

*Social contexts of access to treatment
and care for HIV, hepatitis C and
tuberculosis among people who inject
drugs in European cities*

**END OF PROJECT
EXECUTIVE SUMMARY**
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- 2: *Accessibility and quality of HIV treatment services*
- 3: *Integration of TB and HIV treatment services*
- 4: *Accessibility and quality of HCV treatment services*

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1 THIS EXECUTIVE SUMMARY

Here we summarise the key findings and recommendations emanating from a collaborative project between the European Commission Directorate of Health and Consumers and the World Health Organization Regional Office for Europe, involving the Centre for Research on Drugs and Health Behaviour at the London School of Hygiene and Tropical Medicine (LSHTM) as a main partner.

This Executive Summary focuses on the key findings and recommendations of three main domains of activity:

- A qualitative case study exploring the accessibility of HIV treatment for people who inject drugs (PWID)
- A rapid assessment and literature review of the tuberculosis related services needs and accessibility of HIV/TB integrated service provision for PWID
- A qualitative case study and literature review exploring the accessibility of hepatitis C treatment for PWID

2 BACKGROUND TO THE PROJECT

Considerable progress has been made in Europe towards achieving greater coverage of harm reduction services for people who inject drugs (PWID). In keeping with EU Drugs Strategy and Action Plans and the WHO European Action Plan for HIV/AIDS 2012-2015, all EU Member States where injecting drug use is reported offer access to needle and syringe programmes (NSP) and opioid substitution therapy (OST). Yet access to services remains variable. Alongside developing measures of service coverage (see Work Package 1 of this joint action reported elsewhere) there is a need to assess and improve the *accessibility* and *quality* of harm reduction services delivered across Europe. In its evaluation of its Drug Action Plan to 2008, the European Commission acknowledged the need to make continual improvements to enhance service coverage as well as the quality of service delivery. This project focused on this latter need. It achieved this by developing operational research to better understand the barriers and facilitators influencing universal access to harm reduction services among PWID and which may also influence the quality of treatment and care services delivered.

3 PROJECT AIM

The overall aim of this project was to undertake qualitative research to assist in improving the accessibility and quality of harm reduction services for PWID in Europe, especially regarding HIV treatment, integrated HIV-TB services, hepatitis C treatment, and opioid substitution therapy (OST).

4 PROJECT OBJECTIVES

The project comprised seven objectives, each constituting a separate but linked 'work package' of activity. These are listed below. This Executive Summary describes the key findings and recommendations emanating from Work Packages 2, 3 and 4, which were led by the Centre for Research on Drugs and Health Behaviour at LSHTM.

- Work Package 1: A strategy for improving the accessibility and quality of harm reduction services in the EU and WHO European Region developed (Lead partner: WHO Euro)
- Work Package 2: The accessibility and quality of HIV treatment and delivery systems for PWID assessed (Lead partner: LSHTM in collaboration with the Estonian National Institute for Health development)
- Work Package 3: The tuberculosis related services needs and accessibility and quality of HIV/TB integrated service provision people for PWID assessed (Lead partner: LSHTM in collaboration with the University of Porto Institute of Public Health (ISPUP) and Medical School)
- Work Package 4: The accessibility and quality of hepatitis C treatment services and delivery for PWID assessed (Lead partner: LSHTM)
- Work Package 5: Accessible and quality opioid substitution treatment services for PWID promoted (Lead partner: WHO Euro)
- Work Package 6: Training on the delivery of high-quality harm reduction services in the WHO European Region developed and enhanced (Lead partner: WHO Euro)
- Work Package 7: The formation of policies supporting the delivery of high-quality harm reduction services at European and country level promoted (Lead partner: WHO Euro)

5 WORK PACKAGE 2: HIV TREATMENT ACCESS

5.1 Study context and methods

Near universal access to antiretroviral therapy (ART) for those in need of it is a United Nations global pledge. The achievement of universal access to comprehensive HIV prevention treatment care and support to halt and begin to reverse the spread of HIV in Europe by 2015 is a goal for the WHO European Region. While there has been a significant scale-up in ART availability, research suggests that access to ART is still variable. In transitional countries such as those in Eastern Europe and central Asia where people who inject drugs (PWID) make up the largest proportion of HIV cases, the evidence suggests that **PWID are disproportionately less likely to receive ART**. Earlier ART initiation and high levels of adherence have been found to be linked with better clinical outcomes. We undertook a **qualitative study to explore facilitators and barriers to ART engagement among a sample of HIV positive PWID in Estonia**. Engagement with opiate substitution therapy (OST) was also explored.

The qualitative study was undertaken in 2011 and explored the experiences of PWID in two cities in Estonia vis-a-vis their engagement with, or failure to engage with, ART and/or OST. 44 in-depth interviews were

conducted with 45 people living with HIV with experience of injecting drugs either in Tallin or the Kohtla-Järve region in the north-east of the country. Participants were purposively selected to include those with current, previous or no experience of ART treatment for HIV. We undertook a thematic analysis of interview accounts, the findings of which we summarise below.

5.2 Key findings of the qualitative study

Participants' accounts constitute engagement with ART as a product of interaction between multiple individual, social, systemic and structural factors. Some of the sample actively sought HIV testing; for others it had occurred following hospital admission, during an episode of imprisonment, or following engagement with OST programmes. This initial contact with services marked the start of an ongoing, albeit variable, contact with HIV services, and in particular, immune status testing, for many. Overall, we found that despite relatively good availability of HIV treatment services, **a process of delay between HIV diagnosis and seeking help regarding HIV treatment was normative**, and that **many tended to seek help when experiencing significant everyday disruption related to ill health**. This contributes further to treatment delay, where many new HIV cases are already diagnosed at a late stage. Early diagnosis and treatment are significant factors in prolonged survival and delayed AIDS sero-conversion.

ART engagement

While engagement with HIV treatment can be conceptualised as a process or journey, active **engagement with ART was often narrated as a critical moment of decision-making involving a personal 'tipping point'**. Such 'tipping points' included: experiencing acute ill health and hospitalisation; a sense of 'felt illness' associated for some with an inability to perform usual activities or roles; or an event such as a drop in immune status, pregnancy (or the pregnancy of one's partner), or starting or completing methadone treatment. Though there are others, we can distinguish two prime forms of accounting in relation to tipping points towards ART engagement: **felt illness as a disruption to everyday life; and changes in everyday life circumstances bringing about shifts in health perception**. The 'classic' account of the former is exemplified by ART engagement delayed until there is 'no choice' but to seek treatment as a consequence of physical illness. The 'classic' account of the former is exemplified by pregnancy and child caring responsibility bringing about a life change significant enough to disrupt or foster a change in drug use and health behaviour. At the outset, we can see that **ART engagement as well as treatment demand is embedded in everyday social relations and circumstances and not merely biomedical knowledge and/or awareness of clinical indicators regarding treatment need**.

Analyses of accounts also show that **certain social conditions and contextual factors are enabling of ART engagement**. Here, key themes identified across accounts included: **having a future orientation; having reached a time for change; having access to social relationships and support; and having trust in services**. We can hypothesise that these contextual factors enable social conditions which are facilitative of 'tipping' towards ART engagement, including in light of prolonged treatment contemplation or delay. We found, for instance, that accounts of ART engagement also gave mention to access to social supports or resources – through friendship, partnership and an investment in family relations – which either helped create the context for tipping points in decision-making towards treatment or thereafter reinforced ART engagement and retention. While many PWID we interviewed lacked faith or trust in state health services – experiencing negative attitudes, felt stigma, or fearing the power of specialists regarding their ability to sanction disability pensions – trusting relationships with particular health care providers were a feature of ART engagement accounts. Accounts of engagement in ART and other medical services also commonly featured a narrative of future orientation, in which participants expressed hope for, an investment in, the future. Similarly, it was common for ART engagement accounts to invoke time as a factor facilitating tipping points in decision-making, for instance, emphasising 'maturing out' of drug use and the 'time having come' for recovery or

change. Other contextual factors framing ART engagement included: increasing treatment literacy; and eye-witness experience of the benefits to partners or others in one's social network of ART.

