NALOXONE ACCESS AND ADVOCACY PROJECT (UK)

PROCESS AND FINDINGS REPORT

EuroNPUD
European Network of People who Use Drugs

2019

EUROPEAN NETWORK OF PEOPLE WHO USE DRUGS

IMAGE OF THE DRUG USER SHRINE IN MOUNT PLEASANT, LONDON. THE SHRINE STARTED TO APPEAR FROM 1975 AND IS MADE UP FROM SPOONS, WITH EACH SPOON REPRESENTING SOMEBODY WHO OVERDOSED. YOU WOULD SEE IT IF YOU WALKED TO FARRINGDON, CLOSE TO MOUNT PLEASANT SORTING OFFICE, WHERE THERE ARE STEPS GOING UP THE VIADUCT. HIGH UP ON THE WALL OF ONE OF THESE DANK STAIRWELLS THERE WOULD BE A DOZEN OR SO SPOONS STUCK TO THE TILES.

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MEMORIAL STATEMENT

During the implementation of this project, the international community of people who use drugs suffered a great loss in the passing of Dan Bigg. Dan was an award-winning Chicago-based activist who established the first community-based naloxone distribution programme and pioneered an approach that put naloxone in the hands of active drug users. Community-based naloxone distribution programmes have been implemented across the US and around the world. The significance and urgency of Dan's life work has been highlighted by the current opioid overdose crisis in North America and our community is suffering great sadness and each of our hearts is hurting under the weight of such extensive loss. Due to Dan's efforts, thousands of lives have been saved and EuroNPUD dedicates this project in Dan's name.

ACRONYMS

AMCD	Advisory Council on the Misuse of Drugs
COPD	Chronic Obstructive Pulmonary Disease
CND	Commission on Narcotic Drugs
EuroNPUD	European Network of People who Use Drugs
FGD	Focus Group Discussion
GP	General Practitioner
IV/IM	Intravenous/intramuscular (injection)
LUF	Lancashire Users Forum
NHS	National Health Service
NSP	Needle and Syringe Programme
ONS	Office for National Statistics
OST	Opiate Substitution Therapy
PHE	Public Health England
WHO	World Health Organisation

METHODOLOGY

The delivery model, timeline and the delegated tasks were described in a Project Plan. The EuroNPUD Project Team included:

PROJECT MANAGER (MAT SOUTHWELL) - project design and management, group facilitation, and development of project resources,

PROJECT ADMINISTRATOR (AMY MASSEY) - logistics, administration and liaison with partners

COMMUNICATIONS COORDINATOR (ERIN O'MARA) - design and print project resources and produce supporting webpage

PROJECT WRITER (RUTH BIRGIN) - document the process and findings of the project

PILOT AREA WORKER (EMILIE RESPECT) - peer leader from Bath who tested the naloxone access tools and approach

AREA COORDINATORS - a drug user organiser from each of the study area - Burnley **(PETER YARWOOD)**, Blackpool **(EMMA DAGGERS)** and Liverpool **(FRANCIS COOK)** - who mobilised local peers and networked with local policy makers and providers to deliver the FGD, the mystery shopper exercise and the advocacy meetings

Project planning was coordinated across the pilot and three study sites through Zoom video conferencing and the Slack online collaboration platform. The UK-based team recorded the peer feedback from the structured and facilitated focus group discussions and the debrief from the Mystery Shopper exercises. The project team meetings were also held on Zoom and recorded. The Project Writer reviewed the recordings from the virtual meetings and the peer engagements; these recordings were processed to form the basis for this Process Report.

A debrief meeting was held with the full project team in London on 31 August. The team walked through the different stages of the project allowing the Project Writer to clarify understanding and to address any gaps in knowledge. The working draft of the report was edited by the Project Manager based on consultation with the Project Team.

ACKNOWLEDGEMENTS

EuroNPUD would like to thank Martindales, part of the Ethypharm group, for the unrestricted educational grant that made this project possible. Martindales supported a meaningful partnership between EuroNPUD, the local drug user groups and activists, and their local professional partners in delivering this peer audit of access to naloxone. The project has modelled a constructive approach to addressing barriers to naloxone in partnership with local policy makers, planners and practitioners.

The project has also laid the foundations for the promotion of peer-to-peer distribution of naloxone as an affordable and effective method of scaling up access to naloxone in affected communities. EuroNPUD would like to thank Martindales for their vision and support.

EuroNPUD would like to thank the people who use drugs who took part in the focus groups discussions, the mystery shopper exercises, and the area advocacy meetings. The testimony of the drug users from Burnley, Blackpool and Liverpool was authentic and very powerful. They shared the lived experience of people who use opioids and highlighted the challenges and loss that drug users face living with the risk and realities of opioid overdose in our communities. The peer participants demonstrated through their insights and commitment that people with lived experience of opioids are a significant expert resource in scaling up access to take-home naloxone.

EuroNPUD and LUF both would like to express our sincere thanks to the providers, planners and policy makers in Blackpool and Burnley who welcomed the peer audit of access to naloxone in their local areas. They engaged actively in the project, enabling a thorough and meaningful peer audit of opioid overdose management services. They demonstrated a willingness to engage in the review process, to give serious consideration to the peer feedback and worked collectively to consider advocacy responses to the barriers identified during the peer audit. We would particularly like to thank Emily Davis, Nina Carter and Karon Brown from Blackpool and Lee Harrington from Burnley who went above and beyond to demonstrate their support for meaningful participation with PWUD and to facilitate this project and our access to local drug services.

EuroNPUD would also like to thank AddAction and their new team in Liverpool. We look forward to developing a P2PN initiative with Liverpool AddAction and local peers in Merseyside. We would like to thank Lucy O'Hare from HIT and Max Da Siva Lewis from Blackburne House for helping us set up the Liverpool meetings at short-notice. EuroNPUD would like to thank Emilie Respect, Peter Yarwood, Emma Daggers and Francis Cook for coordinating the work with their local drug using communities and professional partners as part of this project. Their commitment and access to their local peer and professional networks was key to the success of the project roll out.

We thank Dr Jean-Paul Grund for his advice about the structure of the FGD. We look forward to continued collaboration between EuroNPUD's work and Stop Overdose Now about innovative solutions to overdose management.

We would particularly like to thank Stephen Malloy for brokering the funding for this project while working as a private consultant for Martindales Pharma. Stephen has played a key bridgebuilding role helping to connect and link the worlds of drug user organizing and the private sector pharmaceutical industry. Stephen was previously a pioneer of take-home naloxone in Scotland and played a key development role in bringing the drug user friendly Prenoxad form of naloxone to market. This highlights the pivotal role that people with lived experience can play throughout the system from frontline P2PN distributors to senior policy makers.

