letterbox with no instructions – I would have just whacked it all in.'

> 'Peer-led everything... We don't need more professionals. We need more lived experience and living experience.'
>
> GEORGE CHARLTON

The project also cleaned up drug litter, Matt told the conference. 'Twenty years ago in Medway you couldn't walk through an alleyway or a children's playground without seeing syringes everywhere. Now I haven't seen one for sixth months at least.'

PASSIONATE AND COMMITTED

Medway Hope's peers were passionate and committed to saving lives and making a difference, said volunteer and recovery coordinator for Open Road, Jo. 'They embrace all opportunities to develop the project and increase their knowledge and skills. I feel privileged to work alongside the peers and watch them grow in their own personal development, and collectively as a group. They've gone from strength to strength, growing in confidence and self-belief, establishing their own roles, chairing meetings, networking and meeting professionals and partner agencies. I don't have the words to tell you how proud I am of their achievements.'

LIVING EXPERIENCE

Mat Southwell of EuroNPUD had been working with Cranstoun Sandwell to look at the development of peer-to-peer approaches, he told the conference, particularly around naloxone. 'I think it's really important to see active drug user organising starting to come back into UK work. We talk a lot about lived experience, without remembering that people with living experience are engaging with those people engaged in active risk now.' The Sandwell Project SCORE team, as a group of active drug users, had also been helping to engage the






local drug-using community to support Drug Science in its research into the potential for an overdose prevention centre (OPC) in the UK.

The service had been looking at the factors that could influence public injecting locally, said Simon of Cranstoun Sandwell, as well as examining reports of needle litter from the local waste management agency. 'But this didn't give us the full story.' While further research and outreach work was able to identify four potential sites for the most suitable OPC setting, the only way to confirm this was through the privileged knowledge of the people in the local drug-using community.

'So we recruited a team of individuals who were interested in making positive changes to their community and their peers,' he said. SCORE had taken the service 'to places we would never have found otherwise', and were also able to improve service provision outside of the research. 'They were able to tell us about things we were missing as a service, and we've been able to take that feedback and improve the service for everybody.'

VALUABLE INSIGHTS

The main aims of the feasibility project were to consult people about their experience of street-based drug use, said researcher Ben Scher, as well as identify what elements of international OPCs would be useful in Sandwell and get the input of local businesses and residents. 'But the most valuable was the ethnographic field sessions,' he stated. 'Led by the SCORE team, we were taken to areas we would never have been able to access otherwise.' The team also gained valuable insights into issues around not having somewhere safe to use, fear of the police and other practical considerations. 'They wanted to be part of the solution, not just viewed as the problem.' The research had already been presented at the House of Commons, he added, 'and we hope it can have a real impact on UK drug policy reform.'

'We've been in very difficult situation since the pandemic,' Southwell told the conference. 'We had about 30 per cent needle and syringe coverage in the UK before that. One provider told me they've seen a reduction of 25 to 50 per cent in coverage since, and it hasn't gone back up again since the lockdowns ended. So something's gone really wrong.' This had serious consequences for hep C among other issues, he warned. 'If you test and treat but don't sort out prevention we're never going to get to hep C elimination.'

> 'It's really important to see active drug user organising starting to come back into UK work.'
>
> MATT SOUTHWELL

One exception to the rule had been in Bath, where he and his wife had run a local peer-to-peer scheme giving out around 1,000 needles and syringes per month. 'We're a very, very responsive service and we're now starting to network into rural areas through family members and other contacts. So we're starting to look at how peer-to-peer NSP could be used to move us from 30 per cent coverage, recover that 25 per cent loss, and then try to push up to 100 per cent. We're never going to reach 100 per cent coverage unless we involve drug suppliers and users in that process.'

HARM REDUCTION

Magdalena Harris of the London School of Hygiene and Tropical Medicine had been running peer-supported projects around crack pipes, risk practices, and stimulant harm reduction, she said. 'One of the reasons is that there's been a real absence of focus on stimulant harm reduction,' with concerns about blood-borne viruses tending to dominate when it came to funding streams. People had been making their own makeshift crack pipes using plastic bottles and tin cans, she said, which increased the risk of both respiratory harm and burns. Reduced availability during COVID also meant that people had been sharing pipes, with the associated risk of transmission.

Evidence showed that crack pipe provision reduced the likelihood of injecting, she pointed out. 'If you've got a crack pipe you're more likely to smoke.' A proposal was eventually put together around trialling crack pipe provision, and the project

had now been funded following local police approval. 'We need this work to show there's evidence that providing crack pipes reduces health harms,' with the ultimate aim of allowing distribution through treatment services.

