Scoping project: A peer-based needle exchange service in London

LONDON JOINT WORKING GROUP ON SUBSTANCE USE + HEPATITIS C

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1. Executive summary

This report explores the feasibility, acceptability, and practical considerations of developing a peer-based needle exchange service, with additional hepatitis C awareness and testing capacity, in Hackney.

With 43% of people who inject drugs reporting sharing needles or works in the four weeks prior to being surveyed, the overall level of hepatitis C transmission changing little in recent years and serious bacterial infections amongst people who inject drugs increasing since 2013 , there is clearly a need for renewed investment, innovation and prioritisation of harm reduction services.[1]

This scoping report is based on three focus groups, six interviews and an overview of available evidence on peer-based, peer-led and peer-delivered needle exchange services.

It finds that there is strong support among people who inject drugs, peers who work with people who inject drugs, commissioners and health specialists for an innovative peer-based needle exchange service in London. A clear vision emerged from each focus group of a welcoming a service where people could access all the equipment they need (both in type and amounts), be signposted to other support where appropriate, and be treated with dignity and respect by peers who understand their circumstances.

The stigma often faced by people who inject drugs when they access high-street pharmacy services was a prominent theme in every focus group and raised in most interviews. It was felt that a peer-based service would be non-judgemental, respectful, inclusive and more attractive to people who inject drugs.

This report recommends, based on available international evidence and the discussions in the focus groups and interviews, that peer leadership should be embedded in the development and design of the service alongside other stakeholders in a steering committee. Peers, including both people who currently are injecting drugs and people who have previously injected drugs, should deliver the service in a range of clearly-defined roles, with training and supervision, including both paid and volunteer roles.

Aims

The London Joint Working Group on Substance Use and Hepatitis C (LJWG) has been funded by Hackney Council, as part of the ADDER Accelerator project, to scope the feasibility, acceptability, and practical considerations of developing an innovative peer-led and peer-delivered needle exchange service, with additional hepatitis C awareness and testing capacity.[2]

The aim of such a service would be to improve harm reduction services, engage more people from the criminal justice system, and to prevent transmission or reinfection of hepatitis C and other blood-borne viruses (BBVs) in people attending the service.

This scoping project is in line with ‘Opportunity Area 2: working with under-served communities’ of the London Routemap to Hepatitis C Elimination, a collaboration between the Mayor of London and the GLA, the LJWG, NHS England, the Office for Health Improvement and Disparities, and other key partners in London.

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1 Public Health England (2021) Unlinked Anonymous Monitoring (UAM) Survey of HIV and viral hepatitis among PWID: 2021 report - Preliminary data, Health Protection Report, Volume 15 Number 13. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1006242/hpr1321_uam-pwid.pdf

2 Information of Project ADDER: https://www.gov.uk/government/publications/project-adder/about-project-adder

Definitions

What is peer support?

"Peer support involves people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance or practical help to each other, often in a way that is mutually beneficial. Peer support is different from other types of support because the source of support is a similar person with relevant experience" – definition by National Voices

National Voices summarised evidence on peer support from more than 1,000 sources and found that, "there is evidence that peer support can help people feel more knowledgeable, confident and happy and less isolated and alone".[3]

What is a 'peer' in the context of needle and syringe provision?

Peers in this context are people who have lived experience of injecting drug use, either currently or in the past, and who use their shared experiences to deliver education, advice, information or services on safer injecting practices.

What is a 'peer-led' service?

A 'peer-led' service is one that has been developed and designed by peers and is led by peers.

What is a 'peer-delivered' service?

A 'peer-delivered' service will have peers delivering front-line services, but not necessarily involved in the leadership, development and direction of the service.

What is a 'peer-based' service?

A 'peer-based' service embeds peer leadership and peer delivery throughout the service, although the service may not be exclusively led and delivered by peers.

3 National Voices & Nesta (2015) Peer Support: What Is It and Does It Work? Available at: https://www.nationalvoices.org.uk/sites/default/files/public/publications/peer_support_-_what_is_it_and_does_it_work.pdf

2. Methodology

This scoping project (phase 1) includes:

- An overview of international evidence on peer-delivered, peer-led and/or peer-based needle exchange services.

- Two focus groups with people who inject drugs to explore needle exchange accessibility, opinions on current provision, and what people who use needle exchange services would like to see in a new service:

    - 12 participants in a focus group in West London (2 women, 10 men)
    - 10 participants in a focus group in Hackney (3 women, 7 men)

  Both focus groups were facilitated by a peer educator from The Hepatitis C Trust in the summer of 2021 and participants were given a £25 voucher in recognition of their time. Focus groups were not recorded, but notes were taken throughout the discussions and participants worked in groups to answer various questions on large pieces of paper, which were recorded.

- One focus group with 12 peers from The Hepatitis C Trust (2 women, 10 men) to explore their views on the need for a peer-based needle exchange service, opinions on current provision, and what they would like to see in a new service.

- Semi-structured interviews with six specialists:
    - ADDER Accelerator project lead, Hackney Council
    - Support Worker, Turning Point
    - Pharmacist, Pimlico
    - Head of Programme – HCV Elimination, NHS England
    - Head of Alcohol, Drugs and Tobacco, UK Health Security Agency (UKHSA), London
    - Training and Volunteer Manager, The Hepatitis C Trust

Phase 2: Phase 2 would be the implementation of the service, based on this scoping exercise. Costs and funding stream requirements will be developed through the service scoping in Phase 1, though outside of this report.

3. Background

3.1 Reducing harms and eliminating hepatitis C in London

People who inject drugs need new equipment for every injecting episode to avoid harms such wound infections or blood borne viral transmission from sharing equipment. However, 2021 Public Health England data, collected in the Unlinked Anonymous Monitoring of HIV and Viral Hepatitis amongst people who inject drugs (PWID), shows sharing of needles, syringes and other injecting paraphernalia such as filters and spoons (direct and indirect sharing) was reported by 43% of people who had injected in the last month, a proportion which has increased since 2011.[4]

Sharing and reusing equipment leads to wound infections and risk of transmission of hepatitis C, hepatitis B and HIV, amongst other health harms. People who inject drugs experience stark health inequalities, with increased morbidity and early mortality. Deaths from drug misuse have risen steadily over the last decade, with the Office for National Statistics recording a record high number of deaths of almost 3,000 people in 2020.[5]

Harm reduction interventions and services are therefore critical to ensure that people who inject drugs have clean equipment for every injection episode, information about safer injecting, and access to healthcare for related needs. The Tayside NHS Board recently reported that they were “the first region in the world to effectively eliminate” hepatitis C - Professor John Dillon states that elimination “started with a single project in a Dundee needle exchange”, highlighting how central these services can be.[6]

Needle and exchange services are commissioned by local authorities and are usually delivered by pharmacies and drug and alcohol treatment centres. There is limited information on the provision, access and quality of needle exchange services in London, indicating a need for a thorough audit of need and services.