PREFACE

Accidental opioid related overdose is the leading cause of preventable death among people who use opioids in the UK. For the sixth year in a row, the Office for National Statistics (ONS) have recorded an increase; there were 3,756 drug-related deaths registered in England and Wales in 2017 the highest number of registered drug-related deaths since recorded in a single year. Opioids and opiates were involved in 1985 of these deaths.

There is, however, a safe, fast acting, inexpensive and reliable antidote for opioid overdoses: naloxone. Naloxone has a long history of effective use as an opioid antagonist (i.e. it reverses the effects of opioids), and has been included in the World Health Organisation (WHO) Essential Medicines List.[1] The United Nations Commission on Narcotic Drugs (CND) has likewise formally recognised the need to expand naloxone access to reduce overdose related mortality.[2]

Since 2005, various amendments to the UK Human Medicines Act and regulatory exemptions have sought to expand access to the lifesaving naloxone. The Advisory Council on the Misuse of Drugs (ACMD) is an independent expert body that advises Government on drug-related issues in the UK. In 2012, the ACMD advised that naloxone should be made more widely available as a way of reducing deaths from heroin overdoses.

Given the substantial body of international evidence regarding naloxone efficacy and safety, in October 2015, the Human Medicines (Amendment) (No. 3) Regulations 2015 (2015/1503) was enacted in the UK. This allows naloxone to be supplied by:

"Persons employed or engaged in the provision of drug treatment services provided by, on behalf of or under arrangements made by one of the following bodies– a) an NHS body;(b) a local authority;(c) Public Health England; or(d) Public Health Agency.

It can be supplied to anyone in the course of lawful drug treatment services and only where required for the purpose of saving life in an emergency."[3]

Any recognised drug service can now provide naloxone and volunteers or subcontractors can distribute naloxone from such a service. However, UK opioid overdose rates continue to at a concerning level and there is an urgent need to scale up naloxone coverage.[4]

PEER-TO-PEER DISTRIBUTION AND ADMINISTRATION OF NALOXONE

The EuroNPUD Naloxone Access and Advocacy Project (NAAP) was funded with an unrestricted educational grant from Martindale Pharma an Ethypharm Group company in support of activities leading up to International Overdose Awareness Day (IOAD) – 30 August 2018.

Timely administration of naloxone is critical as delay can significantly increase the risk of fatality or injury. In many overdose cases, other people (and in particular, other people who use drugs) are present. Training peers to distribute and administer naloxone will significantly increase coverage among those most likely to be present during an opioid overdose thereby reducing response times and saving lives.

For example, in Glasgow, a peer-to-peer naloxone distribution project (P2PN) run by a recovery group gave out over a thousand units of naloxone in one district of the city, which was more naloxone than every health professional had given out in the proceeding year across the whole of Glasgow. P2PN provides a cost effective and high impact solution to scaling up naloxone distribution.

1. INTRODUCTION

BACKGROUND OF PROJECT

Concerned that access to naloxone remains unnecessarily restricted, the European Network of People who Use Drugs (EuroNPUD) has utilised an unrestricted educational grant from Martindale Pharma, an Ethypharm Group company, to undertake a project aimed at improving naloxone access and advocacy in the UK. Drawing on an action research project piloted in three UK cities, this report sets out background, method, findings, advocacy strategies and recommendations for enhanced naloxone access, particularly through the deployment of the highly efficient and cost effective peer-to-peer distribution method.

EuroNPUD selected Burnley, Liverpool and Blackpool as project sites as they share the characteristics of double or more the national average of opioid overdose deaths and typify many of the wider issues associated with overdose and naloxone access in the UK. In addition, strong local peer partners were sought each of the selected sites with the requisite capacity, community links and professional connections to set up and guide the project in their area.

The focus of the project is to highlight the role of naloxone in responding to opioid overdose, to describe the existing response and barriers to naloxone access in the UK and to advocate for expanded access to this life saving intervention. The local audits have thrown up lessons that can be used to support advocacy campaigns in each area and to technically guide those working to extend access to naloxone.

The EuroNPUD Naloxone Access and Advocacy Project has also produced two technical documents as part of this project:

1.Technical Briefing on Peer-to-Peer Naloxone Distribution.

2. Toolkit for testing access to and promoting advocacy for naloxone using the methodology deployed in this project.

The assessment and advocacy planning phases of this project had to be undertaken within the rapid timeframe of one month. This reflected delays in raising funds for and initiating this project and the opportunity presented by linking key activities to International Overdose Awareness Day (31 August). As a result, the process was somewhat rushed and this did result in some pitfalls around lead in times for stakeholder engagement, event advertising and the production of marketing materials. However, there were also benefits in working to a fixed timeline and bringing an expert team with specialist skills to work at both the national and local levels. EuroNPUD are confident that the research conducted was of high quality and generated valid and verifiable findings.

Data derived from Liverpool reflected two limitations. First, prior to site selection, EuroNPUD was unaware that key drug services in the area had recently been re-contracted and the main service was moving from its long established base to a temporary new base. This presented challenges to the Area Coordinator who had to engage local providers while the main service was in a state of transition. Second, there is currently no drug user group in Liverpool and EuroNPUD partnered with a peer leader from the Wirral who did not have the privileged access into the commissioning and provider system that comes from being the local service user group and/or peer partner.

ABOUT EURONPUD AND OUR LOCAL PARTNERS

The European Network of People who Use Drugs (EuroNPUD) supports the growth and development of drug user networking and advocacy across the European Union and its neighbourhood, and represents the interests of people who use drugs (PWUD) to European institutions. By strengthening and supporting the development of organisations and networks of people who use drugs across in Europe, EuroNPUD provides a vehicle for drug user activists in the European Union to work together on the issues and concerns that directly affect our communities.[5]

In both Burnley and Blackpool, EuroNPUD collaborated with the Lancashire User Forum (LUF). LUF gives service users from all backgrounds, their families and carers, a space to talk and share experiences. Service users work side by side with treatment and other service providers so they can discuss relevant issues, share ideas and best practice, take part in workshops and other activities.

This includes the design, delivery, implementation and evaluation of treatment services in Lancashire. LUF provides a collective voice for current and former service users seeking to address health inequalities in the community.

In Liverpool, EuroNPUD worked with an Area Coordinator who coordinates ***Wirral Service User Forum.*** There were challenges in practice achieving the professional access in the neighbouring area of Liverpool through his service users networks and other connections in the area. The local activities supported with small grants create an opportunity to support drug user organising in Merseyside alongside the delivery of a P2PN pilot. EuroNPUD's Project Manager will provide longarm support to local drug user activists investing resources in support of peers who take a lead on the project. An engagement has been secured with the local service provider AddAction who are willing to work with EuroNPUD to catch Liverpool up with the progress achieved in the other two sites.