NEW RESOURCE

A new national resource for opioid agonist treatment (OAT) had been adapted for Scotland based on peer work by EuroNPUD, said Duncan Hill of the Scottish Drug Related Death Task Force. The aim was to have a leaflet to enable informed decision making and explain the treatment on offer, and that people could then share with their peers. 'When we were looking at what addiction services and organisations had, no one had a single quick leaflet. There were lots of leaflets available, all on individual treatments – some were very technical, some were very simple, but there was nothing that combined everything. We wanted to give information to patients so they were able to go away and think about what they wanted to be treated with.'

Some of the terminology and content of the EuroNPUD leaflet – which was written by peers for peers – was then adapted for a Scottish readership. 'The process of tailoring secures by-in for other partners,' added Southwell. 'There's no point in producing a leaflet that's just recognised by drug users. If clients are going back to their services and saying "these are my rights", that needs to have some type of recognition among partners.'

THE RIGHT DOSE

SODA was another joint project on OAT developed by EuroNPUD, as around half of the people on OAT were under-dosed. This not only reduced the impact and quality of treatment, but it meant that people would then pass on negative messages about their treatment. The aim of SODA was to enable people to have conversations around getting their doses right, said Adam Winstock. 'Getting treatment to work is actually really simple. It's about just getting people on the right dose, and allowing them some control over their treatment.'

Many people who thought they were on the right dose would report feeling 'yawny and achy', he said. 'So many people think pre-dose withdrawal is part of being on treatment, and it's not – it's because you're under-dosed. And so many people think opiate substitution treatment doesn't work, because they've never stopped using on it.' SODA was developed to not only give patients control and understanding, but also to inform clinical staff about how they needed to pay more attention to what people wanted, he pointed out. 'I want patients and treatment providers to have honest conversations.'

THE BEST JOB IN THE WORLD

'I've got the best job in the world,' Paul Huggett, the Hepatitis C Trust's peer coordinator for Leicester and Northampton, told the session. 'I get to tell people like me that they've cleared hep C.' The peers' role was to engage, test, treat and support the way to cure, and having lived experience meant they fully understood the support that people needed. 'It's pointless identifying positives if you can't get them through to cure.'

> 'I've got the best job in the world... I get to tell people like me that they've cleared hep C...'
>
> PAUL HUGGETT

He had 20 years' experience of injecting drug use 'and all that comes with it', including a 13-year jail sentence, he said. 'I'm truly grateful to the Hep C Trust for showing faith in me, because not a lot of people show faith in people like me.'

Hepatitis C was a killer disease, and although the previous treatment was 'brutal' what was available now had no side effects whatsoever. 'I got cured, and that made the impossible possible. It made being stable on a script seem doable, and even sobriety seemed achievable.' Treatment was the catalyst for him to start to get well, he said. 'This stuff is gold for drug workers.'