Impact of COVID-19 on needle exchange provision

The COVID-19 pandemic and lockdown restrictions affected the way people accessed health services, including needle exchanges, although there is a lack of research in this area. Whitfield *et al* collected data through an established comprehensive regional monitoring system from five four-week periods, centred on the implementation of restrictions in the UK in mid-March 2020. Their findings show that the restrictions resulted in the number of needle and syringe programme (NSP) clients decreasing by 36%, visits by 36%, and needles distributed by 29%. NSP coverage for those injecting psychoactive drugs halved, declining from 14 needles per week during the 4 weeks to March 15th 2020 to only 7 needles per week by mid-April, and coverage has remained at this level since then.[7]

However, some areas innovated to ensure that people maintained access to equipment they needed. For example, Bristol Drugs Project (BDP) worked with partners to deliver sterile injecting equipment to those who needed it and people found “it was discreet, convenient and overcame difficulties with accessing equipment through community pharmacies, many of which had shorter opening hours and long queues due to social distancing”.[8]

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4 Public Health England (2021) Unlinked Anonymous Monitoring (UAM) Survey of HIV and viral hepatitis among PWID: 2021 report - Preliminary data, Health Protection Report, Volume 15 Number 13. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1006242/hpr1321_uam-pwid.pdf

5 Office of National Statistics (2020) Deaths related to drug poisoning in England and Wales: 2020 registrations. Release date: 3 August 2021. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsrelatedtodrugpoisoninginenglandandwales/2020

6 University of Dundee (2020) NHS Tayside first region in the world to eliminate hepatitis C. Available at: https://www.dundee.ac.uk/stories/nhs-tayside-first-region-world-eliminate-hepatitis-c#:~:text=Lorna%20Birse%2DStewart%2C%20Chair%20of,to%20effectively%20eliminate%20the%20virus

7 Whitfield M, Reed H, Webster J, Hope V. (2020) The impact of COVID-19 restrictions on needle and syringe programme provision and coverage in England. International Journal of Drug Policy. 2020;83:102851. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7362866/

8 Kesten, J.M. et al (2021) Living Under Coronavirus and Injecting Drugs in Bristol (LUCID-B): A qualitative study of experiences of COVID-19 among people who

Achieving the goal of eliminating hepatitis C as a public health issue by 2025

The World Health Organisation has set a global goal to eliminate hepatitis C as a public health issue by 2030 and NHS England has set an ambition to achieve this important goal by 2025. This ambition is supported by the Mayor of London, charities and patient advocacy groups across the country. In order to achieve this ambition, people who are at risk of having hepatitis C need to be tested and offered treatment, and transmission amongst people who inject drugs needs to be minimised. However, previous Public Health England surveillance data indicated that there is no evidence of a reduction in new HCV infections amongst people who inject drugs over recent years.[9]

Improved access to harm reduction services for people who inject drugs, in particular needle exchange services, will therefore be critical in reducing new transmissions and achieving the national hepatitis C goal.

About the LJWG and the London HCV Routemap to elimination

The London Joint Working Group on Substance Use and Hepatitis C (LJWG) is a group of expert clinicians, patient advocates and voluntary sector leads, working in collaboration to eliminate hepatitis C in London.

The London HCV Routemap to Elimination sets the direction of travel to bring key stakeholders together and make elimination a reality in London, led by a cross-sector steering group convened by the GLA and other partners.[10]

3.2 International evidence on peer-based services

International evidence provides us with examples of peer-based needle exchange services, as well as other innovative needle exchange services such as vans, remote syringe dispensing machines (SDM) and secondary distribution in the community. These have been well-received by people who inject drugs, but this evidence is fairly limited and these services are still very much the exception not the norm in much of the world.

A 2021 rapid evidence review of peer-based harm reduction interventions for people who inject drugs by Rebecca Wilkinson (Public Health Specialty Registrar, Hampshire Hospitals Foundation Trust) shows a range of positive outcomes from peer-based harm reduction services, with these services appearing to reach the most marginalised people who inject drugs.[12] The review highlights:

- That there can be a variety of roles for peers including harm reduction education, direct harm reduction, support/counselling, research assistance and advisory committee participation.
- Barriers to be addressed when developing peer-based harm reduction services can include stigma, a lack of organisational commitment, legal barriers, and a lack of training or supervision for peer workers.
- That there are arguments for and against having current or former PWID as peer workers - current PWID are in touch with the local drug scene and community and can be seen as role models, but may have personal challenges, while former PWID have been on “both sides of the fence”, but may be further from current experience.

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inject drugs, International Journal of Drug Policy, 2021:98:103391. Available at: https://www.sciencedirect.com/science/article/pii/S0955395921002966
9 Public Health England (2020) Latest PHE hepatitis C virus (HCV) reports and supporting documents, for England and the UK. Available at: https://www.gov.uk/government/publications/hepatitis-c-in-the-uk
10 LJWG (2020) New partnership to eliminate hepatitis C in London kicks off at City Hall. Available at: http://ljwg.org.uk/new-partnership-to-eliminate-hepatitis-c-in-london-kicks-off-at-city-hall/
11 Wilkinson, R (2021) Rapid evidence review of peer-based harm reduction interventions for people who inject drugs, Southampton Data Observatory. Available at: https://data.southampton.gov.uk/images/peer-based-hr-evidence-review-injected-drugs_tcm71-440420.pdf

- That there is a distinction between user-led or service-led but a combination of these is recommended as that gives the formality needed for peer workers to be properly valued and supported.
- A New Zealand study which found the rate of health information exchange was greater for peer-based needle and syringe programmes than non-peer NSP.[12]
- A US peer education intervention with young adults produced a 29% greater reduction across six injection risk behaviours, compared with the control participants.[13]
- An evaluation of a peer-based harm reduction education intervention in Australia suggested the project was successful in disseminating harm reduction information to the targeted community through recruitment, training and support for peer educators.[14]
- A New York-based toolkit which describes four types of peer-delivered NSP – storefront, street-based, social network and delivery.[15]

The review makes recommendations for the various stages of developing a peer-based service including preparation, implementation and on-going considerations. It concludes:

> *"Although high quality evidence of effectiveness and cost-effectiveness is lacking, peer-based harm reduction interventions should be implemented as they appear to have positive outcomes and, importantly, seem able to reach the most marginalised PWID. Thus, peer-based harm reduction could potentially address the risk of widening inequalities from the shift to remote services during the COVID-19 pandemic.*
>
> *"Although potentially controversial, evidence on the practicalities of implementing peer-based harm reduction suggests that current PWID should be recruited as peer workers and that they should be rewarded for their time. There are a multitude of other ethical issues associated with this type of service, but these can be addressed through careful design and implementation; such as facilitating onward career pathways for the peer workers if desired. Additionally, PWID and other key partners should be actively involved in designing the service; this collaborative approach is central to developing the shared vision necessary to manage such a change to service provision."*

Vending machines

Countries including the Netherlands, Germany, Italy, Ukraine and Australia use syringe vending machines in addition to other forms of NSPs. Syringe vending machines can accept coins and tokens (distributed by outreach workers) in return for harm reduction packs, and can also include alcohol swabs, cotton wool, sterile water, spoons or educational materials. These can be mounted outside fixed sites or in places where needles and syringes are hard to access.[16]