2. SITE DESCRIPTIONS

The following site descriptions are based on data collected from local area mapping, from local commissioners and the Office for National Statistics[6], with a focus on the current status of overdose management provision and area overdose rates. In all sites, the current system for naloxone distribution hinges on a commissioned system where lead agencies subcontract to providers who can either be health service organisations or non-governmental organisations (NGOs) / voluntary sector.

2.1 BLACKPOOL

In 2017, there were 73 overdose deaths in Blackpool with a rate of 18.5 (over four times the 4.3 average rate for England).

Blackpool Borough Council commission drug services for the area and are supportive of drug user participation and harm reduction. The Blackpool protocol provides guidance on the supply of naloxone by designated staff employed within alcohol, drugs and sexual health support and partner agencies. Staff, service users, family members, hostel workers and others are trained to manage opioid overdose and the administration of naloxone. Training is provided in line with local and national guidelines to reduce the numbers of drug related deaths from opioid overdose. Staff supplying naloxone should have been appropriately trained and have been signed off as competent by the Clinical Service Manager. Each service provider within the partnership is responsible for keeping a register of appropriately trained staff with naloxone.

The local drug service protocol covers access arrangements for the entire Blackpool area. Key drug treatment services are required to work collaboratively to increase access to naloxone across Blackpool.

Currently staff can offer brief training interventions on overdose management including the use of naloxone before equipping the peer with naloxone to take home. To date, since 2017, a total of seventy two active drug users have been given naloxone. Adequate coverage estimates indicate a minimum target of 40% coverage. In 2016/2017, Blackpool had a naloxone coverage rate (measured by the number of THN kits dispensed per estimated opiate users in a local authority area) of only 20%.[7] Fortunately Blackpool is moving towards a peer support and a buddy system, with the "My Recovery" group set to be the first peer-to-peer initiative.

2.2 BURNLEY

In Burnley there were 28 deaths classified as related to 'drug misuse' in 2017, at the rate of 11.7 (nearly three times the English national average of 4.3). The Lancashire County Council (LCC) currently commission the community treatment service in East Lancashire for adults who use drugs. A central aim is to reduce drug related harm and deaths and the provision of naloxone is a key element in reducing drug related deaths by poisoning in Burnley and across the County.

Lancashire County Council LCC's commitment to the distribution of naloxone is demonstrated by the requirement in the service specification for the key drug service to provide naloxone as part of harm reduction programming. This is specified in the following extract from the 2016-2019 Service specification for the adult community treatment service:

"Naloxone will be provided for high risk opiate injectors; this must include the delivery of training around overdose prevention, relapse prevention, Naloxone administration and basic life support for users and their families/carers/supporting others. Wherever possible training should be peer led."

In addition, LCC are working with key partners across the county through the 'Drug Related Harm Group' to develop a county and district specific action plan for tackling and reducing drug related harm and deaths. EuroNPUD were unable to source coverage rates for Burnley however data for Lancashire shows a naloxone coverage rate or 22% for 2016/17 (well short of the minimum target range of 40%).[8] Burnley is planning to develop a P2PN pilot with the development grant provided by EuroNPUD.

2.3 LIVERPOOL

In Liverpool, 135 people died from overdose categorised as 'drug misuse' last year, including those of a total of 41 women. The rate of overdose among people who use opioids in Liverpool is over twice the average rate for England.

Liverpool naloxone access policy is determined by the Health & Wellbeing Committee of Liverpool City Council. Some area councils and commissioners have been faster than others to respond to legislative exemptions and Liverpool appears to have been delayed by technical concerns. Prior to site selection, EuroNPUD was unaware that Liverpool services are being reconfigured, with new providers currently moving from a long established drug agency base to a temporary location. (Incidentally, the new provider performed well in the mystery shopper activity). The small group of local drug users and the manager from AddAction who attended the advocacy planning meeting in Liverpool agreed that launching a P2PN pilot with the small grant provided by EuroNPUD would provide a practical foundation around which EuroNPUD could support the development of drug user organising in Merseyside.

Preparing for International Overdose Awareness Day

Tuesday 28th August
Henfry Seminar Room, Blackburne House, Blackburne Place, Liverpool L8 7PE

A half-day event bringing together service users and professional partners in Liverpool organised by drug users in Liverpool in partnership with the European Network of People who Use Drugs (EuroNPUD).

Liverpool is experiencing one of the highest overdose rates in Britain despite the distribution of Naloxone. What are the barriers? How can we prevent more unnecessary deaths?

Naloxone is a life-saving intervention that can bring someone back from an opioid overdose. So why aren't we getting Naloxone in the hands of people who inject drugs, and their friends and family?

This event will put Naloxone distribution under the microscope, exploring:
- the barriers to getting Naloxone into the hands of drug users, their friends and family in Liverpool
- examples of peer-to-peer distribution of Naloxone from Myanmar to Glasgow and from the USA to London, showing how drug users can reach, train and equip their peers with Naloxone.

How can we equip drug users in Liverpool with Naloxone to save the lives of their peers?

2.4 CROSS CUTTING ISSUES

All three sites have local needle and syringe programmes (NSP) as well as pharmacy based NSP. Blackpool and Burnley share a drug user organisation made up of service users and relevant stakeholders, while Liverpool is currently without a structured drug user group. Burnley has an additional service user group made up of clients of the drug treatment service. All three sites also have pharmacy based NSP,[9] supporting secondary NSP in Blackpool and Burnley. Each site has a designated prime provider that sub-contacts to other providers to deliver services including naloxone provision (with Liverpool). Blackpool and Burnley service user groups have strong local general practitioner allies.

In Burnley, the LCC run group consultations through LUF and the key provider apply a service user representative approach for consultation. In Blackpool, drug user groups are used to consult service users when policy makers or service providers are considering specific changes to service delivery.

In Liverpool, drug user engagement in local practice and policy planning has been minimal, however, there are new opportunities following the retendering of the local drug service. AddAction the service provider are receptive to partnership working with EuroNPUD and it is a strategic moment to engage.

Both Burnley and Blackpool have several allied groups for families of people who use drugs, however this project did not identify such arrangements in Liverpool. All three project sites have a local policy on overdose management and procedures for distributing naloxone – these procedures or protocol are functioning as an exemption framework for the supply of naloxone.

A Liverpool informant noted that the policy is not yet being implemented. Police do not carry naloxone, do not have a focal point on the issue and did not appear to be proactively involved in distribution or administration of naloxone.