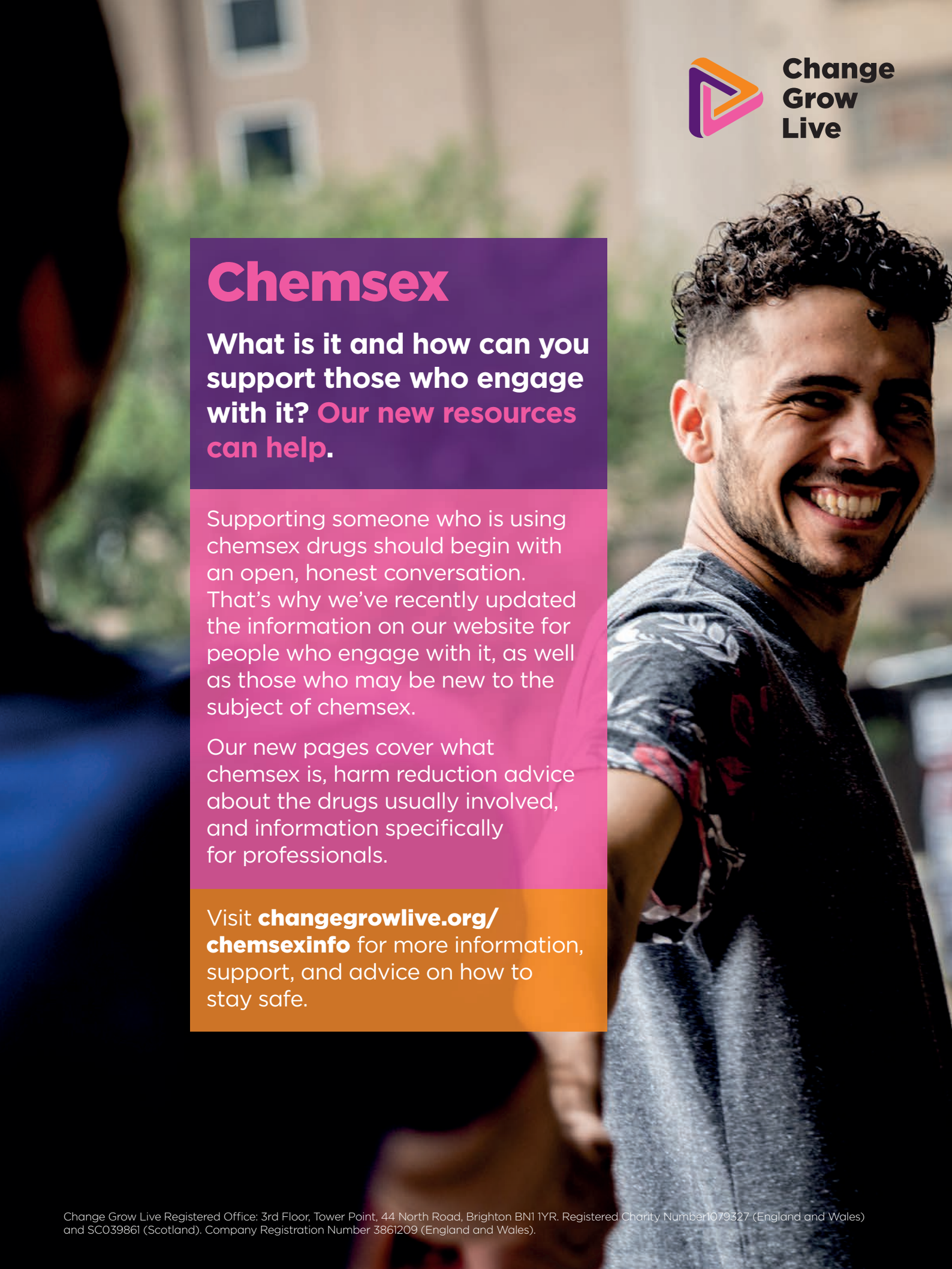
His team consisted of full-time lived experience staff, alongside six volunteers, with most volunteers going on to full-time employment. The majority wanted to work in drug services because they felt comfortable and could put their experience to good use – 'so at the trust we try to upskill them. I'm gutted when I lose them, but there's a lot of pride there as well.'

The team worked with rough sleepers, distributing phones and three months' worth of credit to carry out welfare checks while people were on treatment, as well as picking people up for appointments and reminding them to take their tablets. They also shared their stories at rehabs and drug services. 'They go from being scared to even talk in groups to public speaking – it's massive.'

TEST, TEST, TEST

The peers were also responsible for most of the testing, he added. 'Having a test is win-win. If it's negative it's a win, if it's positive you just take a few tablets and carry on with your life. So if you're a drug service, test, test, test. But test the right people. I know people who've done 200 tests and found none. If I do 200 tests I'm finding 50, because I'm target-testing the right people.'

Last year his peer team in Leicester had engaged more than 2,300 clients, trained more than 900 staff, and tested almost 1,100 people. 'We found 261 positives, and over 200 of them have already started treatment. So you can't tell me lived experience peer programmes don't work.' **DDN**



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Chemsex

What is it and how can you support those who engage with it? Our new resources can help.

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ALL TOGETHER NOW

DDN would like to thank our sponsors and supporters – Camurus, Ethypharm and Nal Von Minden – Active Lancashire, and all our wonderful exhibitors. Thank you to our amazing teams of volunteers from Changes UK and the Hepatitis C Trust – and to each and every one of you who came to the conference and made it such a success.

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We had such a good day and some brilliant, engaging conversations with lots of people. The vibe was great!
Charlotte Thorpe, Broadway Lodge

It was great to see such a supportive and welcoming recovery community of partners and peers with lived experience.
Georgia Patterson, Change Grow Live Birmingham

This was my first *DDN* conference and I wasn't quite sure what to expect. From the moment I arrived, I felt like I was surrounded by people who were full of energy and determination to spread the word that recovery is possible.