Importantly, accounts suggest interplay between the contextual factors which surround ART engagement decisions. We see, for instance, **reciprocal relationships between having a future orientation, having social support, and having reached a time for change**. A classic example concerned pregnancy and responsibility for family which generated an investment towards the future and a realisation that the time for change had arrived, which in turn acted as a resource for social support reinforcing ART engagement decisions.

ART resistance

Those participants (n=15) who had never, or yet, to engage with ART were not a homogenous group. Some were contemplating or actively seeking ART as they were experiencing 'tipping points' like those described above. Others, although potentially open to ART engagement, were not taking it because they did not feel the need, or clinical indicators regarding their immune status did not warrant it. Others still, could be described as actively resisting ART. **Commonly cited reasons in accounts for not engaging in ART included: 'felt wellness'** (the lack of obvious symptoms, an acceptable CD4 count, feeling fit and being able to perform usual activities); **the belief that the body could fight HIV**; and **that strategies other than ART (e.g., rest and good nutrition) could be employed to fight the virus**. Fear of, and concerns about, ART medications themselves, based on eye-witness or lived experience, the anecdotal accounts of others, the perceived level and long-term nature of commitment involved in treatment regimens, and in some cases, poor treatment literacy, were also offered as deterrents to ART engagement. Structural and systemic barriers related to treatment access and perceived scarcity of resources also featured in accounts, especially those of the Kohtla-Jarve participants, including: **long queues; waiting times for test results; few specialists; and difficulties related to treatment in prison**. Some also expressed confidentiality concerns linked to registering at state services.

Awareness of others' having experienced negative side effects of ART appears particularly influential in the accounts of those questioning or resisting ART engagement. **Stories of people faring badly on ART were readily offered**, though even some of those who were actively resistant to start ART, when pressed, were able to recount stories of benefit and health gain amongst acquaintances taking ART.

Levels of HIV and treatment literacy appeared to vary widely. Accounts suggested that information is now more widely available than it was. However, findings suggest that **treatment literacy in relation to ART accumulates as people become more closely engaged with services**, and that **the time of diagnosis is a missed opportunity for increasing ART literacy**. Especially significant, is the need to enable information-giving at the point of diagnosis concerning having children and how to incorporate ART adherence as part of an everyday long-term strategy.

Importantly, **even the accounts of those seemingly actively 'resisting' ART invoked an anticipated time in the future when ART would become an inevitability or likelihood**. The projected tipping points towards ART engagement among those yet to engage in treatment or resisting it mirrored to a large extent the experienced tipping points reported by those currently engaging with ART.

ART adherence

ART adherence proved difficult on a daily basis. Participants reported 'life sometimes getting in the way' of taking medications at the recommended times, and tiredness or forgetfulness leading to non-adherence. Experienced side effects, negative methadone-ART interactions, chaotic drug use, problems in accessing treatment (e.g., when in prison), or simply feeling better were all reported as reasons for stopping or potentially stopping ART. Even for those who were engaging fully with ART, attending clinics to see specialists or undertake immune status testing can be problematic when trying to hold down jobs as well as

keep their HIV and or/ drug using status hidden from employers. Those who reported that they could avail OST and HIV treatment at the same sites could see only **benefits in the co-location and integration of drug and HIV treatment services.**

Opioid substitution therapy

Neither OST and nor ART can be considered in isolation. Registering with an OST programme led some interviewees to being tested for HIV and **the stability brought about by being on methadone served as encouragement to a number to then consider full ART engagement.** However, **stories of the negative drug interactions between ART (stocrin in particular) and methadone** and/or drug use are offered.

Just as perspectives on ART varied considerably, so too did perceptions of OST, and of methadone in particular. Generally, interviewees on OST were either reducing or wanted to reduce their methadone doses, and a number expressed **concern about the apparent longevity of reduction orientated programmes.** In the Tallin sub-sample, in particular, the general perception appeared to be that methadone is widely available and easily accessible; it was also suggested that it is possible to attend the clinic of one's choice. In Kohtla-Jarve the situation appears to be more problematic: fewer services means that, for example, travelling to clinics can be difficult, particularly in winter, and attending the clinic on a daily basis can have a greater impact on the ability to work, and live a 'normal' existence.

Factors motivating interviewees to access OST include 'hitting rock bottom' and being unable to afford drugs (it is widely reported that the cost of drugs has increased and their quality decreased) or cope with the effects of drug withdrawal. As with ART, for some, it is the **encouragement of a friend/acquaintance or the fact that a partner has started taking methadone which serves as a spur to help seeking.** The process of 'maturing' out of drug use, and the desire for a quieter, calmer life, are also invoked.

Perceived barriers or impediments to seeking OST include **hearsay about the negative consequences of taking methadone** (impact on teeth, dependency fostered, difficulty withdrawing, being tied to the clinic etc). Barriers to accessing rehabilitation services include the apparent paucity of such services and the fact that where they are available the cost is seen as prohibitive.

For those who have been, or are currently, on OST, the reported benefits include the **general stability that is said to accompany being on methadone** – there is no need to 'run around trying to score' or engage in illegal activities. The reduced felt impact of drugs makes them seem less tempting (particularly where feeding one's children, for example, is seen as a greater priority). For every benefit accrued, however, there would appear to be a corresponding 'negative'. These include the physical effects on teeth (and the expense involved in dental work) and bones, the addictive nature of methadone, and the difficult withdrawal process involved. Methadone is seen by many as **fostering dependence** (both on the drug itself and the clinic). Other perceived deficiencies in service delivery include the paucity of associated psychological services, opening hours, and issues of anonymity. For a small number of interviewees there appears to be a felt stigma attached to attending the OST clinic. It is suggested that withdrawing from drugs and/or methadone can be easier in prison. While methadone is now available in prison, a couple of interviewees report incidents where they were not able to get methadone while in custody.

5.3 Recommendations

Based on the findings of the qualitative study, we make recommendations in relation to the accessibility of HIV treatment for PWID. We also make some recommendations regarding the delivery of opioid substitution treatments as far as our data enable.

Maximising treatment literacy

Information about HIV appears widely available, but findings highlight possible **missed opportunities for advice-giving**, especially at the point of HIV diagnosis firstly, that ART engagement is a commitment that need not be overwhelmingly disruptive and that it is possible to live a relatively ‘normal life’ and have a future while living with HIV; and secondly, that it is important not to wait until ‘felt’ or acute illness before help-seeking occurs when in crisis. Related to this is the need to raise awareness of the dangers of an over-reliance on CD4 counts as an indicator that treatment is not yet required. Findings also suggest some confusion regarding how to interpret CD4 and immune status indicators, especially in light of international recommendations encouraging earlier treatment engagement. We also found that anecdotal reports of the iatrogenic and side-effects of ART deterred people from engagement as well as reinforced narratives of ART resistance. *We recommend that:*

- There is a need for ART literacy interventions to emphasise early treatment engagement, cautioning against prolonged treatment delay and seeking treatment when in crisis;
- There is a need to provide demonstrated example of the potential health (and preventative) benefits of ART engagement among PWID, possibly through peer interventions;
- ART literacy interventions are delivered through peer-based and social-network approaches, which contain peer mentoring of those contemplating or new to ART (see also below). Social network interventions could be employed to ensure that information reaches those who may not have immune status testing in the recent past or regular contact with services.
- ART/OST and other drug interactions literacy – for clients and service providers

Social interventions

Our findings highlight that decision-making in relation to ART engagement is a process embedded in social relations. This means that how ART and HIV-related health is perceived is shaped as much, if not more, in relation to situated everyday concerns and social relationships than by clinical indicators or awareness of medical need. An important contextual factor framing ‘tipping points’ towards ART engagement was having **access to social supports or resources**, especially through friendship, partnership or family. Often ART engagement was linked to friends or partners contemplating or accessing treatment. Friends and family not only provide a spur to treatment but may also act to reinforce ART engagement once treatment is accessed. We also found that critical changes in social relationships can foster interest in treatment. Pregnancy and having responsibility for children emerged as especially significant in creating a tipping point for ART. *We recommend that:*

- A valuable role for peer interventions, including peer mentoring, both to serve to increase treatment literacy (see above) and to reinforce efforts to access and adhere to ART;
- There is much potential in targeting the family as a unit of change, especially in light of pregnancy and parents with young children, both to encourage as well as sustain ART engagement, including through couples interventions;
- Social and psychological support interventions are a critical feature of HIV treatment and care, including through self-help initiatives which appear weak among PWID;
- There is a general need to appreciate that creating social relationships enabling of ART engagement and adherence may have greater impact than merely seeking to increase people’s awareness of treatment or knowledge of potential health effects;
- There is a need to embed social as well as ART and OST interventions inside broader structural interventions encouraging greater access to housing, welfare support and employment, especially in the Khotla-Jarve region where the weight of structural factors inhibiting health and treatment opportunity was particularly evident.