Currently none of the 3 sites has a peer-to-peer naloxone scheme, however all our planning to implement pilots as an outcome of this pilot. 2 years ago, a group from the LUF in Burnley were trained by a Martindales representative, but the group did not follow on the develop a peer-to-peer distribution scheme. Liverpool has never had peer-to-peer naloxone distribution. Data is collected on naloxone distribution and impact in Blackpool and Burnley but systems for recording distribution and replenishment of naloxone were not confirmed for Liverpool.

Some service providers and some peers have undertaken varying degrees of naloxone training. In Liverpool the focus of training has remained largely on professional drugs staff to date.

3. ASSESSING QUALITY OF ACCESS NALOXONE - METHODOLOGY

PROJECT MANAGEMENT

EuroNPUD used a standardised approach across the three project areas. The methodology was negotiated between EuroNPUD and Martindales and was described in supporting protocols, which were tested in practice and worked up over the course of the project. Our Project Manager, Project Administrator and Communications Coordinator worked as a central team designing the project model, documenting the approach in protocols and developing template resources to support the work of the Area Coordinators.

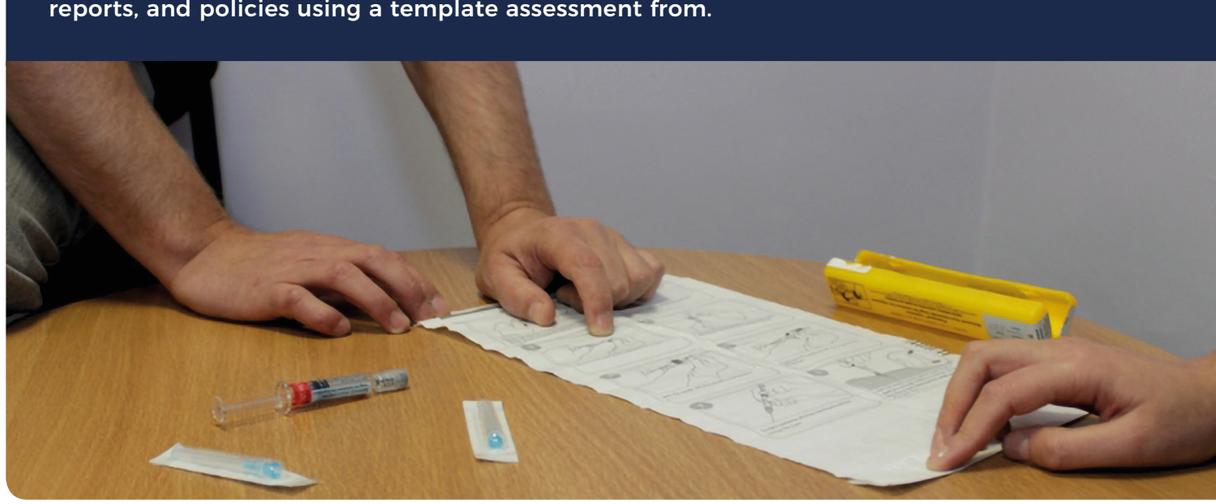
Project methods and resources were trialled by the central team and tested in Bath by a member of West Country Respect (Project Manager's local drug user group).

COLLABORATION PLATFORMS

EuroNPUD coordinate our activities using Slack, an online collaboration platform. Other virtual systems are networked together through Slack - GoogleSheet (budget, project and logistics management), Dropbox (document storage and sharing) and Zoom (e-teleconferencing and webinars). Area partners were connected through these systems supporting effective coordination and communication.

MAPPING EXERCISE

The local partners firstly undertook a mapping exercise to identify key actors, agencies, reports, and policies using a template assessment from.



FOCUS GROUP DISCUSSIONS

The Area Coordinators mobilised a group of local peers and family members to take part in peer focus group discussions (FGD). EuroNPUD identified the ideal mix of FGD participants and supported local partners to identify local pathways to engage the desired mix of participants through their peer and service networks. Participants included active heroin injectors, clients of OST programmes, people discharged from inpatient detoxification or residential rehabilitation services in the last year, and prisoners released in the last 12 months and family members of people using opioid drugs.

THESE STRUCTURED DISCUSSIONS WERE DESIGNED:

- TO TEST KNOWLEDGE OF OPIOID OVERDOSE, OVERDOSE ASSESSMENT AND MANAGEMENT,
- TO GATHER PEERS' EXPERIENCES OF DRUG SERVICES AND THE WIDER PUBLIC SECTOR TO THE PREVENTION AND MANAGEMENT OF OPIOID OVERDOSE,
- TO REVIEW AND EXPLORE PARTICIPANTS' EXPERIENCE OF OVERDOSING OR WITNESSING AND MANAGING FATAL OR NON-FATAL OVERDOSES,
- TO DISCUSS ATTITUDES TO NALOXONE AND OPIOID OVERDOSE MANAGEMENT AMONG PEOPLE WHO USE DRUGS.

Many of the experiences were intimate and emotional and would not have been shared in such a candid way outside a peer-led environment. One of the participants had lost his partner to overdose only two weeks before the FGD was held. Importantly, the focussed discussions included time to explore overdose experiences, to clarify any evident misunderstandings relating to overdose and naloxone, and to debrief.

The EuroNPUD Project Manager facilitated the FGD in all three sites. The Project Manager is an experienced and trained motivational group facilitator, grief counsellor and community mobiliser. Relevant tips and principles from these three practice models are included in the supporting Toolkit. These are key to creating an environment within which PWUD are supported to debrief from these intimate and emotional experiences in order to draw out local lessons.

#END OVERDOSE

THE TRAUMA ATTACHED TO LOSING FRIENDS AND FAMILY, AS WELL AS PERSONAL NEAR DEATH EXPERIENCES IS PALPABLE AND UNDERSCORES THE NEED FOR REDOUBLED AND URGENT EFFORTS TO IMPROVE ACCESS TO NALOXONE.

Group activity included a knowledge questionnaire testing peers' understanding of the key messages that would normally be taught in a brief intervention delivered prior to the distribution of naloxone. Answers were reviewed with participants to afford differentiation between issues of interpretation (e.g. about pinned eyes being a sign of opioid use generally rather than a sign of overdose) and factual errors about practice (i.e. IV not IM administration of naloxone).

MISTERY SHOPPER ACTIVITY

Following the group discussions, EuroNPUD trained local peers to deliver a mystery shopper activity to test access to naloxone for drug users and family members across a range of provider settings including drug treatment services, NSP or harm reduction services, pharmacies and general practitioners. The mystery shopper approach and tools were focus tested in a separate area [Bath] and amended prior to use in project sites. The purpose of the mystery shopping activity was to assess any local level dissonance between good practice with naloxone distribution and actual practice. Focus group discussion and mystery shopper debriefings were recorded, carefully documented and further augmented by knowledge questionnaires.