I felt proud to spend the day working alongside my amazing Change Grow Live colleagues, as well as honoured to meet many staff members and service users from other organisations. It was plain to see that as a collective, we all share a great passion for helping people to change their lives for the better and I look forward to attending again next year.
Lydia Broom, Change Grow Live

We felt so honoured to be asked to attend the *DDN* conference and present our research. We have been working on this pilot for the last six months. We want to help generate interest around the potential for safer injecting centres, along with issuing naloxone to peers that are not currently accessing Cranstoun to ensure as many people have the life-saving kit that is naloxone.
Ria Davinia Butcher, Cranstoun

A FORCE TO BE RECKONED WITH

Jennie Chapman shares Red Rose Recovery's DDN conference experience

Almost 50 service users, volunteers and staff at Red Rose Recovery made the five-hour road trip to Birmingham to participate in the conference.

Many were attending for the first time and among those making their *DDN* debut was Linzi Jackson, a lead volunteer in Red Rose Recovery's Lancaster-based north team, who said the event was everything she'd hoped for. 'I just had a massive sense of pride,' she said. 'What I loved was that there were no distinctions – whether you were a service user, volunteer, staff member or a senior director, everyone belonged, was valued, and had something to contribute.'

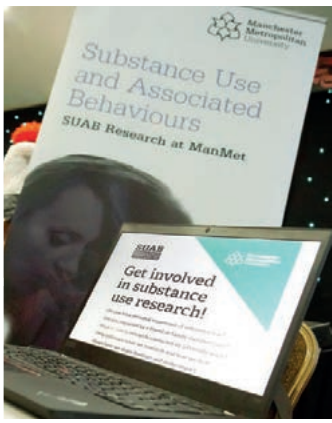
She added: 'I'm so proud of what I do [as a volunteer]. It's taken a lot of years to build my sense of self-worth. Now I see that transformation in others – people going from having major social anxiety, to integrating into peer support groups, finding a community, and finally being able to support others. Together, we are a force to be reckoned with.'

Jason Hayes, another lead volunteer who works with the charity's Central team in Preston, said the *DDN* Conference was a 'celebration of all the people doing the hard work behind the scenes' – the volunteers and peer supporters 'fighting for change and saving people's lives'.

The conference had additional significance for Jason – almost 20 years ago, he heard a speech delivered by Dr Ed Day and become a fan, reading his articles, listening to his speeches and seeing how lived experience has progressed from the peripheries of services to centre stage.

'Back then, you didn't see people with lived experience at needle exchanges, going out to feed the homeless, leading support groups,' said Jason. At this year's *DDN* conference, he finally shook hands with the man whom he said had been 'massively important' for his own recovery.

We had a fantastic day at the *DDN* conference and to join our LERO voices with the service user lived experience voice was amazing. *Dave Higham, The Well Communities*



There was a great turnout and vibe from attendees – and it was lovely to have done this face to face. *Rebecca Odedra, head of reintegration, Recovery in Action Team, WDP*

The conference was brilliant – we got a chance to meet other LEROs from across the country and to present/display BAC-IN's peer led recovery model and cultural challenges faced by many from minoritised communities in accessing and engaging mainstream treatment and recovery services. *Sohan Sahota, BAC-IN*

UNSTOPPABLE FORCE

Juan Fernandez and **Jamie Bridge** look back at the Support Don't Punish campaign's decade of local actions against the global 'war on drugs'

As always, 26 June marked the United Nations' 'International Day Against Drug Abuse and Illicit Trafficking' – a day in which many governments around the world choose to 'celebrate' their efforts to interdict drug markets and arrest those involved (including people who use drugs). Historically, this date has even been used for public executions of drug offenders. But, ten years ago, a bold new campaign was launched to reclaim the narrative of the day, and to promote more humane drug policies: Support Don't Punish.

The initial brief was simple – design a message and some visuals that a handful of country partners from the Dutch government-funded PITCH Project could use to promote harm reduction and decriminalisation. On 26 June 2013, we were blown away when we learned about campaign activities happening in 41 cities and 22 countries around the world, most completely unrelated to the project! Support Don't Punish has continued to grow in size and influence since then.

Around 26 June 2022, on the 10th Global Day of Action, thousands of people have been mobilised through a range of activities in at least 281 cities across 91 countries. In each country, local partners have the freedom to design their own events and approaches – and even the campaign brand and logo has been widely translated, adapted and personalised over the years. Crucially, each local partner also decides on their key advocacy messages – as long as these fit under the broad Support Don't Punish principles (see opposite page).

Materials, leaflets, logos, designs and ideas are provided whenever possible by the International Drug Policy Consortium (IDPC), a global civil society network that is also

SUPPORT DON'T PUNISH PRINCIPLES

- The drug control system is broken and in need of reform.
- People who use drugs should no longer be criminalised.
- The death penalty should never be imposed for drug offences.
- Drug policy should focus on health, wellbeing and harm reduction.
- Drug policy budgets need rebalancing to ensure health and harm reduction-based responses are adequately financed.

the campaign's co-creator and coordinator. Thanks to ongoing support from the Elton John AIDS Foundation and the Robert Carr Fund, we were also able to provide more than 100 small grants to partners all around the world. IDPC's role as the campaign's central hub is also strengthened by a number of thematic, community-based or regional 'sister hubs' that support partners to mobilise under our collective banner.