Systemic interventions

A number of systemic factors were found to undermine ART engagement. These include bureaucratic factors (such as appointments procedures), variable trust relations between potential patients and providers, as well as felt stigma linked to past help-seeking experiences. *We recommend that:*

- There is an ongoing need for provider training so as to maximise awareness of the lifestyles of PWID and communication with them, as well as to reduce the chances of help-seeking being experienced as stigmatising;
- There is a need for clear guidelines in relation to information sharing and the protection of client confidentiality, as this is a concern for some;
- There is a need to make appointment procedures as flexible as possible, including minimising the need for multiple visits before treatment can begin;
- There is a need to incorporate and strengthen social and psychological support interventions within HIV treatment clinic sites;
- There is need to ensure that prisoners or those held in custody, who are accessing ART prior to being imprisoned, have rapid access to appropriate medical care and ART medication in order to facilitate continued adherence.

Integrating HIV and drug treatments

Participants who were receiving ART and OST at the same health service setting could only see the **benefits of integrating HIV and drug services**. OST helped to foster ART engagement in some cases. We also found concern about methadone-ART drug interactions. Perceptions regarding the potential afforded by OST were also variable, especially among those who saw drug treatment as a means of becoming drug free. *We recommend that:*

- ART and OST interventions are integrated as much as possible, including co-located in a shared site as well as by referral links;
- There is a need for clear guidance concerning potential methadone-ART drug interactions, and moderation of methadone doses accordingly;
- There is a need for treatment literacy interventions concerning the role OST as there is evidence of widely differing expectations concerning the role of OST as well as narratives of resistance borne out of concerns that methadone treatment constitutes an additional dependence;
- There is a need to maximise the accessibility of OST, especially in Khotla-Jarve where geographical access is more restricted than in Tallinn;
- There appears a lack of alternative affordable drug treatment intervention available, especially rehabilitation services.

6 WORK PACKAGE 3: TB-HIV TREATMENT INTEGRATION

6.1 Study context and methods

Injecting drug use is associated with high risk of tuberculosis (TB) and reduced retention in treatment. Provision of opioid substitution therapy (OST) improves HIV and TB treatment outcomes among people who inject drugs (PWID) but there is a need to document strategies for the effective delivery of integrated HIV, TB and drug dependency treatment. We therefore **reviewed the literature on TB epidemiology and care among people who inject drugs (PWID)**. We included published studies describing rates of TB mono-/co-infection (with HIV or hepatitis C (HCV)) among PWID, and published and 'grey literature' models of TB or HIV-TB care for this population. The full review is available as a published paper [1].

Conscious of the dearth of descriptive case studies of integrated HIV and TB service provision for PWID in Europe and elsewhere [1], we also undertook a **rapid assessment to describe the accessibility and integration of HIV and TB services and delivery systems for PWID in Porto, Portugal**, with the goal of developing ‘best practice’ guidance in relation to integrated HIV, TB and drug dependency care. We combined the following methods and data sources: a mapping of existing HIV, TB, hepatitis C virus (HCV) and drug dependency treatment services in Porto; a review of existing data on HIV, TB and drug treatment service use and integration; semi-structured interviews with 30 PWID with experience of HIV and/or TB, and with seven providers representing HIV, TB, drug treatment, outreach and prison health services. We analysed quantitative data descriptively and qualitative data thematically, triangulating findings throughout data collection and analysis.

6.2 Key findings from reviewed literature

Latent TB prevalence was high and active disease was consistently more common among HIV-positive PWID. Data on multidrug-resistant (MDR) TB and co-infections (with HIV or HCV) among PWID were scarce.

Models of TB care identified fell into six categories: screening and prevention within HIV risk studies; prevention at TB clinics; screening and prevention within needle-and-syringe-programmes (NSP) & drug dependency treatment programmes; pharmacy-based TB treatment; TB service-led care with harm reduction/drug treatment programmes; and TB treatment within drug treatment programmes. **Co-location with NSP and OST, combined with modest incentives, consistently improved TB screening and prevention uptake.** Similarly, small-scale combined TB treatment and OST programmes achieved good adherence in diverse settings. Where there was a need to attend off-site TB services, for example to screen for active disease, **incentivised and facilitated referral from NSPs and OST centres significantly improved attendance rates. The most common reason for not completing TB prevention or treatment was ceasing OST.** Barriers to uptake of screening included unstable housing, limited contact with harm reduction or health services, stigma attached to attending TB services and difficulty keeping appointments when in employment.

Key components of successful interventions included: collaboration across services; a flexible, client-centred approach to care; and concurrent social care support. No peer-reviewed studies described integrated HIV-TB care for PWID. Grey literature highlighted multiple **key components of integration: co-located services, provision of drug treatment, multidisciplinary staff training; and remaining barriers: staffing inefficiencies, inadequate funding, police interference, and limited OST availability.**

Integration with drug dependency care effectively improves PWID engagement in TB services but there is a need to better document approaches to HIV-TB care, to improve surveillance of TB and co-infections among PWID, and to sustain advocacy for improved OST availability.

6.2 Key findings from the rapid assessment study

Portugal has made concerted efforts to move towards integrated service delivery in relation to the provision of TB, HIV and drug dependency treatments. **The rapid assessment documented two models of integrated HIV, TB and drug dependency care for PWID.**

The first ‘combined’ model provides all services within a designated centre staffed by a co-located team of specialists with shared case management protocols. This approach facilitates multidisciplinary care but is resource-intensive, limited to a specific location and offers reduced scope for community/home-based care.

The second 'collaborative' model is a less formalised, client-centred approach in which multiple and existing health programmes work together to achieve co-located treatment delivery in a location convenient to the patient, with outreach teams often acting as mediators between services. This model allows prompt access and adaptability to clients' circumstances but is highly dependent on the participation of multiple services.

The relative success of integration was shaped by four key factors: the extent of collaborative networks and shared protocols; the central involvement of outreach teams; provision of uninterrupted OST; and flexibility over treatment location. Engagement in services more broadly was shaped by social network and outreach support; recognition of patient autonomy; patient-provider relationships; timing of testing and treatment provision; treatment literacy; and the availability of social care. Few quantitative data were available to assess service integration. Targeted rapid HIV testing in drug treatment centres has achieved high coverage among PWID but equivalent rates of TB and HCV screening were low and incompletely reported. Most TB patients knew their HIV status but no equivalent data were available on TB among patients receiving HIV care.

6.3 Recommendations

Based on the findings of the literature review and rapid assessment study, we make recommendations in relation to the integration of TB and HIV treatments and care for PWID below. These recommendations are oriented to the study context of Portugal but also have broader implication.