An Australian study suggested that some people accessing services who feel stigmatised will choose to access vending machines, expanding access to the marginalised: "I didn't follow it up…I just stopped going there. I can use the machine now". Some participants did not view machines as their most common access point for equipment, but this service type provided a useful out-of-hours back up when preferred sites were unavailable:

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12 Hay, B, Henderson, C, Maltby, J, Canales, JJ (2017) Influence of Peer-Based Needle Exchange Programs on Mental Health Status in People Who Inject Drugs: A Nationwide New Zealand Study, Frontiers in Psychiatry, 7. Available at: https://www.frontiersin.org/article/10.3389/fpsyt.2016.00211

13 Garfein RS, Golub ET, Greenberg AE, et al (2007) A peer-education intervention to reduce injection risk behaviours for HIV and hepatitis C virus infection in young injection drug users. AIDS; 21: 1923–32. Available at: https://pubmed.ncbi.nlm.nih.gov/17721100/

14 Newland J & Treloar C (2013) Peer education for people who inject drugs in New South Wales: Advantages, unanticipated benefits and challenges, Drugs Education Prevention Policy; 20: 304–11. Available at: https://www.tandfonline.com/doi/full/10.3109/09687637.2012.761951?scroll=top&needAccess=true

15 Harm Reduction Coalition (2020) Peer Delivered Syringe Exchange (PDSE) Toolkit. Available at: https://harmreduction.org/issues/syringe-access/pdse-toolkit/

16 Avert (2019) Needle and syringe programmes (NSPs) for HIV prevention, Last updated:10 October 2019. Available at: https://www.avert.org/professionals/hiv-programming/prevention/needle-syringe-programmes

“I prefer the NSP, but I will go to a pharmacy or use the machine if it’s not open”.[17]

Peer distribution of injecting equipment

Some peer models of needle exchange and harm reduction include distribution of sterile injecting equipment to others off-site (termed ‘peer distribution’ or ‘secondary supply’). In Australia research has noted that the law about this practice varies by internal jurisdictions, and fear of the law “may have potential impact on supporting more formalised secondary distribution of equipment to groups of people who may not otherwise access formal NSP outlets”.[18] Extended distribution is widespread and the profiles of those “who do and do not distribute were similar”, but the practice is not always organised.[19]

Peer-based needle exchange services in New Zealand

New Zealand developed the first state-funded nationwide peer-based needle exchange programme, developed in response to HIV/AIDS in the 1980s, which is now replicated in other parts of the world.[20] This system distributes over 3 million needles and syringes a year through a national network of dedicated outlets and a network of pharmacies, including 20 dedicated exchanges, 1 mobile exchange, and 197 pharmacies and alternative outlets. There are five trusts responsible for the operational delivery of services in their respective regions and a national trust that provides leadership and national co-ordination for the programme as a whole. The approach is “peer-led and peer-based, and committed to a health and human rights based service approach for people who use drugs”.[21] The NZNEP has operated under a unique organisational model, with a national network of peer organisations formalised and supported to provide “user pays” needle exchange, and has “retained a significant degree of community control”.[22]

Research in New Zealand has also found that the exclusive or preferential use of peer-based needle exchanges had a positive impact on the mental health of people who inject drugs, predicting significantly lower depression and anxiety scores, greater satisfaction with life, and increased health-related information exchange with the service provider.[23]

Peer-based needle exchange services in Australia

Australia has invested in peer-delivered needle exchanges, resulting in overwhelmingly positive feedback from people accessing the exchanges. Many of those in contact with services have stated that they prefer peer-led services, as they are non-judgemental, friendly and easy to access. Experiences of stigma were identified as playing a role in decisions to use a particular service type or to engage with service staff. Even in the case of remote syringe dispensing machines, this also included ensuring the location is not

17 Carruthers, S (2018) Needle and Syringe Programs in Australia: Peer-led Best Practice - Prepared by Dr Susan Carruthers for the Australian Injecting and Illicit Drug Users League. Available at: https://idpc.net/publications/2018/04/needle-and-syringe-programs-in-australia-peer-led-best-practice http://fileserver.idpc.net/library/AIVL_needle_and_syringe_report_-final%20(1).pdf

18 Carruthers, S (2018) Needle and Syringe Programs in Australia: Peer-led Best Practice - Prepared by Dr Susan Carruthers for the Australian Injecting and Illicit Drug Users League. Available at: https://idpc.net/publications/2018/04/needle-and-syringe-programs-in-australia-peer-led-best-practice http://fileserver.idpc.net/library/AIVL_needle_and_syringe_report_-final%20(1).pdf

19 Brener L, Bryant J, Cama E, Pepolin L, Harrod ME (2018) Patterns of Peer Distribution of Injecting Equipment at an Authorized Distribution Site in Sydney, Australia, Substance Use & Misuse. 6;53(14):2405-2412. Available at: https://pubmed.ncbi.nlm.nih.gov/29889588/

20 Avert (2019) Needle and syringe programmes (NSPs) for HIV prevention, Last updated:10 October 2019. Available at: https://www.avert.org/professionals/hiv-programming/prevention/needle-syringe-programmes

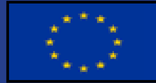
21 About Us (2021) New Zealand Needle Exchange. Available from: https://www.nznep.org.nz/about-us

22 Harris, M (2021) Creativity, care and ‘messy’ drug use: A collective history of the early days of peer-led needle exchange in Dunedin, New Zealand, International Journal of Drug Policy. Available at: https://www.sciencedirect.com/science/article/pii/S0955395921002917

23 Hay, B, Henderson, C, Maltby, J, Canales, JJ (2017) Influence of Peer-Based Needle Exchange Programs on Mental Health Status in People Who Inject Drugs: A Nationwide New Zealand Study, Frontiers in Psychiatry, 7. Available at: https://www.frontiersin.org/article/10.3389/fpsyt.2016.0021

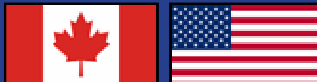
stigmatising (e.g. with unnecessary surveillance). Research also recommended and creating pathways for employment of peers.[24]

Research into the experiences of trust among clients and staff of NSPs in one area of Sydney, Australia underlined the importance of identity, legitimacy and people who use drugs not feeling stigmatised and having high levels of trust in staff, especially when compared with drug treatment services.[25]



Peer-based needle exchange services in continental Europe

In Germany, the "JES Network" have been involved in harm reduction initiatives at various levels, including carrying out needle and syringe exchange and organising seminars on harm education. In Italy, a group of people who currently or formerly used drugs, the Indifference Busters, provide a range of harm education initiatives including mixed training for peers, peer operators and professionals aiming to spread information and knowledge on hepatitis C virus (HCV), in addition to outreach work distributing sterile injecting equipment and a testing service.[26] In the Netherlands peer support methods have been used for harm reduction through education and the provision of risk reduction materials, including aluminium foil.[27]