The campaign events continue to demonstrate the incredible ingenuity and creativity of this sector. Over the years, we've seen art displays, music concerts, demonstrations and processions, street performances, political workshops, press conferences, webinars, radio shows, and so much more. In June 2022, the campaign partners organised media events in Nigeria, community events in Canada, harm reduction workshops in Colombia, rallies and speeches in Morocco, naloxone training in Ireland, film screenings in Australia, community outreach in Portugal, street performances in Zimbabwe, and the list goes on. Here in the UK, the powerful Anyone's Child network held a lobby event outside Parliament calling for reform of our own drug laws.

By giving local partners the flexibility, resources and tools to organise based on their own needs and advocacy targets, the campaign has fostered a decentralised movement that brings together thousands of people – whether attending events, engaging with policy makers, or simply taking a photo as part of the campaign's photo project (as participants at last month's *DDN* conference were invited to do). This power in numbers helps to open doors to advocate for better drug policies: local partners report that the campaign has facilitated access to decision makers that were once inaccessible to them. The campaign has been specifically cited as an important contributor to policy changes in places such as Ghana, Ukraine, Mauritius and Thailand – to name just a few.

'Thanks to ongoing support from the Elton John AIDS Foundation and the Robert Carr Fund, we were also able to provide more than 100 small grants to partners all around the world.'

Over this past decade, we've seen rapid spurs of progress in drug policies in places we would not have imagined. More and more countries are moving towards the decriminalisation of drug use, which has now been explicitly endorsed by every UN agency through their 'Common Position' on drugs. Harm reduction measures such as drug consumption rooms and drug checking are growing in acceptance. But change is not a linear road and should never be taken for granted – and the last decade has also seen regression and rising authoritarian policies elsewhere, and the reversal of key wins where we thought they were well established. Here in the UK, at a time when Kate Bush tops the music charts and *Top Gun* is back in cinemas, Kit Malthouse's rhetoric of 'clear, certain, swift and escalating consequences' that are 'increasingly painful' for 'recreational drug users' (*DDN*, June, page 4) feels like it's following a trend by taking us back in time to the 1980s.

It therefore remains invaluable that we can all still come together, as a global drug policy reform community, under the umbrella of a unified Support Don't Punish message. The campaign's growth is also measured in the way local partners have cultivated solidarity between different movements who are also affected by the 'war on drugs'. We remain convinced that the question is when, rather than if, global drug policies will change. Until prohibition is consigned to history, campaigns such as Support Don't Punish have an important role to play in seizing every political opportunity as and when it arises.

Juan Fernandez is campaigns and communications officer and Jamie Bridge is chief operating officer at IDPC

HEPATITIS C ELIMINATION: THE TIME IS NOW

Between 2015 and 2020, The UK Health Security Agency (UKHSA) reported an estimated 37 per cent reduction in hepatitis C infections.[1] Now the whole system is readying itself for a final push to eliminate the disease

Hepatitis C is in decline in England. In its latest progress report UKHSA revealed that domestic cases of people living with chronic hepatitis C virus (HCV) infection fell to 81,000 in 2020.[1] The reduction in cases has been driven largely by improved access to treatment in recent years,[1] and through an innovative partnership which has seen NHS England, the pharmaceutical sector and health services working together to identify programmes and practices which will help reach the national goal of HCV elimination.

UKHSA also reported 'incredible progress' in HCV-related mortality, which fell by 35 per cent between 2015 and 2020;[1] exceeding the World Health Organization's (WHO) target of 10 per cent.[1] In fact, with HCV-related annual mortality now lower than two per 100,000, England has already met the WHO's interim target for 2030 well ahead of schedule.[1]

These figures are of course to be welcomed – but a bigger goal remains on the horizon. In 2016, WHO set out its roadmap to eliminating HCV as a public health threat by 2030 – meaning a reduction in new chronic infections of 90 per cent and a 65 per cent decrease in mortality compared with 2015 levels.[2]

The time is now. Across the health system, people are coming together to unite around one vision: achieving elimination of HCV. Professor Graham Foster, clinical leader of NHS England's hepatitis C programme, told *The Sunday Times* in February that by 2025 it is a 'realistic aspiration' for England to become the first nation to eliminate hepatitis C.[3]