Developing guidelines on integration

The 'one-stop shop' approach, in which all services are provided in one dedicated care setting, is often hailed as the ideal model of integrated HIV-TB care. However, **its scale-up requires considerable resource, staff, administrative, infrastructural and political commitment** which may not always be feasible or available [2]. **An alternative approach involves collaboration across multiple, existing health and social care services** [3-5], with facilitated and responsive referral mechanisms and arrangement of co-located treatment across healthcare and community settings [4-7]. The rapid assessment identified two models - broadly reflecting these contrasting approaches - that can serve as a basis for developing guidelines on integration. The first 'combined' model involves provision of HIV, TB and drug dependency treatment within a designated centre. The second 'collaborative' model is a less formalised, client-centred approach involving communication between multiple and existing health programmes, relying on informal referral networks to achieve co-located treatment delivery at a venue convenient to the patient, with outreach teams often acting as mediators between services. *We recommend that:*

- The development, implementation and strengthening of national and regional joint policies, guidelines and standard operating procedures for HIV and TB prevention and management and drug dependency treatment
- The development of local, national and regional 'good practice' guidelines emphasizing the importance of context-specific approaches is needed to improve the consistency and scope of integrated HIV-TB care for PWID in Portugal and elsewhere.
- These guidelines should reflect the importance of: multi-agency collaboration; uninterrupted provision of drug dependency treatment accounting for HIV-TB-OST treatment interactions; a client-centred approach recognising clients' autonomy; involvement of outreach programmes to ensure access for the most marginalised PWID.
- The relative advantages and disadvantages of 'combined' and 'collaborative' models of integration need to be considered and discussed with PWID when establishing the most appropriate integrated service delivery for each individual.

Achieving effective collaboration across health programmes

Collaboration across health programmes was as a key factor shaping integration of HIV and TB care for PWID in Porto, and central to the success of TB interventions identified via the literature review [4, 5, 8]. Studies evaluating attendance of off-site TB services to screen for active disease found that incentivised, facilitated referral from NSPs and OST centres significantly improved referral uptake [6, 7].

In Porto, **collaboration was facilitated by training and case management across specialties, the development of informal professional networks and communication channels to minimize bureaucracy and expedite referrals, and recognition of outreach programmes' capacity to reach the most marginalised PWID.** Effective collaboration in turn enabled (1) an adaptable, responsive approach to treatment delivery and location and (2) uninterrupted provision of OST accounting for interactions with HIV/TB treatment. **However, collaboration remained impeded by bureaucratic formal referral channels and the absence of written guidelines and shared protocols on integrated care.** Similar emphasis was placed on multidisciplinary collaboration in combined care centres in Ukraine and similar challenges to its achievement [9]. *We recommend that:*

- Collaboration across health and social care programmes should be facilitated by: establishing cross-service agreements on staff training, responsibilities and resource allocation; harnessing existing professional networks to develop mechanisms for expedited and integrated access to services; taking a multidisciplinary approach to care; and involving local outreach programmes, particularly in settings where access to harm reduction and governmental health services is poor.
- There is a need to develop and share written protocols across services to achieve and expand consistent and effective collaboration.
- Efforts to reduce bureaucracy and streamline referral mechanisms are required to enable efficient and timely delivery of integrated care to PWID.

Ensuring access to opioid substitution treatment

Co-locating TB screening, prevention and treatment with NSP and OST programmes has consistently achieved good uptake, when coupled with provision of incentives and appropriate social care support [3, 5, 8, 10-17]. **The most common reason for not completing TB prevention or treatment across geographic and care settings was ceasing OST.**

The reviewed literature shows that combined HIV, TB and drug dependency care centres in Ukraine echo the importance of providing drug treatment [9] but identify limited OST availability as a significant challenge to integration in the region [2, 9]. In the Russian Federation, Turkmenistan and Uzbekistan, OST is prohibited [18]. While pilot OST programmes and their scale-up have begun in other parts of the region, availability remains highly restricted by the highly limited number of OST centres, high cost and user fees, long waiting lists, strict eligibility requirements, police harassment, unavailability of take-home doses and interrupted supplies [19]. Access to OST is limited in many EU countries – notably those which more recently joined including Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland and Romania (see Work Package 1 of this joint action reported elsewhere). **In Portugal, the decriminalisation of drug use and widespread availability of OST in healthcare and community settings, and more flexible conditions of its provision, remove important structural constraints to integration.** The absence of accounts of police intervention in this assessment contrasts with experiences of PWID in Ukraine [9] and Russia [20], where harassment and arrest of OST clients posed a major barrier to treatment access and integration. *We recommend that:*

- Uninterrupted drug dependency treatment, accounting for treatment interactions with HIV and TB treatment, is vital to ensure access to and integration of HIV and TB care for PWID. This needs to be

made available to all PWID clients of HIV and TB services, civilian and prison-based, preferably in one location and with flexibility to allow take-home doses if considered clinically appropriate.

- Sustained advocacy for improved availability and scale-up of OST and harm reduction programmes is vital to efforts to improve TB treatment adherence and integration of care for PWID.

Client-centred care and user involvement

A flexible approach to the timing and location of service delivery is key to reducing identified barriers to TB and integrated HIV-TB care access [4, 5, 8]. **Given the link between dropping out of TB preventive therapy and ceasing OST, there is a need to develop tailored adherence strategies for PWID not in drug treatment or in drug dependency treatment without OST**, in conjunction with clients themselves and other health and social care services. Provision of client-centred care and flexibility over treatment location were key factors shaping integration in Porto. The assessment illustrates the feasibility of this approach, by recognizing and adapting to clients' individual needs and circumstances. However, it also identified a lack of client involvement in wider service design and delivery. *We recommend that:*

- A flexible approach to the timing and location of HIV, TB and drug dependency treatment delivery is key to engaging PWID in integrated care, allowing for health-facility, community and home-based care, with flexibility to adapt to individual clients' home and work lives. It is vital that clients are involved in decisions regarding their care, and that their sense of autonomy is recognised and valued.
- Where clinically appropriate, there is a need for flexibility over take-home medication for clients who have the capacity, or social support, to manage their own adherence. This is likely to reinforce trust between client and provider.
- There is a need for wider involvement of clients and PWID representative groups in service design, delivery and evaluation of HIV, TB and drug dependency treatment services. This would help to sustain and enhance the quality and accessibility of care. This approach has proved highly successful in Australia, among other settings [21].

Incorporating care regarding hepatitis C (HCV)

HCV is highly prevalent among PWID and there is a risk of hepatotoxicity associated with TB prevention and treatment [22]. In Porto, HCV treatment was seen as a low priority among PWID, recognised by service providers as a gap in integrated care requiring renewed focus. **Perceived normalcy of HCV, fear of side-effects and mandatory abstinence from substance use were important barriers to treatment uptake**, as documented in other settings [23]. *We recommend that:*

- Poor access to and uptake of HCV treatment among PWID requires urgent attention. Perceptions of inevitability and extreme side-effects need to be addressed through communication between individual providers and clients, as well as through dialogue between services, to establish ways to improve engagement.
- Integration guidelines and multi-service collaboration need to incorporate HCV care.

Harnessing peer and social support

The importance of social outreach interventions in reaching PWID is widely recognised [24, 25]. **Social support was an important trigger for prompting care-seeking in this assessment, suggesting scope for network interventions**. Peer education among PWID has been shown to improve adherence to TB preventive therapy [26], reduce HIV-related risk behaviours [27], increase ART adherence [28] and engage clients in HCV care at a multidisciplinary care centre [29]. *We recommend that:*

- Peer education programmes may be an effective way of improving PWID engagement in TB services. There is a need to increase awareness of TB symptoms and available treatment among PWID,

drawing on narratives of preventive and public health benefits. Development of peer education resources should involve PWID service users and peer educators.

- Peer education programmes are also needed to challenge the perceived inevitability and extreme side-effects of HCV treatment among PWID.

Increasing the involvement of mainstream health services and tackling stigma

Integration and continuity of care for PWID requires good collaboration between specialised and mainstream health services, civilian and prison-based. In Portugal, there is scope for wider involvement of mainstream health services in providing care for PWID. However, **PWID continued to experience stigma in mainstream services compared with a notable and welcome absence of discrimination in specialized treatment centres**. Outreach programmes also noted that their clients were more positively received in health services when referred or accompanied by outreach staff.

In Spain, a small but effective prison-based combined DOTS and OST programme [16] and a pharmacy-based DOTS programme [30] indicate the potential for effective TB interventions targeting PWID in prison and community settings. **Pharmacies play an important role in the delivery of harm reduction services in Portugal and could be more formally engaged in HIV and TB screening as well as delivery of DOTS**, if an agreement can be reached between the relevant organisations. *We recommend that:*

- There is a need for wider involvement of mainstream health services in providing care for PWID in Portugal, in close collaboration with specialised HIV, TB, drug dependency and outreach services.
- The potential for pharmacy-based DOTS to engage PWID in treatment in the community warrants further attention in Portugal and elsewhere.
- There is a need and potential for specialist services to work with mainstream health services to improve understanding of and sensitivity to PWIDs' healthcare needs and to challenge discrimination.