Peer-based needle exchange services in North America

In the United States, research into peer-based recovery community organizations (RCO), including a hybrid recovery community drop-in centre and syringe exchange programme, suggested that RCOs "are well situated and staffed to also provide harm reduction services, such as syringe exchange programs", and recommended additional education and outreach for homeless, justice-involved, and LGBTQ+ identifying individuals.[28]

In Canada, findings into peer volunteer-led intervention by local needle exchange programmes suggests that peers "were taking on important education and safety roles and were able to alter the behaviour, attitude, and intention of injection drug users" in Vancouver. Further, peers were able to reach individuals who were reluctant to seek medical help, housing, or prevention services, and served as an agent of change to disseminate information and risk-reduction skills to the most marginalized people.[29] An external evaluation of a peer-run outreach-based syringe exchange programme in Vancouver, the Alley Patrol, suggested that access to this service was associated with lower levels of needle reuse among people who inject drugs, and it was suggested that "this form of peer-based [syringe exchange programme] may extend the reach of HIV prevention programmes by contacting [people who inject drugs] traditionally underserved by conventional syringe exchange programmes".[30]

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24 Carruthers, S (2018) Needle and Syringe Programs in Australia: Peer-led Best Practice - Prepared by Dr Susan Carruthers for the Australian Injecting and Illicit Drug Users League. Available at: https://idpc.net/publications/2018/04/needle-and-syringe-programs-in-australia-peer-led-best-practice http://fileserver.idpc.net/library/AIVL_needle_and_syringe_report_-final%20(1).pdf

25 Treloar, C, Rance, J, Yates, K & Mao, L (2015) Trust and people who inject drugs: The perspectives of clients and staff of Needle Syringe Programs, The International Journal on Drug Policy, 27. Available at: https://www.researchgate.net/profile/Paul-Dessauer/post/Seeking_evidence_for_the_effectiveness_of_Peer-based_delivery_of_Needle_and_Syringe_Programs_NSP_or_Needle_and_Syringe_Exchange_Programs_NSEP/attachment/59d6528079197b80779aab45/AS%3A512685710479361%401499245206323/download/Trust+and+people+who+inject+drugs_The+perspectives+of+clients+and+staff+of+NSPs+Treloar+Rance+Mao+Yates+NSP+trust+IJDP+online+2015.pdf

26 Webster, R (2017) User-led interventions: an expanding resource? - a Background paper commissioned by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) for Health and social responses to drug problems: a European guide. Available at: https://www.emcdda.europa.eu/system/files/attachments/6236/EuropeanResponsesGuide2017_BackgroundPaper-User-led-drug-interventions.pdf

27 Kools, JP (2010) From fix to foil: The Dutch experience in promoting transition away from injecting drug use, 1991 – 2010, Exchange Supplies. Available at: https://www.exchangesupplies.org/article_moving_from_fix_to_foil_dutch_experience_by_John-Peter_Kools.php

28 Ashford, R.D., Curtis, B. & Brown, A.M. (2018) Peer-delivered harm reduction and recovery support services: initial evaluation from a hybrid recovery community drop-in center and syringe exchange program. Harm Reduction Journal, 15, 52. Available from: https://doi.org/10.1186/s12954-018-0258-2

3.3 UK peer education

Peer networking was first piloted in the South West of England in 2014/15 in a partnership between the national substance misuse treatment provider Addaction (now We Are With You) and The Hepatitis C Trust. The pilot includes peer education workshops, in which a peer educator with lived experience of hepatitis C delivers workshops based on key messages about HCV prevention, diagnosis, care and treatment to people attending drug services, rehabs, detoxes and day programmes. A subsequent evaluation showed that the programme had both good reach and "that the peer educators have proven to be an effective means through which to communicate a small number of core (but vital) messages about HCV to a high-risk group of clients".[31]

29 Jozaghi, E & Reid, A.A. (2014) A Case Study of the Transformative Effect of Peer Injection Drug Users in the Downtown Eastside of Vancouver, Canada, Canadian Journal of Criminology and Criminal Justice, 56:5, 563-594. Available at: https://www.utpjournals.press/doi/abs/10.3138/CJCCJ.2013.E30

30 Hayashi, K, Wood, E, Wiebe, L, Qi, J & Kerr, T (2010) An external evaluation of a peer-run outreach-based syringe exchange in Vancouver, Canada, The International Journal on Drug Policy, 21(5):418-21. Available at: https://www.researchgate.net/profile/Paul_Dessauer/post/Seeking_evidence_for_the_effectiveness_of_Peer-based_delivery_of_Needle_and_Syringe_Programs_NSP_or_Needle_and_Syringe_Exchange_Programs_NSEP/attachment/59d6527e79197b80779aab23/AS%3A512665283379200%401499240336334/download/An_external_evaluation_of_a_peer-run_outreach-based+NSEP.pdf

31 The Centre for Public Innovation (2017) Evaluation of the South West Hepatitis C Partnership Pilot – Final Evaluation Report. Available at: http://hcvaction.org.uk/sites/default/files/resources/Hepatitis%20C%20Partnership%20Evaluation_1.pdf

4.1 Results

The findings of our two focus groups with people who inject drugs, our focus group with peer educators from The Hepatitis C Trust, and interviews with specialists, are summarised below.[32]

4.1 Experiences and limitations of traditional NSP

Most people at the West London and Hackney focus groups reported using pharmacies to collect clean needles and equipment, with some stating that they use drug service provision as well. The accessibility of pharmacies in every community was highlighted as offering flexible and widespread access to needle and syringe exchange services.

Stigma

Participants in the three focus groups raised stigma and discrimination as a key barrier to accessing supplies, particularly at pharmacies. There was a general consensus in all three focus groups that the attitudes of some workers in some pharmacies can be dismissive or stigmatising and that structures of services could be unresponsive to needs. For example, focus group participants described how they would feel anxiety about getting needles from a pharmacy because they felt they were asking in front of other members of the public (especially if they had to explain what a "blue bag" was to untrained staff), or that they feared they would be questioned by the pharmacist if seeking clean equipment from the same chemist where they get their methadone script.

"Degrading, isn't it?" – focus group participant, West London, on their experience when accessing pharmacies for needle exchange.

"Don't look at anything, don't touch anything" – focus group participant, Hackney, reporting what they had been told while waiting for their methadone prescription.

"Friends can't come in – they have to wait half way up the road" – focus group participant, Hackney.

"In pharmacies sometimes they question you about the amount. The way they talk to you, make you feel nervous to ask If asking for a lot, you feel belittled and done with judgement and disdain. You shouldn't have to explain yourself" – focus group participant, Hackney.

Interviewees also raised stigma and discrimination as a major issue with pharmacy-based provision, with several interviewees reporting those in contact with services often felt judged, discriminated against or worried about confidentiality (*"it's more of a public space so you don't know who you're going to bump into"; "I don't know if I'd want to go into my local pharmacy and ask for needles"*). One suggested the freedom to visit a pharmacy other than their local or regular pharmacy might counteract this issue somewhat, while others suggested pharmacies need to adjust their approaches and train staff to ensure they are respectful and person-centred.