FROM TREATMENT TO ELIMINATION

HCV is a blood-borne virus which most commonly affects the liver.[4] People often don't experience symptoms of HCV until several years after infection, and if left untreated, it can cause scarring to the liver, cancer, and even death.[5]

Fortunately, modern treatments have transformed the medical options available to patients, making HCV a curable disease for the majority of patients and meaning that most people who contract the virus and receive treatment will have a normal life expectancy.[6]

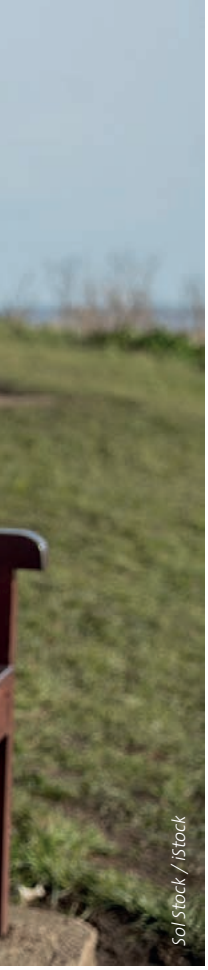
And treatment is having a positive impact on individuals beyond physical health. A 2019 study led by Gilead in partnership with the clinical community found that HCV treatment had a positive impact on their engagement in society, emotional wellbeing and other aspects of their mental and physical health.[7]

THE ROLE OF DRUG TREATMENT SERVICES

A critical part of that journey is drug treatment services (DTS). HCV is a condition that disproportionately affects people from marginalised and underserved parts of society. Injecting drug use remains the main driver of HCV transmission in England and needle sharing remains a problem, posing a challenge in preventing transmission.[1]

Gilead Sciences has supported the formation of a provider forum which brings together the national leads of the six largest DTS providers in England including the NHS Addictions Provider Alliance (NHSAPA) covering more than 150 services across England, with the shared goal of eliminating HCV in partnered drug treatment services by the end of 2023 – two years ahead of the national target.

Dr Prun Bijral, medical director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Far left: Véronique Walsh, general manager, Gilead Sciences UK & Ireland.
Left: Hep C Trust Peer, image courtesy of The Hepatitis C Trust.

of the health and social care charity Change Grow Live, said: 'Thanks to the efforts of DTS providers and partners across the health system, we have made great progress towards our goal of ensuring a better quality of life for our clients. It is vital that we continue to work together to reduce incidence of HCV, increase testing and ensure that more patients can access the hep C services they need.'

In London recently, around 150 people gathered – with hundreds more joining online – to re-energise the drive to HCV elimination across DTS, under the banner: *The Time to Act is Now*. The event, organised by Gilead, was the culmination of years of successful partnership, determining how to deliver elimination in DTS in 2023.

Bringing together clinicians, drug and addiction service providers, patient advocacy groups and public health experts among others, the event was designed to help share best practice, discuss challenges and identify solutions to providing the best care in DTS. By integrating representatives from all parts of the system, it underlined how crucial working together is to the pursuit of this ambition.

Rachel Halford, CEO of the Hepatitis C Trust, said: 'For so many years, there was an urgent unmet need for effective treatments for hepatitis C. But thanks to medical innovation, we now have not just a cure, but an opportunity to eliminate this devastating virus as a public health issue. We cannot let that opportunity slip, and we will only succeed if we work together. That's why events like this are so important – enabling people from all parts of the health system to meet, collaborate and agree joint approaches to finding, diagnosing and treating more patients and ultimately achieving our goal of elimination.'

CHALLENGES TO ELIMINATION

There remain significant hurdles to overcome before elimination can become a reality. Because HCV often displays no visible symptoms until it has already done significant damage to the liver, many patients are simply unaware of their illness: an estimated 50 per cent of people living with HCV do not know that they have the virus.[8]

Due to the patient population, testing in itself is a challenge, and a significant number of people with active HCV infection may not engage with testing services. In addition, a person can be reinfected with HCV – and the challenges around needle sharing of drug users means this is an ongoing concern. And despite positive progress in recent years, there remain concerns that rates of new infections and reinfections could outstrip efforts to prevent transmission.[1]

There is also the impact of the COVID-19 pandemic to consider. Since March 2020, all parts of the system have worked tirelessly together to maintain HCV treatment services and continue finding patients for testing, but social distancing measures and the wider disruption to health services have posed a significant hurdle.[1]

ACHIEVING ELIMINATION

In its latest status report on progress towards HCV elimination, UKHSA said: 'If elimination is to be achieved and sustained, efforts and investment in prevention, testing and treatment will need to be redoubled to ensure that the ground lost during the COVID-19 pandemic is made up.'[1]