LOCAL ADVOCACY ACTIVITY AND SMALL GRANT

The project methodology incorporated follow-on advocacy and action. Local naloxone access and advocacy planning events were held with relevant stakeholders in each project site to present findings and good practice recommendations. The Blackpool and Burnley events secured the engagement of key professional participants including managers, harm reduction coordinators and outreach workers from local providers, managers of a specialist hostel or supported housing projects, public health commissioners from the local authority, specialists in drug-related deaths, and Public Health England Regional Office. The challenges of engaging professional partners in the Liverpool Area Advocacy Event has already been discussed and a remedial strategy has been agreed.

Barriers to accessing naloxone in the local area were presented and discussed, and area specific advocacy strategies were developed for addressing identified barriers. A small advocacy grant was provided for local advocacy teams to implement their area strategy.

REPORT WRITING

The EuroNPUD hired Ruth Birgin as a dedicated project writer to support the Naloxone Access and Advocacy Project. Ruth Birgin is an international peer technical consultant who contributed to the development of the WHO global guidelines on the *Community Management of Opioid Overdose*[10] which in turn were influential on the development of the WHO's *Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations.*[11]

The Project Writer generated two written resources for this project:

- ***This Process Report describing the project methodology, findings and recommendations***
- ***A Naloxone Access and Advocacy Toolkit describing the methodology developed in support of this project for testing access and promoting advocacy for naloxone that can be further deployed in the UK and by other EuroNPUD country member groups.***

PEER-TO-PEER NALOXONE DISTRIBUTION TECHNICAL BRIEFING

The EuroNPUD Project Manager interviewed 6 providers of peer-to-peer naloxone distribution and reviewed academic articles, media reports, and supporting policies and documentation. Key lessons were drawn out from these interviews to inform the partners in this project and other interested parties about the values of peer-to-peer naloxone distribution. The presentation developed from this review was presented as part of the local advocacy meeting. The peer-to-peer naloxone distribution presentation was advertised to local commissioners, policy makers and providers to attract them to the joint peer and professional advocacy review meeting.

MEDIA EVENT

On 31 October 2018 EuroNPUD held a media event in Brixton London linked to International Overdose Awareness Day (IOAD). A press release was issued to advertise the launch of the project report and the Peer-to-Peer Naloxone Distribution Technical Briefing. Named London-based media contacts were provided by a media agency and targeted directly by email. EuroNPUD hired a community centre in Brixton and provided peer demonstrations of naloxone administration. No media turned up to the event. However, following through with the activity allowed for the generation of key products that support the NAAP Toolkit.

MARKETING MATERIALS

EuroNPUD's Communications Coordinator produced a series of general and project specific marketing materials to support the branding and profile of the project:

- EURONPUD BANNERS PROVIDING A BACKDROP TO LOCAL AND MEDIA EVENTS
- T-SHIRTS FOR PEER AND PROFESSIONAL PARTICIPANTS IN THE AREA ADVOCACY PLANNING MEETINGS WITH THE EURONPUD LOGO AND AN IOAD LOGO AND STRAPLINE FROM THE IOAD WEBSITE,
- WEB-PAGE TO DESCRIBE THE NALOXONE ACCESS AND ADVOCACY PROJECT AND TO LODGE THE VARIOUS OPEN-SOURCE RESOURCES DEVELOPED IN SUPPORT OF THIS PROJECT.

In addition, the Project Manager developed a photocopied flyer to support the peer recruitment for the FGD. A designer was commissioned to produce e-adverts for the Area Advocacy Planning Meetings that were circulated by email and on social media. These materials will inform the development of the NAAP Toolkit.

4. FINDINGS

These findings draw on results from mapping, focus group discussions, mystery shopper and advocacy meeting activities.

FOCUS GROUP DISCUSSIONS SUMMARY

A total of 34 participants (people who are active heroin or opioid injectors; people on OST; people with a history of drug use; and 5 family members of a heroin or opioid user) were involved in the 3 area focus group discussions. 20% of the focus group discussion participants were women.

Participants reported that different services have different policies on naloxone varying from ready access through to attending a pre-booked half-day training first. All participants have lost friends and/or family due to opioid overdose. The majority of peers, and all of the people with a history of injecting, had experience of overdosing themselves. Very few of their experiences involved other peers able to produce naloxone in time.

Two thirds of the participants have been trained in naloxone administration (with a much smaller proportion in Liverpool). Those who had not yet been trained were interested in working to contribute to preventing overdose deaths and are willing to undertake training if conducted in congenial conditions.

> **"EVERY COUPLE OF WEEKS, ANOTHER DEATH"**
> FGD participant, Liverpool

Participants reported varied reactions and responses to an overdose emergency. In the past (when police attended overdose scenes with the ambulance) it was not uncommon for people to feel unsafe and flee the scene or to dump casualties away from drug using or supply venues given the fear of exposure. Participants described stories from their past of wrapping dead bodies in carpets to remove them from a location associated with drug use. Further, they described bodies being dumped in the large communal rubbish bins found in multi-story flats. This was such a barrier to the ambulance service that they informally asked drug users to write H on a casualty's head before leaving their body in a public space and calling an ambulance. Nowadays, without the immediate threat of police scrutiny, peers tend to try to help and are more inclined to call for an ambulance.

One of the participants had, some years ago when aged 14, managed to provide effective rescue breathing for a peer until the ambulance arrived. Opioid overdose impacts more on injectors rather than smokers as borne out from the discussion groups where all participants who smoke opiates had no history of overdose while all the injectors had overdosed.

From their own lived experience and that of their peers, the following risk factors were identified:

REDUCED TOLERANCE due to a period of abstinence (on release from custody, post-rehab discharge or other). Many of the overdose experiences involved this scenario, including for example, five participants who themselves had overdosed shortly after release from prison.

> **"...BECAUSE MY TOLERANCE LEVELS HAD DROPPED RIGHT DOWN."**
> FGD participant, Liverpool

TOLERANCE OVER-ESTIMATED - In other cases, tolerance was simply over-estimated. This was particularly evident among men, some of whom agreed that, in retrospect, there has been a 'macho' element of feeling a need to prove that they could push the limits further than others.

GENDER, PARENTING STATUS AND ENGAGEMENT WITH SERVICES: Women who inject opioids, particularly those with children, are at added risk of fatal overdose due to disenfranchisement from available (largely male focused or gender blind) services and because of the threat of loss of child custody in the event of being identified as a drug user. These factors mean that women tend to have limited access to naloxone, may inject alone, and that their peers may hesitate to call for an ambulance (being aware of the potential custody and tenancy implications) all of which increase the potential for fatal outcomes.