"The challenge we have is making sure those pharmacists are all engaged in delivering things appropriately and making sure they're person-centred in the way that they're thinking" – interviewee, Hackney Council.

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32 Information about The Hepatitis C Trust's community peer work available here: http://hepctrust.org.uk/services/community-peer-programme

One interviewee noted continued stigma in high-street pharmacies or small communities, and gave an example that in Market Street in London, people accessing services had been threatened by stall holders.

The pharmacist interviewed recognised that stigma was an issue in some pharmacies and explained how they ensured equity of service for all at their pharmacy:

> *"If staff at a pharmacy are very busy, they will discourage the needle exchange clients, which shouldn't be so. Here [at my pharmacy] we treat everybody the same… Even in a pandemic, it shouldn't be an issue… In some pharmacies they are told to wait outside, which shouldn't be because then you are discriminating and that is against our practice… It makes them feel uncomfortable, it makes them feel unwanted, shunned by society...which makes them worse"* – interviewee, pharmacy.

Opening times and choice of equipment

Other barriers included pharmacy opening times (with many closing at 5pm), and people being given insufficient amounts of equipment or only standardised packs rather than being able to access the specific equipment (e.g. a certain size of needles) that they need.

> *"A lot of the feedback I get is that equipment is available, but it's not always the equipment that individuals want and it's not always available in the quantities they would want."* – interviewee, NHS England.

Experiences of using needle exchange services at drugs services were mixed. In the peer focus group, peers reported drug services generally did not have good needle exchanges, as workers were reluctant to provide it, and there felt to be an attitude in some services that people coming in will not change, which could be a barrier to access. However, some focus group participants in Hackney and West London said that their local drugs service provided an excellent needle exchange.

> *"I'm absolutely sure that there has been some feeling of lack of access to needle exchange, and my overall driver would always be that you can't have too much"* – interviewee, UKHSA London.

> *"You've got two choices - a pharmacy or a drug service, that's it. And drug services have been, for the most part, withdrawn from that. And so have the pharmacies now, because financially they're getting less per transaction for doing it"* – interviewee, The Hepatitis C Trust.

Some people accessing needle exchange services were unable to seek clean needles if they didn't return used needles or were only allowed two blue bags, though some services gave people as much equipment as they wanted, e.g. one drugs service in Holloway Road "would give as many as you wanted".

> *"It's like a postcode lottery. Some people find it quite easy to get packs, but generally in most it's not the right options, not the right equipment, and it doesn't feel easy for the customer" – interviewee, The Hepatitis C Trust.*

Many focus group participants in West London relied on high-street chemists for provision, though some went to hospitals or drug services. They picked up a wide variety of sizes of needles including 1ml, 2ml, red packs, and orange packs, though some found half-inch needles were "not sharp enough". They found a lack of choice and variety in provision of needles and syringes, with smaller supplies than they would like. One participant said they would rather get their preferred equipment from somewhere else than use equipment they didn't prefer.

"It's a choice they make [to reuse unclean works], but sometimes it's not an informed choice, and that's where we come in" – interviewee, Turning Point.

4.2 Implications of inadequate access

The impact of the barriers to access, such as stigma, opening times and availability of the right equipment, meant that many people in the focus groups reported reusing needles and equipment.

In the Hackney focus group, most participants said that they don't have enough equipment to have a clean needle every time they injected. Some reported washing or reusing needles and filters, and five people in the Hackney group who use drugs reported they will even break into sharps bins due to inadequate supply. One participant explained that they "marked" needles in the bin so they would know which were theirs, "but everyone in the bin has the same markers" another raised.

There was a discussion in the peer focus group about concerns that pharmacy provision was not linked clearly to active harm reduction measures, and the nearest available service could also be some distance.

However, the pharmacist interviewed explained that they see their role as more involved than simply delivering new NSP packs: *"We shouldn't be just providing needles, I think we should be...telling them how they can access healthcare"*. The interviewee highlighted how positive relationships can be built, and how the community pharmacist can be a gateway for other medical interventions and signposting to support.

4.3 Perspectives on a peer-based needle exchange service

Focus group participants were asked to discuss in groups what their ideal needle exchange service would be like.

There were a few key elements highlighted by people in each of the three focus groups, with agreement across each group. These included a service that was free and easy to access, where people would be treated with dignity and respect, and where people could get everything they need as well as connections to other services. There was consistent support across all focus groups for peers to be involved in the development and delivery of services: *"a peer-led service from the ground up"*. There was also strong support for outreach services to be connected to a 'hub' base and different models suggested.

Involvement of peers

Peer educators from The Hepatitis C Trust described how peers could build respectful relationships so that a peer-based needle exchange would be "much more than just giving out works".

"I've got a clear understanding from my own personal experiences of some of the breakdowns in communication that can occur accidentally… a peer has an understanding of the mindset and the struggles that their customer has" – peer educator, The Hepatitis C Trust.

"Of course, 100%" – Hackney focus group participant when asked if they wanted a new and bespoke peer-delivered needle exchange service.

"Somewhere a little bit more independent and peer-led would be really helpful and encourage people who are not necessarily engaged in treatment but [need to] access clean equipment" – interviewee,

Peer service delivery

Focus group and interviewees suggested that peer delivery should include a mix of people who have previously or still do inject, with volunteer and paid positions for peers who are currently injecting as well as former injectors. Training was highlighted as key to ensuring people can give effective harm minimisation advice, including what needles and equipment are best to use for what kinds of drugs and how to use them, and to signpost people to other services.

Peers suggested that people accessing services could also be gradually supported into volunteering or working at services, starting with small responsibilities and with additional responsibilities built up at their own speed. Volunteering could include volunteer forums and opportunities for them to volunteer elsewhere in settings that aren't related to drug use, to broaden their experiences.

Focus group participants in West London felt there was an opportunity to have both those in recovery and people still actively injecting as peers, and that this would extend more people the opportunity to gain work experience and paid employment. One participant said volunteering alone could feel like a "glass ceiling" without progression to paid work.

> *"Ultimately we're in the business of making sure that people who feel marginalised feel less marginalised, so saying to them 'you can't volunteer because you're still using' is a really bad approach"* – interviewee on allowing people who inject drugs to volunteer with needle exchanges.

Peer leadership

Interviewees spoke about the importance of lived experience in the leadership, commissioning, design and delivery of a service:

> *"Integrating individuals with lived experience into every stage and aspect of the delivery of a needle exchange is important...actually integrating them into the strategic and operational planning of how they're delivered is important…not just delivering"* – interviewee, Hackney Council.

As a service would be publicly funded and commissioned, some interviewees recommended some "professional" management aspect to the leadership and delivery of the service, although with a strong element of peer leadership. It was suggested the service should be independent of and separately commissioned from drug services or pharmacies, to avoid negative associations held by some people who access the services and free them from some existing commissioning constraints, while still working in partnership with them and located either nearby or within same building.