Addressing wider social care needs

The literature review identified a number of social and structural barriers to uptake of TB screening among PWID, including: unstable housing; limited contact with harm reduction or health services; stigma attached to attending TB services; and difficulty keeping appointments when in employment. In Portugal, **provision of support for social care needs was central to ensuring the accessibility and quality of integrated care for PWID**. However, **financial cuts to government benefits and funding for PWID support services have already begun to be felt by clients and service providers**. Integrated care often relies on NGO-funded outreach programmes which may be particularly susceptible to fluctuations in funding. *We recommend that:*

- Collaboration with social services to secure access to housing and financial aid is critical to facilitating PWIDs' engagement in treatment and access to wider care among already-marginalised PWID.

Improving monitoring, evaluation and surveillance

The literature review indicated a scarcity of data on MDR-TB and TB co-infection with HIV and HCV among PWID. Multidrug resistance exceeded 60% among PWID in Georgia [31], for instance, and poses a major threat to TB control across Eastern Europe and Central Asia [32]. In Portugal, PWID form a large minority of PLHIV and a significant proportion of TB patients. Although rates of MDR-TB are low relative to the rest of Europe [33], the proportion of extensive drug resistance (XDR) among these cases, both in PWID and the wider Portugal population [34], are high.

Targeted HIV testing in drug treatment centres and collaborative TB-service-led efforts to increase TB case detection have improved screening coverage among PWID [35], and the vast majority of people who use

drugs with active TB were aware of their HIV status. Interview accounts suggested that TB testing is routine and widely accepted among drug treatment centre clients but service records indicated very low coverage and no data were available on uptake of referral to TB services for testing. While this discrepancy may reflect incomplete data collection, it could also indicate a gap in service integration. Similarly, limited data were available regarding screening and treatment in hospital-based HIV and HCV services, including TB screening coverage among HIV patients. *We recommend that:*

- There is a need for expanded infectious disease surveillance among PWID. The introduction of rapid HIV testing in drug treatment centres across Portugal, complemented by active referral, has resulted in high screening coverage among PWID. The development of similar initiatives, through collaboration between national bodies responsible for drug treatment, TB and HCV care, could help to expand TB and HCV screening in drug treatment services. XDR-TB poses a threat to TB control in Portugal and requires further attention.
- There is a clear need to improve health information systems within and across treatment centres, locally and nationally, to monitor HIV, HCV and TB screening, treatment outcomes and levels of integration between services. Standardisation of data collection and reporting, and improved surveillance of infections among PWID, would facilitate information-sharing across treatment centres and improve capacity to respond to clients' HIV, TB and other health needs.
- There is a need to promote WHO's recent guidelines on determining eligibility for TB preventive therapy in resource-stretched settings, which replace mandatory chest x-rays with a simple four-symptom algorithm to exclude active TB [36]. With appropriate training of staff delivering, or referring PWID for, TB care, these new guidelines are likely to reduce barriers to screening and prevention uptake among PWID.
- All patients infected with HCV are offered HIV testing and counselling.
- Screening and diagnosis for HCV is offered to all people who inject drugs.
- Provide access to ART for all people co infected with HIV and HCV.
- HIV testing and counselling for all those with confirmed or suspected tuberculosis
- Co-trimoxazole preventive therapy for tuberculosis patients living with HIV
- Isoniazid preventive therapy to people living with HIV in whom active tuberculosis has been reliably excluded
- Integrated infection control plans for tuberculosis to minimise transmission in health care and congregate settings, including prisons.

Operational research on models of integrated care

The literature review did not identify any peer-reviewed studies describing integrated HIV-TB care for PWID. Case studies from the grey literature highlight key components of integration via pilot combined care centres but do not report on service uptake or treatment outcomes. The rapid assessment in Portugal documented models of integrated HIV and TB care for PWID within an existing health system, in the context of decriminalisation of drug use and widespread availability of OST, but there remains a lack of documented evidence from other settings and evaluations of models' effectiveness. *We recommend that:*

- There is a clear need to further describe and evaluate models of integrated HIV, TB and drug dependency care, to identify approaches which can be applied and expanded in different health-system contexts. This will help to better inform delivery and integration of services for PWID.

7 WORK PACKAGE 4: HEPATITIS C TREATMENT ACCESS

7.1 Context and methods

Current injectors are not precluded from HCV treatment access in a number of European countries, yet uptake rates are substandard. Accordingly, in 2011, we undertook a **literature review of evidence regarding barriers to hepatitis C treatment access, uptake and completion among PWID**, and a **qualitative case study exploring the barriers and facilitators to HCV treatment access for PWID** in drug and alcohol (D&A) settings.

The literature review focused on social science and medical literature pertaining to HCV treatment for PWID, focusing primarily on barriers to treatment access, uptake and completion. Medline and Scopus databases were searched, supplemented by manual and grey literature searches. Two searches were undertaken, with the second focusing specifically on structural factors. In total, 596 references were screened, with 165 articles and reports selected to inform the review. The full review is available as a published paper (Harris M., Rhodes T. and Martin A. 'Hepatitis C treatment access and uptake for people who inject drugs: A review focusing on social structural barriers', 2012).

The qualitative study aimed to assess the barriers and facilitators to HCV treatment access and completion for PWID in drug and alcohol (D&A) settings in two sites in London, UK. Two London-based service delivery partnerships were selected for the study: Site A (an established community-based partnership offering HCV treatment delivery and support for PWID); and Site B (a nascent partnership about to pilot a HCV outreach programme). In-depth interviews were conducted with service users (n=35) and service providers (n=14) from both sites. Through a thematic analysis of these qualitative interviews we described the experience of HCV treatment access in order to develop recommendations to enhance the accessibility and quality of delivery of HCV treatment.

7.2 Key findings from reviewed literature

HCV treatment provision for PWID is most effective as a combination intervention, encompassing social as well as biomedical dimensions, wherein **the provision of social, welfare and psychological support is critical**. Current operating definitions of 'combination intervention' in harm reduction for PWID, such as those promoted by the World Health Organization tend, however, to be narrowly defined around biomedical and behavioural interventions, giving less emphasis to social support and community action interventions or to wider structural interventions. However, the WHO European Action Plan for HIV/AIDS 2012-2015 devotes particular attention to reducing vulnerability and removing structural barriers to accessing services including addressing laws and regulations related to the HIV response; eliminating stigma, discrimination and other human rights abuses that impede the HIV response; strengthening community systems and ensuring gender and age equity in access to HIV and related health services. Our review clearly identified structural factors – especially **social stigma, housing, criminalisation, health care systems, and gender** – as important dimensions in the conditionality of HCV treatment access, and thus also, as important targets for social and structural change.

As elsewhere, the review highlighted the **pervasiveness of social stigma** in the HCV treatment experience. Felt stigma may shape the HCV treatment experience specifically because it pervades surrounding social relations and the experience of drug injecting more generally, and thus becomes internalised among those most marginalised [37]. Felt and enacted stigma [38] impacts on HCV disclosure decisions [39]. Health status disclosure creates or constrains avenues for support, especially in the context of HCV treatment [40].

Ethnic minorities and **women who inject drugs can face particular challenges accessing treatment**. It is apparent that caring responsibilities [41], lack of engagement with services, due to fear of child removal, for example, [42, 43], incidences of physical, sexual, emotional and structural violence [42-44], and/or the demands of funding a drug habit, including through sex work [42, 43], may impact on HCV treatment access and uptake for female drug users. With women poorly provided for at some drug treatment services [45] co-locating HCV treatment at drug services alone may not increase uptake among women who inject drugs.