> **"SOME OF OUR PEERS ARE GREAT PARENTS, SOME NOT – DRUG USE DOES NOT HAVE AN EFFECT ON PARENTING QUALITY"**
> FGD participant, Burnley

"WE NEED TO CREATE A NON-SHAME ENVIRONMENT AROUND OVERDOSE SO PEOPLE HAVE SPACE TO PLAN AND NEGOTIATE THEIR OWN STRATEGIES FOR OVERDOSE PREVENTION AND MANAGEMENT, CARRYING AND USING NALOXONE LIKE A SORT OF LIFE INSURANCE."

Burnley FGD participant

MIXING DRUGS. This was also a common element in accounts of overdose experience. For example, one peer participant had not been aware of half-life of methadone which he had in the morning, followed by heroin in the evening. Other similar cases likewise involved alcohol and/or other depressants.

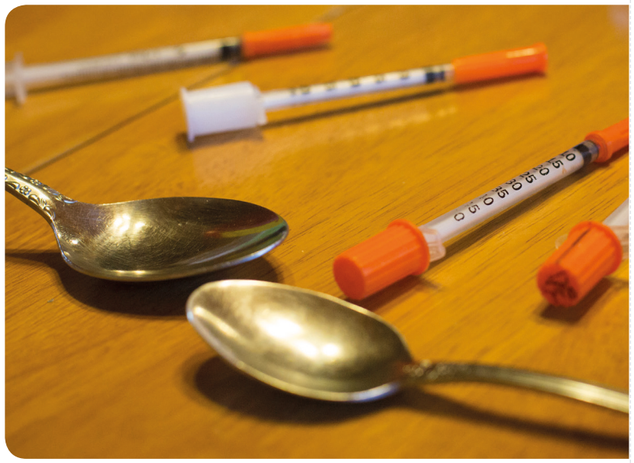
AGING AND MORBIDITY. Some overdose fatalities, particulawrly among older users, have been attributed to COPD (from smoking tobacco and/or crack and/or heroin over many years) as a co-causal factor. Aging itself also influences overdose vulnerability according to participant experiences.

NEW BATCHES of stronger opioids have sometimes been associated with overdose deaths in all sites.

"MANY OF US ARE QUITE NEW TO LEARN ABOUT NALOXONE AND A CHANGE FROM THE OLD DAYS– KNOWLEDGE IS POWER".

FGD participant, Burnley

ISOLATION AND USING OPIOIDS ALONE. The groups identified that injecting alone is a major risk factor. One woman said she had overdosed a few times and had been revived with peers calling an ambulance. She noted that she has difficulty injecting herself and always needs to ask someone else to help her, which (while not ideal in terms of blood born virus transmission risk) has meant that she never uses alone and so could be revived by others each time she overdosed. FGD participants identified that shame and secrecy are part of the risk and that there is need to break through stigma and try to normalise the use of naloxone as well as personal planning for overdose prevention.



"IT IS SCARY WHEN YOU DON'T KNOW WHAT TO DO"

FGD participant, Blackpool

KNOWLEDGE GAPS. A number of participants reflected on years passed when people would often abandon the scene of an overdose not just for fear of police involvement, but because they were lacking response skills and information.

All FGD participants were asked to rank which types of providers they would be comfortable to have help them in an overdose scenario. Confidence in asking for help was highest with known peers and all participants were also welcoming of the notion of receiving support from trained peer volunteers. Participants were reluctant to involve family members due to embarrassment and guilt. All reported that they would not be likely to seek help from a GP. Some expressed particular concerns seeking help from a drug treatment service due to concern of being reported to social services (with attendant consequences of possible loss of tenancy and/or child custody).

Participants across all three sites who had been revived from an overdose in hospital were not debriefed about the experience or offered naloxone.

" ... THEY DON'T TAKE TIME WITH US."

FGD participant, Liverpool

KNOWLEDGE LEVELS OF PEERS ABOUT OVERDOSE AND NALOXONE ADMINISTRATION

Across all three sites the knowledge levels of peer participants were quite strong, particularly around the causes and prevention of overdose. Many of the peer participants were aware of the broad steps involved in appropriate management such as rescue breathing, naloxone administration (if available) and placing the person in recovery position if they are breathing while waiting for the ambulance. This reflected the involvement of many peers in training events linked to the roll out of take-home naloxone. The participants were involved in peer work, recovery support or volunteer work in drug services.

However, many participants continued to have confusions about particular elements of the opioid overdose response. For example, some participants were uncertain or confused about naloxone dosing, administration, shelf life and steps to take in the event of an opioid overdose. For example, 4 respondents to the knowledge questionnaire incorrectly identified "Slap the person around the face firmly with your open hand" as an appropriate response to overdose.

The mystery shopper activity revealed that some of these knowledge gaps can be tracked to misinformation or failure to engage people who use drugs on the subject of overdose. In a knowledge vacuum, people will respond as best they can with limited understanding and sometimes misinformation e.g. 'just walk the person around'. Having said this, many of the peer participants were aware of the broad steps involved in appropriate management such as rescue breathing, naloxone administration (if available) and placing the person in recovery position if they are breathing while waiting for the ambulance.

An opioid overdose is a crisis situation that requires the peer responder to act in a calm and measured manner, working through an assessment process that informs subsequent steps. This ability to such respond in this manner comes from repeated practice and reinforcement and can be backed up with checklists – hard copy or in the form of a smart phone app.

5. BARRIERS TO NALOXONE ACCESS

Stigma was identified as a key barrier to effective overdose prevention and management. The image on the inside cover of this report is a spontaneous memorial created by people who use drugs in acknowledgement of their peers lost to opioid overdose. The spoons were removed from the wall when the bridge was repainted. One peer remarked "It's like those people, those lives, were erased from the public memory". Often families and communities hush up overdose deaths, experience shame and guilt and do not fully acknowledge overdose. The same stigma drives people to inject in secret and alone, dramatically increasing their risk of fatal overdose.

Bound together with stigma, criminalisation of drug use brings both increased risk of overdose (making people more likely to use secretly and alone, creating black market of supplies with unknown purity and dose) as well as a barrier to naloxone access. EuroNPUD advocate for humane drug policy and non-punitive alternates to the failed policy of drug prohibition.

Information sought on area level naloxone access policy and procedures revealed some significant shortcomings and unnecessary obstacles.[12] For example, included in the brief intervention checklist for service providers in one area is advice regarding contra-indications in pregnancy, as follows: "It should be acknowledged that naloxone may affect the foetus in pregnant women but NOT giving naloxone may result in the death of both the mother and foetus." This would not appear to be appropriate advice for lay persons receiving a brief training and would likely serve only to delay or prevent the resuscitation of pregnant women. The brief training checklist includes a segment on recognising overdose – listing 'pinpoint pupils' among the more traditional and easily observed symptoms. Using vital time to open eyelids and try to determine pupil size wastes valuable response time and is unnecessary to the protocol. Lastly, there appears to be an unhealthy preoccupation with the assumption that naloxone recipients will somehow 'misuse' naloxone.