One interviewee suggested that a partnership between an independent peer-led exchange and drug services could combine close geographic location with separation, as many people accessing services would find this convenient. However, some people might be turned off by the association with the drug service and this could be a barrier to access for them.

Interviewees raised the need for a balance between choice and informality on the one hand and access to broader support, duties of care and the adequate funding on the other:

> *"As organisations, we have to have a level of duty of care, of statutory protection around people, of*

actually ensuring that we're not just putting plasters on things" - interviewee, UKHSA London.

NSP services required

Peer workers emphasised the need for flexibility and responsiveness to client needs in a service, suggesting there shouldn't be restrictions on the amount of equipment given to any one individual client at any one time; that the service should be accessible on evenings and weekends; and also that centres should encourage distribution. People should be able to "take more for their mates", or even have outreach volunteers distributing as a "satellite service".

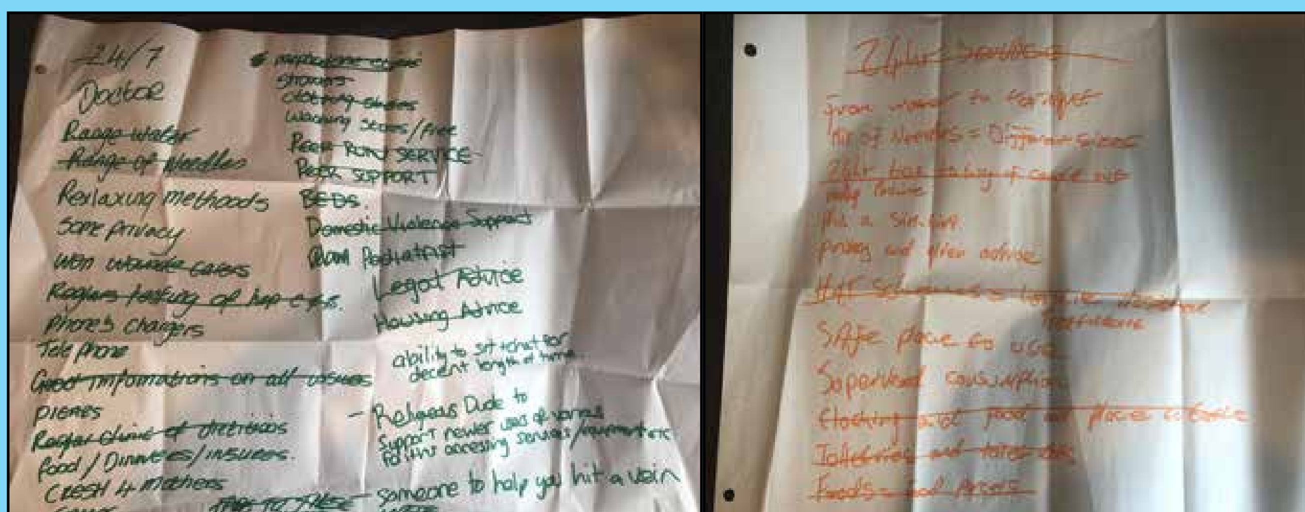
People in the focus groups raised the following equipment that should be readily available, with no quantity caps: full boxes and ranges of needles, barrels and paraphernalia; smooth pins; sterile water; foil; tourniquets; bags of citric acid or vitamin C; condoms and sanitary products.

Location and facilities

Participants in the Hackney focus group expressed concern that a needle exchange site could be the target for stigma, therefore it should be carefully and discretely branded to ensure the confidentiality of clients.

It should also be in a convenient and safe location. While some focus group participants expressed a willingness to travel - e.g. one said "*I'd travel to the end of the world for it*", another commented that *"you shouldn't have to go far to be treated with respect and get good service"*. One focus group participant suggested subsidised bus travel as a solution.

Focus group participants emphasised the importance of a space for comfort, hygiene and recreation, with meals or food parcels, snacks, tea and coffee, toiletries, washing, showers, clothes, beds, games, phone chargers, and simply opportunities to sit and chat. Other suggestions included a center that could also feature a creche for mothers and facilities for pets. A religious duty to support and accommodate people accessing services from all faiths was also mentioned.



Examples of what focus group participants in West London and Hackney said their ideal needle and syringe exchange could feature.

4.4 Suggestions to enhance access and health benefits

People in the focus groups and interviewees suggested many other services and benefits that could be connected to a peer-based NSP site or 'hub', including access to BBV testing and support, access to nursing, mental health and other services.

Harm reduction advice (e.g. *"someone to help you hit a vein right"*), consistent information about hepatitis C (*"I get told different things…told I am antibody positive.. Told I might still have it...keep giving me different information"*) and naloxone training could be specific features of a peer-led exchange.

It was suggested that a health inclusion team could be incorporated to provide wound care, sexual health and support with broader health services, along with testing and routes into treatment for hepatitis C and other BBVs. Dieticians, podiatry and mental health were mentioned as specific medical needs, as well as a methadone clinic for scripts. The exchange could link those visiting the service to other kinds of support (e.g. domestic violence support, legal and housing advice). Information and signposting were suggested, but in an accessible format for a range of literacy levels.

However, it would be important to consider potential conflicts with the peer-led and peer delivered ethos of the service, including whether having NSP and methadone co-located, or whether too many other "statutory" services could act as a barrier to some accessing services.

An NSP hub could provide a convenient location for hepatitis C, hepatitis B and HIV testing (*"If you tell them they have to go here or here, they probably won't go, but if it's there and then, they probably will have it done"*, an interviewee suggested). Peers could be trained in dry blood spot testing (DBST). However, as follow-up polymerase chain reaction (PCR) positives from antibody tests were becoming rarer as more people were treated for hepatitis C, there were questions raised about the efficacy of antibody testing in the first instance.

"It shouldn't be just dishing out the works, I think it should be a whole overall approach - medical, mental, social - which I think the peer would be in a very good position to provide" – Interviewee, pharmacy.

"The whole point is to link people in to get other support. Even if you've been a drug and alcohol user for users, most people have physical, mental [health issues too]…Nobody ever has just one problem" – Interviewee, UKHSA London.

"People should be offered the test when they come to pick up the packs, which is what we did with the hep C pilot...everybody who came in for a pack was told about this testing and 50% were happy to have it done there and then, others said they'd come back and they did come back days later" – Interviewee, pharmacy.

One interviewee favoured a safe consumption room under peer supervision:

"it's win win win. There's safe disposal of used paraphernalia, there's healthcare on hand" – peer educator, The Hepatitis C Trust.

4.5 Outreach or mobile options / vending machines

Peer distribution

There was broad support in focus groups and interviews for peer distribution to be an accepted practice. There were some caveats about safety or whether centre workers would be able to build relationships or link people to other services on-site, but interviewees suggested it was better for those further from provision to access clean needles through another person "than not at all and reusing".

Mobile

Participants in all three focus groups raised the benefits of mobile NSP services, with many suggesting this could be an additional element to the NSP site 'hub'.