Without further research it is impossible to disentangle the relative contribution of social factors such as stigma, gender, experiences of inequitable service provision, distrust toward medical providers, unstable housing, poverty, incarceration, limited geographic access, the prioritisation of acute health concerns, substance use demands, OST access, management of co-morbidities, low HCV literacy, fear of HCV treatment side effects, concerns about uncertain treatment efficacy and provider reticence to treat.

Reviewed evidence suggests that **HCV treatment provision for PWID is effective particularly when delivered in an integrated and multidisciplinary framework** [46-57]. Evidenced and recommended HCV treatment facilitators for PWID include linked targeted interventions to provide 'low threshold' treatment access, social support, adherence support, and treatment literacy support. The review of the literature indicated that evidenced targeted access supports include: HCV treatment provision in OST services [49, 58, 59]; relaxed eligibility requirements [59]; and flexible opening hours and appointment times [46]. Targeted social supports include: peer support groups [50, 51]; peer-workers integrated into HCV treatment provision [52]; improved psychological services [46]; and assistance with practical problems, such as transportation, accommodation and welfare benefit access [51, 53]. Targeted adherence supports include: electronic reminder systems [53]; co-ordination with pharmacies for medication dispensing [46]; directly observed therapy [60]; respectful client-centred continuity of care [53, 61]; nurse provided interferon injections [61]; improved phlebotomy services [46], including provision to use external jugular venepuncture [54]; and flexible OST provision, including access to take home doses [55]. Targeted treatment literacy supports include: education for PWID [62], as well as training and support for drug and alcohol staff [56] and primary care providers [57, 63], including the use of video conferencing [57].

Well evidenced is the important role of **OST provision in enhancing HCV treatment access, tolerability and adherence** [46, 60, 64]. While a majority of the literature reports favourably on HCV treatment provision in Drug and Alcohol settings, a growing body of Australian-based research identifies the dangers inherent of just 'adding on' HCV treatment to drug and alcohol services that are ill equipped to offer flexible and multi-disciplinary care [65, 66]. Pharmacotherapy services may preclude disclosure of current drug use by clients, which may make use of such services as a point of low threshold access for HCV treatment difficult. Attention to the social context of drug and alcohol services, including provider attitudes, is a pivotal component of successful HCV treatment support.

7.3 Key findings of the qualitative study

Our thematic analysis identified three key domains affecting HCV treatment access for PWID: social structural factors; system factors; and the integration of care. We summarise key findings relating to these below.

Social structural factors

Multiple social and structural factors affect HCV treatment access, including: felt stigma; housing; access to social and welfare supports; access to employment and income; family and caring responsibilities; language and ethnicity; gender; and criminalisation. These then, are also important domains for social and structural change.

HCV stigma, for example in the form of prejudicial treatment from medical providers, could negatively impact on participants' decisions regarding HCV disclosure, health care access and HCV treatment uptake. We found that the service partnerships acted to mitigate stigma and encourage HCV treatment access by fostering a welcoming non-judgemental environment, the development of trusting relationships and provision of practical supports. Individualised stigma interventions, such as the re-location of medication provision, acted as facilitators to treatment access.

The majority of participants were in unstable **housing**, such as hostel accommodation. While unstable housing and homelessness do not preclude successful HCV treatment completion, they can be a significant barrier to treatment uptake. Many participants prioritised the obtainment of adequate housing over HCV treatment commencement; this could create a tension between an individual's urgent medical need for HCV treatment and their reluctance to commence treatment until they were appropriately housed. Some service providers played a vital role in helping participants' access housing and hostel accommodation. The provision of practical supports, such as fridges, acted as facilitators to treatment access and uptake for those in unstable accommodation.

Participants with HCV treatment experience reported a variety of **treatment side effects**. Fatigue and depression were the most commonly mentioned. For many, HCV treatment side effects impacted on their ability to carry out day to day tasks such as cooking, cleaning, shopping and getting to appointments. Caring responsibilities, such as sole parenting, could exacerbate these difficulties. For many participants family members and partners provided invaluable emotional **and practical supports**. Reported adequacy of supports received by services were mixed – some participants spoke favourably of support received from service providers, others less so. Recommendations from participants regarding needed **social supports** included home visits and voucher provision for transport, home help and nutritious food.

Financial concerns formed a large part of the participant data. The current financial climate negatively impacted on participants' ability to access disability support allowances while on treatment, even when recommended and supported by their medical providers. Treatment was perceived to increase daily living costs, for example in regard to public transport access. For some, this created a barrier to treatment uptake. Income generation demands also impacted on HCV treatment decision making. The need to maintain appearance and stamina arose as an issue for women engaged in sex work and acted as a barrier to treatment uptake. Service providers reported that **women drug users** were more difficult to engage with HCV treatment than their male counterparts, possibly due to income generation demands, caring responsibilities, stigma and fear of child removal.

Employment demands were not always a barrier to treatment access. Immigrants with HCV, for example, were described by service providers as very motivated to access HCV treatment. A number of these immigrants were not entitled to **welfare benefits**, and worked long hours while on HCV treatment. Additional challenges faced by providers and immigrant service users included **language barriers**, the threat of deportation, lack of benefit access and potential coercion – especially for women – to enter into treatment by partners and/or relatives. Services acted to mitigate these issues, by fitting appointments around working hours and ensuring clients were seen with translators to ensure treatment readiness.

Incarceration was not found to preclude successful HCV treatment uptake and/or continuation. It can, however, be a barrier to treatment completion if the custodial facility is not equipped to support HCV treatment continuation. Service providers reported assessing clients as unstable and therefore not suitable for treatment if they were experiencing frequent custodial periods.

System factors

The two HCV treatment partnerships we studied acted to facilitate HCV treatment uptake and completion among PWID by making modifications to aspects of more traditional treatment regimes, such as those operating within many hospital settings. Key system modifications that were found to encourage HCV treatment access involved appointment policies and HCV treatment eligibility criteria.

Regarding **appointment procedures**, a number of HCV treatment hospitals in the UK enforce 'did not attend' policies, whereby a patient who fails to attend successive appointments is removed from the treatment process, until they are re-referred. High levels of hospital appointment non-attendance by PWID were reported by service providers at both sites. Interviews with providers and service users uncovered a number of barriers to appointment attendance in the hospital setting. Complex or expensive hospital phone lines for patients to schedule appointments acted as a deterrent, as were appointments scheduled for the early morning. Many PWID are late risers, and/or have to prioritise picking up methadone or obtaining drugs before appointment attendance. Appointments made by service providers on behalf of service users were at times experienced as coercive, especially if the service user had not fully engaged with or understood this process. Typically, hospitals will schedule a number of pre-HCV treatment appointments in order to assess treatment 'readiness' and undertake required tests. Service users could experience multiple pre-treatment appointments as futile and fail to attend, especially if each appointment involved a considerable waiting time. For service users on treatment, the side effects of treatment could act as a barrier to appointment attendance, particularly if the hospital was difficult to get to, and/or funds for transportation were lacking. Prior stigmatising experiences at hospital settings were also a barrier to appointment attendance.

The two HCV treatment partnerships worked to mitigate a number of these barriers by **making the appointment processes more flexible** and streamlined. Appointments were often made with cognisance of the service users' daily schedule, for example allowing for time to pick up methadone or arranged around the long work hours of some immigrant service users. Flexible appointment policies were common, whereby service providers were given a large window of time in which to attend, and 'did not attend' policies were not in practice. Services acted to streamline the treatment process, reducing the number of pre-treatment appointments in order to hold service users interest. In this way services were tailored to meet the service users' needs, resulting in increased engagement and uptake of treatment.

Regarding eligibility criteria, **hospital based restrictions in regard to HCV treatment eligibility were also found to be a barrier to treatment uptake** in this setting. Despite NICE guidelines changing in 2004 to include current injectors as eligible for HCV treatment access, some hospitals still used this as an exclusion criterion. Participants described being refused access to treatment in the hospital setting due to their drug use, even if reduced. **Eligibility criteria adopted by the two treatment partnerships included provision for ongoing drug and alcohol use**, with varying degrees of flexibility. **Stability arose as a key in assessing eligibility** at both sites, which was assessed on a case by case basis. As the services gained experience of successfully treating more marginalised individuals (those with co-morbidities, unstably housed etc) **definitions of 'stability' were increasingly relaxed**. In this way the development and implementation of eligibility criteria operated as a constantly evolving process, drawing on service provider experience and lessons learned from similar services.