People who use drugs are sensitive to all types of stigma against us, including the assumption that we will invariably misuse any substance. This assumption of course has no evidence base. In at least one agency, before the provider can supply naloxone, the recipient must sign a four-point agreement as follows:

1. I have been given training in the dangers of opiate overdose, what to do in an emergency and the appropriate administration of naloxone.

2. I understand that naloxone is a treatment specific drug that reverses the effect of overdose and needs to be used ***solely for the purpose*** of saving lives.

3. I am aware that the needle supplied is ***strictly for naloxone use only.***

4. I agree to be contacted at a later date to assess my knowledge and/or use of overdose training and naloxone.

EuroNPUD note that the same, stigmatising assumption is unnecessarily reflected in two of a four point agreement. Finally, point 4 of this agreement can function as a barrier as, in the current environment of prohibition and criminalisation of drug use, many peers would understandably not be comfortable with the prospect of being contacted by the service provider at an unspecified future date.

FINDINGS FROM THE MYSTERY SHOPPER ACTIVITY

Mystery shopper findings are presented in a generic format to avoid singling out particular areas. The three areas were chosen because they were viewed as largely typical of the development of an opioid overdose response in the UK. The barriers to access identified on the ground and resulting learning has application across the UK. As such, the feedback provides insights for providers across the UK which could help them look for ways to strengthen access to naloxone including the option of introducing peer-to-peer distribution.

Mystery shoppers (5 - 6 people in each site) made visits to a selected range of agencies: drug treatment services/OST clinics; fixed-site needle & syringe programmes (NSP) / harm reduction centre; pharmacist, GP; and homeless hostel / drop in centre. Each mystery shop was scripted to a scenario such as " … my friend overdosed last week so I want to have naloxone to be ready next time", in order to convey urgency and validity to the request for naloxone.

In summary, each area has at least one access point to naloxone in specialist drug services and mystery shoppers were able to access naloxone from specialist services in all areas. Non-specialist services referred drug users to specialist drug services but the quality of the referral was varied. Specialist services have struggled to sustain the intensity of the opioid overdose response beyond the initial launch phase given their multiple responsibilities and the recovery focus of services.

Drug workers did not work through the approved check list that comes with the Prenoxad unit (primary version of naloxone distributed by services in the UK) to guide their brief intervention. This meant the training was not systematic and comprehensive. In places, drug workers made assumptions about the knowledge of peer volunteers, which a systematic model would help guard against. Drug services no longer had the demonstration unit of Prenoxad that was provided with the roll out of naloxone. The demonstration unit is intended to support the training of peers so they have seen and were familiar with the opened Prenoxad unit before an emergency situation. The checklist and the demonstration kits should be on hand to guide a consistent and structured training intervention.

Family members are most likely to access the healthcare system for advice via GPs and pharmacies. It is evident in all three sites that receptionists or counter staff in busy GP surgeries and pharmacies are a major barrier. Pharmacy counter staff and GP reception staff are poorly informed about naloxone. However, they stood strongly by their misunderstandings and did not seek professional advice. Some mystery shoppers felt judged and unwelcome in these settings.

THE COUNTER STAFF "LOOKED SHOCKED AS IF NEVER ASKED BEFORE"
Feedback from Mystery Shopper Burnley

Mystery shoppers seeking information on naloxone use and access were variously almost turned away or given incorrect information by GP reception or pharmacy counter staff.

This included a confusion of the regulations surrounding naloxone and epi-pens for allergic reactions. This led counter and reception staff to say that naloxone could not be prescribed without a direct prescription from a doctor and that naloxone could not be prescribed to one person for use with another. One service was confused about the difference between naloxone (short acting opioid reversal drug) and naltrexone (long acting opioid blocker for people working to aid abstinent from opioids).

Two had no knowledge and provided no access or referral. One GP receptionist didn't know anything about naloxone but asked the doctor, returning to say "no we don't do that here" before shutting the door in the shopper's face. One site told the shopper to google for information about naloxone.

ADVOCACY PLANNING

The participants in the Area Advocacy Planning Events worked together in mixed teams of peers and professionals to consider how to promote progress in one of four areas:

ENSURING ACCESS TO NALOXONE PRISON LEAVERS

- Work with prison liaison forums to ensure that overdose management is included in the pre-release training programmes for prisoners
- Promote message that carrying naloxone is about being a responsible community member as most naloxone used on second party. This can help overcome the reserve of those who are abstinent and don't want to consider that they might relapse.
- Ensure that naloxone kits are dispensed on discharged or stapled to prisoners possession bags so the prisoner leaves with naloxone on the day of release.
- Target family members of prisoners coming up for release through community drug services or family support groups.
- Train prison officers in opioid overdose management and promote prison officers to carry nasal naloxone so it becomes routine and normal.

SUPPORTING GP AND PHARMACY RECEPTION STAFF TO BE NALOXONE CHAMPIONS

- Provide training to frontline GP reception and pharmacy counter staff in opioid overdose management.
- Target community pharmacies that dispense OST (methadone, buprenorphine etc) or take part in community pharmacy-based needle and syringe programmes. Train counter staff to deliver 5 – 10 minute brief intervention before distributing naloxone, particularly if they have a side room for PWUD.
- Ensure that all people who inject drugs are offered naloxone when picking up a needle and syringe pack from the community pharmacy. Check that the person still has their naloxone if it has been provided before.
- Have a referral path from the community pharmacy brief training back to an extended training on overdose management in drug services.
- Have clear pathways for PWUD or their family members to re-stock their naloxone and to share feedback on any reversals or deaths.
- Share stories of reversals back to GP and pharmacy reception staff with photos of the person or other images that help make a connection (their dogs, garden, begging pitch etc). This helps keep attention on the issue and humanizes the intervention.
- Use peer trainers to educate GP and pharmacy reception staff to address stigma and discrimination indirectly by making a human connection with the people whose lives are at risk.

MAINTAINING PEER KNOWLEDGE LEVELS AND REINFORCING POSITIVE COMMUNITY NORMS

- Make available leaflets or apps that support PWUD.
- Make video available online that allow peers to follow up on the brief training so they can develop and update their knowledge.
- Encourage peers receiving naloxone to think about the training of the friends and family who might be around if they overdose and agree with the family where to store the naloxone.
- Run a community YouTube project encouraging peers to share their tips for remembering the recovery position or other components of overdose management. Offer a prize for the video that receives the most likes and shares on social media.
- Use people with lived experience to visit community centres, drop in centres, recovery cafes, self-help groups and informal community setting to raise general knowledge of opioid overdose management.
- Use peer educators to engage active drug scenes through drug using and buying venues and the homes of peers and to run informal teach in sessions in support of peer-to-peer distribution of naloxone.