A mobile exchange extension with vans or a "taxi" were also suggested, with one worker citing a previous mobile service in Southwark. However, one participant in the peer focus group recalled how a previous mobile service was "so mobile I could never find it". A linked 24-hour help line could also make the service more accessible.

"Something that moved around maybe that could capture people from different areas of the borough, simply because City & Hackney is a very large area, even though there are needle exchanges dotted about" – interviewee, Turning Point.

24/7 vending machine access

Vending machines with a code were also mentioned for all-hours access, or even just for those who would prefer to access clean equipment without direct contact. However, some interviewees cautioned about the loss of opportunities for relationship-building, active harm reduction advice and data collection through direct contact. Others raised concerns about security and safety, particularly if e.g. children in the area were to gain access.

4.6 Commissioning

Interviewees suggested that a peer-based NSP service should ideally be commissioned separately from drug services, so that it would not be tied into the 3-5 year local authority recommissioning cycle. A co-commissioning approach with a pot of money from all relevant departments could break down silos, drawing on existing examples of Glasgow, Aberdeen and Waltham Forest doing the same (Waltham Forest had brought together CCG, DWP and public health money, for example). Mobile outreach services would benefit from stable funding over a number of years to ensure continuity and service focus.

It was suggested that Greater London Authority involvement might help facilitate this co-commissioning, possibly even as part of a pan-London approach. There is a GLA pan-London approach to rough sleeping as a potential model, including existing support for Find and Treat teams. We can also see potential pan-London commissioning models in the City of London's role as commissioner for sexual health and inpatient detoxification, Lambeth's management role in Do It London (part of The London HIV Prevention Programme) and the pan-London smoking cessation programme run by the Association of Directors of Public Health. However, in line with several of these examples, a local authority would likely still need to be the lead commissioner, with Hackney or Tower Hamlets good candidates as the two London boroughs with ADDER Accelerator funding.[33]

4.7 Data collection

As a new and innovative service, data collection and service evaluation will be important to show value to commissioners in London and for other potential future services.

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33 Information on the London Sexual Health Programme: https://www.londoncouncils.gov.uk/our-key-themes/health-and-adult-services/public-health/sexual-health-0/london-sexual-health
Information on the Pan-London programme of substance misuse services for people who sleep rough/risk of return to the street/risk of homelessness: https://www.healthylondon.org/our-work/homeless-health/pan-london-rough-sleeping-and-substance-misuse-programme/
Information on Do It London: https://doitlondon.org/
Information on the London Smoking Cessation Transformation Programme (LSCTP): https://adph.org.uk/networks/london/programme/smoking-cessation/

Peer workers in the peer focus group emphasised data collection being quick, easy and not intrusive in terms of questions about life circumstances, though it was also suggested more detailed questions could perhaps be put to people who were more engaged with the services. One suggested asking people visiting services if they have reused equipment in the past week (anonymously for purposes of recording).

Interviewees highlighted a wide variety of existing data practices in different parts of the system, but also had varied views on what could practically be collected. Collection of demographic data was discussed by several of the interviewees, but there was acknowledgement of the risk of this being invasive. Some suggested that people accessing services might be happy to give their date of birth and initials or be assigned a unique anonymised number, but not provide information on where they live, for example.

Interviewees found more of a consensus around the need for data collection on equipment being distributed to understand demand.[34]

While people accessing services would probably not like to have their individual usage practices recorded, collecting anonymised data on distribution would allow a general sense of what equipment people are using, in order to guide stock-checks and the advice they were given about their preferred equipment. A picture of what is being handed out, returned, and how many individuals it is for would be important to ascertain "if we are getting the level of offer right".

> *"While service users will want it informally, if we're not counting that 20 service users turned up today and needed 20 needles, then there is no way of putting that data together [and] getting a picture of the need across London, getting the money from whoever we need"* – interviewee, PHE London.

Examples of similar or comparable schemes highlighted by focus group participants and interviewees

- One peer highlighted a needle exchange in Southwark run by the substance use charity Blenheim, incorporating a mobile element, partnership with a health inclusion team and access late at night and on weekends. They recounted that this service could reach high volumes of people, "give people what they wanted", pick up people who had dropped out of opioid substitution treatment and also link them to other services, such as housing.

- A decade ago there had been good examples of needle exchange within commissioned services in other parts of England, e.g. Lincolnshire, Derby, Sheffield, Newcastle, Sunderland and Hackney itself, but that these have been closed due to cuts or commissioning changes.

- One interviewee suggested hubs with wraparound services could be modelled on Connections in Trafalgar Square, offering food, referral into Employment Education and Training, drug services and mental health support (it "wouldn't take too much to amalgamate" different service strands with needle exchange, they suggested).[35]

- South London and Maudsley NHS Trust was mentioned as having a good example of street-based exchange, albeit with individual practitioners rather than a van.[36]

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34 It should be noted that NICE guidance suggests that commissioners and providers of NSPs should monitor the number and types of packs or equipment they distribute, the amount and type of equipment distributed, the demographic details of the person who is injecting, along with details of their injecting practices and the drugs they are injecting. NICE (2020) Needle and syringe programmes overview. Available at: https://pathways.nice.org.uk/pathways/needle-and-syringe-programmes/needle-and-syringe-programmes-overview.pdf

35 Information on Connections at Trafalgar Square is available at: https://www.connectionsattrafalgarsquare.com/

5. Discussion and recommendations

The focus group and interview findings clearly demonstrate that a peer-based needle exchange service would be welcomed by people who use needle exchange services and by peers who work with people who currently inject drugs. The key elements raised by focus group participants for the service were that it should be a welcoming place where people could access all the equipment they need (both in type and amounts), be able to access or be signposted to other support where appropriate, and be treated with dignity and respect by peers who understand their circumstances.

The stigma faced by people who inject drugs when they access high-street pharmacy services was a prominent theme in every focus group and raised in all interviews. It was felt that a peer-based service would be non-judgemental, respectful, inclusive and more attractive to people who inject drugs.

Whilst there are complexities with developing a peer-based service, peers from The Hepatitis C Trust described how peer-led services often lead to 'virtuous cycles' – for participants, seeing someone who has 'been there, done that' and now has an important role in a service can inspire them to also become a peer. New peers then benefit from training, education, and work experience. The rapid literature review completed by Wilkinson earlier this year highlights that, while "high quality evidence of effectiveness and cost-effectiveness is lacking, peer-based harm reduction interventions… appear to have positive outcomes and, importantly, seem able to reach the most marginalised PWID".[37]

Some people said they would be willing to travel for a peer-led needle exchange, particularly with the potential additional services and links. However, some people would only travel locally to pick up equipment. This suggests that some people would travel from different boroughs to attend, and the service would not want to turn anyone away. Therefore, a cross-borough co-commissioning model would be ideal, with one council as the lead commissioner.

As this service would be innovative and different to other current NSP models of delivery in London, it will be important to embed thorough evaluation and data collection mechanisms. While data collection on people using the service may need to be light-touch to allow people anonymity and be as inclusive as possible, useful data could be captured on how many people engage with the service (potentially including basic demographic information), amounts of equipment being used and links made to other services for individuals.