This type of joined-up approach has already been key to micro-elimination success. Strong partnerships, close working across all pathway stakeholders, dedicated 'site stars' who champion the elimination goal at a regional level, and targeted HCV testing events have been crucial to achieving micro-elimination in DTS in Thurrock, West Kent, Reading and Bromley.[9]

Véronique Walsh, general manager, Gilead UK and Ireland, said: 'Effective joint working is crucial to our chances of eliminating HCV in the England. Achieving micro-elimination across a number of sites in partnership with other organisations has provided a roadmap for how elimination can be achieved – but it is not done and we need to continue our efforts, and push together so that every patient with HCV can access testing and rapid treatment, supporting our shared goal of elimination.'

If you would like to find out more about hepatitis C, including ongoing practices to support elimination, visit http://hepctrust.org.uk/

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GILEAD
Creating Possible

AT THE HEART

We should value lived experience at its true worth, heard the APPG

'The drug strategy values the voice of lived experience,' John Murray of With You told the All-Party Parliamentary Group on Drugs, Alcohol and Justice. But we had to bear in mind that some of these people had had poor experiences of drug services in the past. So how did they fit in to the recovery process?

The government's recovery champion, Ed Day, said his role was to encourage greater partnership working, which needed to be accompanied by an understanding that 'the course of dependence and the achievement of stable recovery can take a long time'.

Partnership working was about parity of esteem, said Tim Sampey of peer-led organisation Build on Belief (BoB), who drew on his own personal experiences as well as those of his organisation.

BoB's work aimed to complement the local treatment system, but at the heart of it 'the social space is incredibly important,' he said. We were 'tribal creatures' who benefited greatly from the concept of mutual aid – helping each other.

Many of the big service providers had worked with his organisation, which hadn't always been successful, he said. But one big positive was that lived experience was being 'inch by inch embedded'.

Alex Boyt asked how recovery was measured – relating to the statement that half of people achieve recovery – and Day referred to the work of William White in this area. Boyt made the point that most people with living experience were still using drugs or alcohol, and that keeping people alive was the main thing. 'Focusing on recovery instead of keeping people alive is an issue in services,' he said. 'We tend to use the experience of those who make progress.'

Lived experience should guide the treatment system, 'and not in a tokenistic way', said Sunny Dhadley. He was concerned about the exploitation of people with lived experience – 'they're not there to prop up the workforce'. He also wanted to know what was happening to people who left the treatment sector to work elsewhere – were there people to support them?

Day, whose main role was as a doctor working in the NHS, said the NHS needed to engage better with people with lived experience and respect and reward their round-the-clock dedication. Supporting people to set up and run peer-led organisations deserved a ringfenced part of the budget, he said, together with an investment in mentoring roles.

The value of peer engagement was confirmed by others, including former chief inspector Jason Kew who mentioned the 'speed of engagement' achieved by involving people with lived experience. But there was concern at the lack of awareness by professionals, including GPs, of recovery organisations and all they could offer, and a feeling that this valuable resource was not yet being recognised, used properly, or rewarded. **DDN**

UNITED VOICE

Let's turn the energy into evidence, says the CLERO

We had a fantastic day at the *DDN* conference, and to join our LERO voices with the service user lived experience voice was amazing. It was great to hear Ed Day and Rosanna O'Connor talking about the opportunities of the Dame Carol Black report and the new OHID monies and how lived experience is essential in delivering and implementing the new drug strategy.

We look forward to building on the relationship between the College of Lived Experience Recovery Organisations (CLERO) and *DDN* to bring a united lived experience voice to enable change, so we can create better services for everyone while evidencing the work we all do.

In the modern world of treatment for people with a substance use disorder, it's all about this evidence base, isn't it? If the evidence says something works, OST for example, then we would be foolish not to continue its provision. However, the lack of an evidence base leaves some parts of the system twisting in the wind – recovery support services and LEROs to name but two. We know what we do is a vital component of the wider system, and we know it works. We just don't have an evidence base to back it up – and what little we do have is mostly qualitative. Nevertheless, qualitative evidence is a good place to start.

One of the first pieces of work undertaken by the CLERO was to agree a set of standards with the membership that could be adopted by LEROs big and small across the country. It was both fascinating and encouraging to realise that in many cases these standards were already the basis on which many LEROs were founded and run – we'd just never talked about them or written them down!

We're currently collating examples of how individual LEROs implement a given standard across the UK and intend to produce a report showing the variety of ways in which they are implemented – our first step on the long road to a LERO evidence base.