A key facilitator for HCV treatment access and engagement is the provision of **integrated networks of care**. Many PWID have complex health and social needs and may have to access a variety of service providers to address these issues. The service partnerships helped to engage participants in HCV treatment uptake by **co-locating HCV treatment services in the same building as OST and harm reduction services**. Communication between D&A key workers and HCV treatment providers enabled service user appointments to be coincided, thus facilitating appointment attendance. The service partnerships comprised **multi-disciplinary teams**, with all D&A key workers at Site A also trained as nurses and psychiatry and **specialised phlebotomy services were located onsite** at both services. Service user engagement was enhanced when individual service

providers were able to deal with a broader range of issues, and/or refer the service user to a provider in the same building.

For many PWID, HCV treatment may not be a priority. The provision of **holistic care**, such as wound and sexual health care, at the services – particularly at site A – was seen as a way of engaging service users and initiating conversations about HCV testing and treatment. **Continuity of care** was reported as very important by service users and, in some cases, high staff turnover could lead to disengagement. While many PWID prefer to attend services specifically designed for their needs, where they are less likely to feel discriminated against, this is not the case for all – for example people who are transitioning away from drug use may prefer to access generalised services.

Communication between general practitioners and HCV treatment providers was vital – especially in regard to the provision of medications for HCV treatment side effect management. Ideally such medications should be provided onsite but this was not always possible. Adequate pain medication for people experiencing severe HCV treatment side effects is important. **An increase in OST dosage may help with side effect management.** For many service users the configuration of OST access was a concern. Service users who were on daily supervised OST consumption spoke of the difficulty of visiting a chemist daily when experiencing HCV side effects and feeling that they were not trusted, were more likely to disengage with services. PWID often have difficult venous access and can experience having blood taken as stressful and potentially stigmatising, the **co-location of a skilled and non-judgemental phlebotomist at the services aided HCV treatment access and completion.**

Clear communication between service providers involved in an individual's care is important for ensuring that the correct decisions are made and optimal care is provided. Modes of communication varied depending on the service location and the provider skills, but can include patient appointments attended by multiple service providers, clinical meetings between service providers, shared access to IT databases and clinical letters. **Information sharing systems between the partnerships were at times experienced as a barrier to effective communication** between teams. The sharing and storing of data is a sensitive matter and it is important to have protocols in place that ensure patient confidentiality is respected, while allowing service providers to fulfil their roles as efficiently as possible. Formal shared care partnerships, incorporating general practitioners for example, can lead to better services available throughout an area, with increased access to a variety of health and social services. However, there is some evidence that more 'stable' PWID who are relocated from specialist to non-specialist settings may not be able to access the same level of care and that important functions, such as HCV case management, may fall by the wayside.

7.4 Recommendations

Following the key findings summarised above, we make recommendations in relation to improving hepatitis C treatment accessibility and delivery in three domains: social structural interventions; systemic interventions; and integrated care interventions.

Social structural interventions

Our findings emphasise that access to HCV treatment can be understood as a product of social condition, wherein a **combination of systemic and structural factors affect help seeking**, treatment engagement and service provision. **Enabling environment interventions oriented to creating opportunities for stable housing, stigma reduction and systemic changes in policy and health care delivery can play a critical role in enhancing HCV treatment access and uptake for PWID in the European region.**

Our study highlights the pervasiveness of **social stigma** in the HCV treatment experience. Service providers should understand the impact of stigma on HCV treatment outcomes and work to improve the service environment for PWID to ensure better treatment uptake and outcomes. *We recommend that:*

- The treatment journey should be tailored with individual service user needs in mind to ensure that contact with services in no way exposes them to potential discrimination or perceived stigma. Relocating medication dispensing and providing personal fridges to keep medication safe are examples of such personalised interventions.
- Services should monitor stigma and discrimination and document impact on access to and quality of health services and outcomes.
- Services should establish easily accessible dispute resolution procedures for alleged stigma and discrimination.

Housing can be an important factor in determining how well individuals adhere to HCV treatment and unstable housing can be a reason for low uptake. Many service users may not want or be able to undergo treatment while street homeless or in unstable housing situations. It is important, however, that unstable housing is not an automatic contraindication to HCV treatment eligibility. *We recommend that:*

- Individuals are assessed on a case by case basis, with resources available to support service users who wish to undertake HCV treatment while unstably housed.
- A service provider with knowledge of the accommodation system should be available to assess the housing needs of individuals and help them navigate the system.
- Basic resources such as bedding and fridges should be available to service users in unstable accommodation who feel comfortable to commence treatment in such circumstances.

Social support is vital for helping PWID to adhere to and complete the HCV treatment regime. *We recommend that:*

- Before treatment commencement service providers ascertain an individual's support resources and needs and provide links to additional supports where necessary.
- Assistance with obtaining appropriate welfare benefits should be available for service users and, ideally, voucher schemes or subsidised support for home help, child care and travel expenses should be available where necessary.
- Support and information about HCV treatment should be available for friends, family and/or carers of those undergoing HCV treatment.

Women who inject drugs face particular challenges accessing treatment. *We recommend that:*

- Personalised social interventions such as the provision of childcare, respite care and assurances regarding child custody may help to encourage HCV treatment access among women.

Immigrants can also face additional challenges in accessing treatment. Communication between service users and providers is pivotal. Relying on family or friends to translate undermines provider-patient confidentiality and may result in inappropriate or incorrect decisions being made. *We recommend that:*

- Interpreters should be available for service users with poor English
- Even when relatives or friends of the service user are available to translate one session should be scheduled with an impartial interpreter to ascertain treatment readiness.
- Flexible service provision is desirable, especially when service users have to maintain long work hours and have little ability to take leave.

Imprisonment may be a barrier to HCV treatment adherence and completion [67, 68]. Enhanced access and funding of HCV testing and treatment in prisons and pre-trial places of detention can reduce HCV transmissions and associated morbidity and mortality as well as provide a valuable opportunity for HCV assessment and treatment [69]. *We recommend that:*

- Specialist HCV services should be available in custodial settings and relationships between the criminal justice system and D&A and HCV services developed so that continuity of care is facilitated for incarcerated individuals.

Systemic interventions

Our findings support the notion that **HCV treatment delivery may reproduce social stigma in the environment indirectly as well as directly**. For instance, HCV treatment eligibility criteria which incorporate demonstrations of 'stability' or 'treatment readiness', which may also involve regular attendance at appointments or regular urine screens, may be experienced as stigmatising or disempowering, recreating an atmosphere of mutual suspicion and distrust that can permeate relationships between PWID and medical providers. Similarly, attendance requirements at clinic appointments as a demonstration of 'readiness' may be experienced as patronising or disciplining and can be a barrier for individuals who want to commence treatment immediately and/or who find hospital environments problematic.

In relation to **appointment procedures**, *we recommend that:*

- Non attendance of appointments should not be used to remove a service user from the system. DNA policies should be removed where possible.
- Services that operate appointment based systems should be as flexible as possible to allow service users to choose appointment times that are realistic and do not coincide with other commitments. Where possible, flexible windows of time or drop in periods should be available.
- Service providers making appointments on behalf of service users should be very clear about the purpose of the appointment and ensure that service users are clear that access to D&A services is not dependent on attending healthcare services.
- There should be no service targets around referrals that may encourage coercive referring.
- Where service users make their own appointments, free phone lines should be available.
- Where possible, provision should be made for a service provider (from the D&A service for example) to accompany service users to hospital appointments.