In order to ensure the service is inclusive to all people who inject drugs, it should be operationally independent from drugs services, although could be located close by for convenience and service coordination.

Service recommendations:

- **A welcoming place with basic comforts provided.** People in the focus groups had lots of ideas for key services that should be available at the NSP service, primarily access to warm drinks, food, a comfortable space and bathrooms.
- **Full range of NSP equipment available** with people encouraged to take as much as they need and also to take for people they know who might need supplies.
- **Close links to healthcare and other relevant services.** Easy access, either directly or through signposting and support, to other services to support with other needs, such as nurses for wound care and BBV treatment, counsellors and housing advice.
- **The service should be 'peer-based'** with peer leadership embedded in the development and design of the service, alongside other stakeholders, and in the delivery of services.
- **A Leadership Steering Committee that includes peers as well as commissioners, providers, police and other stakeholders** should be set up to design and develop the service (as recommended by Wilkinson).[38]

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36 Information at needle exchange at South London and Maudsley NHS Foundation Trust is available at: https://www.slam.nhs.uk/patients-and-carers/treatment-and-care/addictions/needle-exchange/

37 Wilkinson, R (2021) Rapid evidence review of peer-based harm reduction interventions for people who inject drugs, Southampton Data Observatory. Available at: https://data.southampton.gov.uk/images/peer-based-hr-evidence-review-injected-drugs_tcm71-440420.pdf

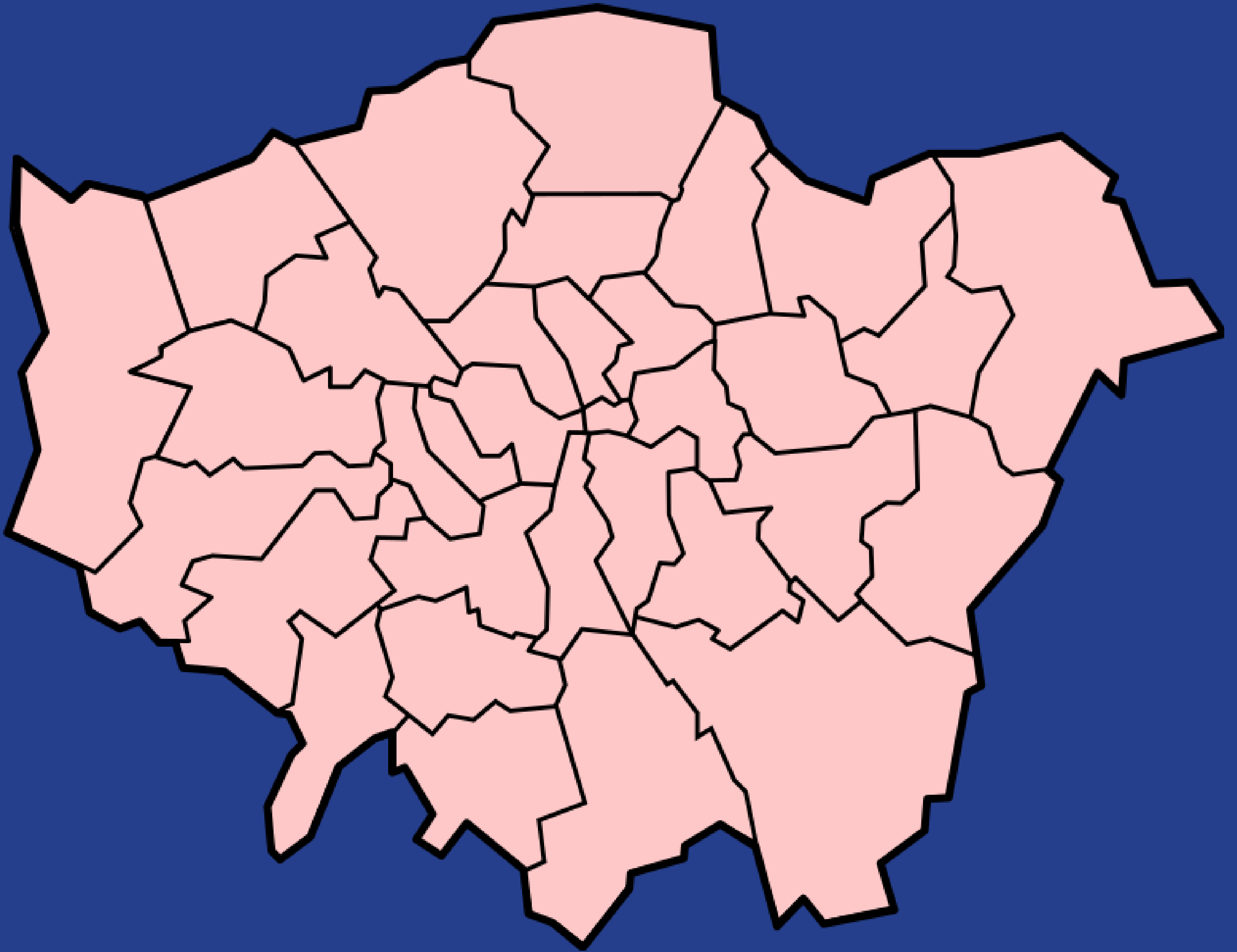
38 Wilkinson, R (2021) Rapid evidence review of peer-based harm reduction interventions for people who inject drugs, Southampton Data Observatory. Available at: https://data.southampton.gov.uk/images/peer-based-hr-evidence-review-injected-drugs_tcm71-440420.pdf

- **Peers should include people who have past experience of injecting drugs and people who are currently injecting drugs.** Roles and responsibilities, including voluntary and paid and at all levels, should be open to all, clearly-defined, well-supported through training and supervision, and appropriate to a persons' level of commitment.
- **Outreach services should be considered by the Steering Committee.** Many people in the focus groups also suggested using the needle exchange service as a 'hub' or 'base', with outreach services connected, with either vans or people going out to communities where people inject drugs, in order to access more people who need clean equipment. The feasibility and desirability of having a 24/7 vending machine should also be considered. These options should be considered by the Steering Group and could be developments once the site is set up.
- **Monitoring and evaluation mechanisms should be clearly embedded in the service** to enable data collection, service improvements and to allow learnings for other future similar peer-based services.
- **A 3-5 year initial funding commitment from public health authorities to provide stability,** so that the service does not have to continually spend time and resources chasing funding.

6. Conclusions

There is clear support from people who inject drugs, people who work with people who inject drugs, commissioners and from public health specialists for an innovative, peer-based needle exchange service in London. This will support important public health goals including reducing health inequalities, reducing harms from drug use, and reducing hepatitis C and other BBV transmissions.

There are complexities in developing and delivering such a service, which would need to be designed and led by a cross-stakeholder Steering Committee which will include peers. Robust evaluation mechanisms should be put in place so this service could become a blueprint for services across the UK and beyond.



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