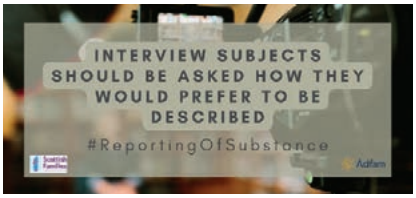
So we're asking LEROs across the country to pick a single standard and write a short piece about how they implement it in their day-to-day work. It doesn't have to be an essay – a simple 'one pager' will suffice. If you wish to contribute to this paper please pick a standard, write your blog and email it to us (address below).

Alternatively, if you wish to have a copy of the standards, or an example of matching practice to standards, please email us at the same address. Don't forget to include the name of your organisation and a logo if you have one. Together, we can evidence that LEROs nationwide provide many thousands of hours of recovery support, delivered to high quality and person-centred standards.

Demonstrating our belief in good practice, the paper will not be made public until every contributor has signed it off!

Contact the College of Lived Experience Recovery Organisations (CLERO) at lero.connectors@gmail.com

A LITTLE RESPECT



A new campaign aims to uproot the stigma embedded in mainstream media, as **DDN** reports

Challenging stigma about drugs, alcohol and any kind of addiction has become part of life for all of us. We've seen how it affects us, our families and friends, and people we work with. But being bombarded by stereotypes each day in the media can make the task feel overwhelming, as stigmatising words and images have become the norm and part of everyday communication.

A mum who had experience of being interviewed by journalists about supporting her daughters with their recovery said, 'showing needles, spoons and paraphernalia... that's what really upsets me. To see that they're never moved away from that over the years... that's the first thing they put up. What's behind the story of that paraphernalia is always very sad, it's very upsetting to people to see how addiction affects our loved ones and the family... but before people have got to that bit of the story, they've judged it already.'

DDN embraced the opportunity to help create a resource for journalists. As part of a working group organised by Scottish Families Affected by Alcohol and Drugs and Adfam, we met online regularly as a group that included a family member, a person in recovery, a national journalist and Alcohol Health Alliance UK, to look at how we could help journalists and editors to report on alcohol and drugs with dignity and respect.

The result was a toolkit for journalists and editors, which gave clear recommendations about avoiding stigmatising language, treating interviewees with respect and using appropriate imagery. It also suggested including support information in articles. The ambition was to encourage journalists to see their subjects as people – professionals, family members, members of the community who were experiencing problems – rather than defining them by negative labels and images.

The key recommendations were:

Images of alcohol and drugs should only be used where appropriate, and should not contain people in vulnerable conditions, including being drunk or unconscious. Articles about alcohol harm should not contain images which glamorise drinking and pictures of drug paraphernalia should only be used where the context is informative. Images should tell the human side of the story in a positive and responsible way, using photos of interview subjects, support services or the community.

Stigmatising language and labels should be avoided, and journalists should take care to reference interview subjects as parents, professionals and so forth, rather than 'user', 'addict' and 'alcoholic'. Interview subjects should be asked how they would prefer to be described. Words like 'druggie' or 'junkie' should always be avoided.

Case studies should be encouraged – there are many people who are happy to share their stories to help others find support. Anonymity must be respected when requested, and interview subjects should be offered the chance to approve their own quotes.

Support information should always be included in any article reporting on alcohol or drugs.

Improving education through such positive practice could play a vital role in changing culture. Including honest accounts promoted the message that people can and do recover, and also helped readers to relate to and empathise with those involved. Journalists and editors were encouraged to reach out to groups and communities to learn more about their work.

'We've seen fantastic progress over the years around reporting of mental health issues, including support information being included at the end of every article, stigmatising language decreasing, and the use of positive and educational images,' said Justina Murray, CEO of Scottish Families. 'We want to see the same progressive approach in the reporting of alcohol and drug issues... We know the media can play a huge part in sharing the voices and experiences of family members and in encouraging people into recovery.'

The toolkit would help to challenge the stigma faced by those struggling with drugs and alcohol, and their families and friends, added Vivienne Evans, chief executive of Adfam. 'Journalism has a key role to play here, and we have produced this toolkit in collaboration with journalists who want to see more respectful reporting on alcohol and drugs across the board.'

The #ReportingOfSubstance media toolkit from @ScotFaADrugs and @AdfamUK is available online at https://bit.ly/3zC6MnV

Share the toolkit on social media and join in the campaign!

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TAILORED TO YOU

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CONTACT DERBY.RESIDENTIAL@PHOENIXFUTURES.ORG.UK FOR MORE DETAILS, ACCEPTING REFERRALS FROM AUGUST

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