MAKING NALOXONE DISTRIBUTION ROUTINE FOR PEOPLE IN DRUG SERVICES

- Include a naloxone knowledge review in 3 monthly drug treatment review. Ask participants to complete survey so they check and reinforce their knowledge allowing GP and/or support staff to focus on gaps in knowledge.
- Ensure that naloxone is given out at first appointment for an OST assessment so the person has naloxone while they are being assessed and receive their first prescription.
- Remember the important role that OST has in preventing opioid overdose so ensure fast access and work to retain people in treatment.
- Have videos reinforcing overdose prevention and management strategies running in waiting rooms and Drop in Centres in clinics with subtitles so they can be played silently in the background.
- Ensure that drug services staff have naloxone training check list and demonstration kits available in the needle and syringe programme or other practice areas so staff are supported to provide quick and effective training to those receiving naloxone.
- Don't cap access to naloxone supply. People may want to keep a unit at home in the family first aid kit and carry another in their bag. Support this type of risk management planning.
- Include naloxone in drug related death reviews to understand whether the deceased or their friends and family had access to naloxone and/or had received training on opioid overdose management.

NEXT STEPS IN BURNLEY AND BLACKPOOL

EuroNPUD will support LUF by providing a small grant of £1000 to each area that can be spent improving local access to naloxone. The Area Coordinators from LUF will support teams of local peers to develop a peer-to-peer naloxone distribution scheme. The peer teams will be integrated into the local service model ensuring professional support and sustainability. These teams of peers will also continue to engage professional partners in order to ensure progress on the different peer education, practice development and system strengthening strategies identified during the Area Advocacy Event. The EuroNPUD Project Manager will providing virtual coaching via Slack and Zoom. EuroNPUD will advise on the selection or development / tailoring of existing resources to be used as part of the peer training.

RETURN TO LIVERPOOL

The Area Coordinator in Liverpool struggled to recruit the target number of peers and only one professional attended the Area Advocacy Planning Event. The barriers to progress included the Area Coordinator coming from a neighbouring area and lacking established connections in Liverpool, the recent recommissioning of community drug services, and the move of the frontline drug service to a new location during the set up period. In addition, different generations of drug user activists were exposed to different types of capacity building. Active drug user organising was pioneered as part of the HIV response and was founded on community development principles. This is the background of the EuroNPUD staff. The recovery orientated Area Coordinators in Burnley and Blackpool used language and organising approaches that indicated that they shared this expertise in community development.

The Area Coordinator in Liverpool came from the NTA-led service user approach and this focussed more on individual advocacy in treatment, consumer rights and service user representation, which impacted on the participant range and therefore the quality of the consultation and Area Advocacy Planning Event.

This combination of factors meant that the Area Advocacy Planning Event in Liverpool did not engage the sufficient peers to form a drug user group or peer-to-peer naloxone distribution team. Also, it did not engage the range of professionals required to inform and influence the policy and practice environment. As such, the Project Manager re-orientated the working groups to focus on considering the future development of community mobilisation in Liverpool and partnership working with local drug services. The EuroNPUD Project Manager will return to Liverpool to work with the local peers and building on the goodwill and commitment of AddAction.

6. RECOMMENDATIONS

EuroNPUD underscore the centrality of the involvement of people who use drugs; *drug users must be regarded as the primary target group for naloxone distribution and administration.* EuroNPUD believe that unless we prioritise peer access to naloxone, the roll-out of naloxone will remain sub-optimal and preventable loss of life will continue at this artificially high rate.

- **Peer-to-peer distribution and administration of naloxone should be featured in all plans for naloxone distribution.**
- **Audit local level brief training, checklists and naloxone provision protocol to ensure safety and appropriateness for community take-home context, with a view in particular to removing unnecessary barriers to access for people who use drugs.**

- Take-home naloxone needs to be integrated into induction assessment and medical review checks in OST clinics to ensure that people on OST are equipped with and remain up-to-date in the overdose management skills.
- A UK drug user health and rights group should be formed to begin a UK network of stakeholders to coordinate and accelerate actions on peer-to-peer naloxone distribution and administration.
- Frontline staff in pharmacies and GP receptions require up skilling on take-home naloxone.
- EuroNPUD proposes a model for one-hour training and brief interventions in its Peer-to-Peer Naloxone Technical Briefing. These should be used as the basis for the P2PN pilots.
- Expanded access to OST. The National Drug Treatment Monitoring System[13] estimate that there are currently 257 000 people who use opioids in England, with up to 166 900 receiving OST. OST is well established as protective against overdose, so an additional focus should be given to expanding low threshold OST options and meaningfully involving clients to develop strategies for expanding access and uptake and to improve client retention.
- According to the project findings, an important opportunity for overdose education and naloxone provision is being missed in emergency departments for people recovering post-overdose. EuroNPUD strongly recommend that effort be made to ensure this important window is not overlooked. Peer support models have been used successfully in the emergency department context in other countries,[14] reducing demand on emergency services, while providing peer support and opportunity to develop strategies to reduce the risk of future overdose.

CONCLUSION

People who use drugs clearly have the instinct to help each other and naloxone is an effective life-saving tool. There is a need to look at the reasons behind the overall reduction in OST treatment numbers in the UK and this should consider any potential link with high number of opioid overdose deaths. Peer-to-peer is the future for naloxone distribution in the UK. We must now work collectively and urgently, with lives literally in the balance, to realise that future.

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3 For more detail see: http://www.legislation.gov.uk/uksi/2015/1503/pdfs/uksiem_20151503_en.pdf and https://www.gov.uk/government/publications/widening-the-availability-of-naloxone/widening-the-availability-of-naloxone

4 See data re coverage rates at: https://www.release.org.uk/blog/take-home-naloxone-england

5 For more information, please visit the EuroNPUD website: https://www.euronpud.net/home2

6 Office for National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/drugmisusedeathsbylocalauthority

7 See data re coverage rates at: https://www.release.org.uk/blog/take-home-naloxone-england

8 See data re coverage rates at: https://www.release.org.uk/blog/take-home-naloxone-england

9 Needle and syringes provided to peers to onward distribute within the peer networks

10 www.who.int/substance_abuse/publications/management_opioid_overdose/en/

11 www.who.int/hiv/pub/guidelines/keypopulations/en/

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facebook.com/groups/euronpud twitter.com/euronpud instagram.com/euronpud

To access the Naloxone Advocacy and Awareness Project's range of downloadable and free resources, visit EuroNPUD's website:

www.euronpud.net/naloxone

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