If high rates of missed appointments are normal, service providers can draw on prior experience to overbook clinics to ensure that as many people as possible are seen. *We recommend that:*

- Service providers should work to structure appointments to be as time-efficient as possible, maximising contact with service users by including multiple components in a single contact, that reducing the number of contacts a service users needs to make and shortening the lead-in time to accessing treatment.
- Phone or text reminders for appointments should be considered vital as postal reminders may not reach the desired recipient.
- Extra support to service users receiving HCV treatment may be necessary to reflect the problems they may face in attending services. Extra transport support, flexible appointments and allowing trusted relatives to pick up medication when monitoring is not necessary are among the strategies that can be used to encourage adherence.
- If service users are not attending appointments it is necessary to discuss with them their fears/barriers to attendance and provide personalised interventions – such as medication – where feasible.

Regarding **eligibility criteria**, national guidelines for HCV treatment should enshrine access to treatment for all, and be clear in their message that injecting drug use alone is no reason to preclude an individual from HCV treatment. *We recommend that:*

- The criteria used to determine eligibility for HCV treatment at individual services should be developed with consultation between hepatology and D&A staff who can use their complementary experience to draw up guidelines that both are comfortable with and ensure patient safety. Emphasis should be put on moving away from rigid checklist-style guidelines and drawing more on individual circumstances that indicate a level of stability necessary to successfully undertake treatment. Guidelines can be adapted over time to reflect providers' growing experience and confidence and changes in the social profile of the clients attending services.
- All services should adhere to UK NICE (National Institute for Health and Clinical Excellence) guidelines. Current substance use alone should not be a treatment contra-indication.

Integrated care interventions

Our study findings support the notion that **integrating HCV testing, education and treatment into drug and alcohol services** already attended by PWID can prove an efficient way of reaching more clients successfully. Settings such as D&A services that provide OST and clinics that provide acute care to PWID are ideal locations for providing HCV information and testing to those who require it. Physical health care services co-located directly alongside specialist D&A services are in an especially good position to offer HCV treatment to clients. The co-location or availability of specialist psychiatric support in these services can be an important support to service providers making difficult judgement calls about the effects of treatment on potentially unstable clients. *We recommend that:*

- Delivering effective integrated care requires a multidisciplinary team, who are able to share knowledge across disciplines.
- Linking viral hepatitis services to drug dependence treatment services, particularly OST and NSPs.
- Providing screening and diagnosis for hepatitis to all people who inject drugs and all people living with HIV.
- Providing access to ART for people co infected with HIV and HCV.
- Training should be available for BBV service providers in D&A issues, and vice versa.
- Where possible, services should be available that respond to the immediate and pragmatic needs of PWID. It is recommended that information about HCV testing and treatment is incorporated into these services.
- Services providing integrated mental and physical health services should move to integrate some level of social support, or a liaison with social support services, to improve the social well-being of the service user, reduce stress associated with dealing with housing or financial issues and improve uptake and adherence to treatment
- Where a number of options for treatment location exist, service user preference should be taken in to account when deciding where to treat.
- Efforts should be made to ensure continuity of care at both D&A and HCV services. When staff turnover is unavoidable, good notes and thorough 'hand-over' procedures are important.

Further, we note that services need to ensure that their services are welcoming and clients are not deterred from attending by discriminatory service features or provider attitudes. Well-trained and highly experienced service providers, who are familiar with issues faced by PWID, are well-placed to provide non-judgemental services to what can be perceived as a difficult client group.

Our findings suggest that accessible medication provision helps alleviate HCV treatment side effects which can improve HCV treatment adherence. **Reducing multiple contacts with service providers** by cutting out the additional need to visit a GP to prescribe such medications or buying potentially prohibitively expensive **medication directly from a pharmacy** are important tools in improving adherence. PWID often have difficult venous access, which – when not well managed – can be a barrier to testing and treatment uptake. In addition, **the important role of OST provision in enhancing HCV treatment access, tolerability and adherence is well evidenced**. Taken together, *we recommend that*:

- Where possible, medications for side effect control should be provided on-site.
- Appropriate and sufficient pain control should be prescribed to prevent service users self-medicating with street drugs.
- Services need to provide access to a non-judgemental skilled phlebotomist (preferably onsite) who has a remit to access veins such as the femoral and jugular and is open to letting service users draw their own blood.
- PWID considering HCV treatment should have access to OST, and where possible – provision for OST takeaways.
- Increasing OST dose while on HCV treatment can help with side effects, OST dose reductions while on HCV treatment are generally not recommended.

Attention to the structural and cultural context of drug and alcohol services, including provider attitudes, is a pivotal component of successful HCV treatment support. For example, ‘one-stop-shop’ models of integrated treatment can run the risk of breaching patient confidentiality regarding their HCV status through **information sharing**, which clients may wish not to disclose. *We recommend that*:

- Services working closely together should ensure that well considered information sharing protocols are in place and that they obtain patient consent before sharing information with other providers
- IT systems should be designed with the needs of the staff accessing them in mind and aim to avoid duplication where multiple systems exist.

Where **shared-care agreements** exist or are being put in to place, working groups need to ensure that the benefits gained from such arrangements do not compromise the quality and individualisation of care available to service users that can be such an important factor in determining uptake and success of HCV treatment.

8 DEVELOPING INDICATORS OF SERVICE ACCESSIBILITY AND QUALITY

In keeping with the aim of the project to draw upon the findings and recommendations to assist in improving the quality and accessibility of harm reduction and treatment service delivery for PWID, we conclude below by outlining some useful domains for the development of indicators to assess the qualitative and accessibility of HIV, TB-HIV and hepatitis C treatment services for PWID. To do this, we draw upon the combined findings presented above from each of three project work packages. Our focus is to identify some *key domains for the development of indicators*, alongside some preliminary suggestions for indicators. In taking forward the development of such indicators, it is important to ensure that they are 'SMART' (specific, measurable, attainable, relevant and time-bound).

Since our qualitative studies focused on the lived experience of HIV, HIV-TB and hepatitis C treatments, our suggested domains for service quality indicators draw on patient perspectives of quality, and less upon outcome indicators of service effectiveness or impact. While it is important to note that that our qualitative study findings and related indicators are inevitably context-specific, and thus should be treated with caution regarding their generalizability across European settings, we focus on identifying indicator domains which appear to have relevance across the three qualitative studies and across different harm reduction and treatment settings. We identify the following domains as important: **service integration and collaboration; ensuring access to OST; eligibility and appointment procedures; client-centred care and user involvement; peer and social support; reducing stigma and involving mainstream services; gender, language and culture; addressing wider social and welfare needs; and monitoring.**

8.1 Service integration and collaboration

Indicators of service integration and collaboration might include evidence of:

- Local, regional and national 'good practice' guidelines on integration (including co-location, appropriate linkages and referrals) of HIV, TB, HCV and drug treatments
- Cross-service agreements on staff training, responsibilities and resource allocation, relevant professional networks, and expedited referral mechanisms
- Mechanisms to 'fast track' referral of PWID clients between HIV, TB, HCV and drug treatment services
- Flexible appointment schedules for PWID referred between HIV, TB, HCV and drug treatment services
- Frequency of cross-service meetings to monitor progress of integrated provision of HIV/TB care for PWID
- % staff in HIV, TB, HCV and drug treatment services trained in HIV, TB, HCV and drug treatment care
- % staff in HIV, TB, HCV and drug treatment services aware of their responsibilities regarding provision of integrated care for PWID
- % managers of HIV, TB, HCV and drug treatment services aware of their service responsibilities and resource allocation regarding provision of integrated care for PWID
- % of general practitioners participating in local shared care consortiums of HIV, TB, HCV and drug treatment services
- % of PWID clients of HIV, TB and HCV services who are offered testing for HIV, TB, and HCV
- % PWID clients in HIV, TB, HCV and drug treatment services requiring HIV, TB, HCV and drug treatment care who report receiving timely referral and appointment (through 'fast track' and/or flexible referral appointments)

- % of PWID clients of HIV, TB and HCV services who are offered HIV, TB, HCV and OST treatment in one location

8.2 Ensuring access to opioid substitution treatment (OST)

Findings across studies highlighted the importance of low threshold access to OST as part of a combination intervention approach to HIV, TB-HIV and HCV treatment. At the service-level, indicators may include evidence of:

- % civilian PWID clients of HIV, TB and HCV services who are offered OST
- % imprisoned PWID of HIV, TB and HCV services who are offered OST
- % of PWID clients of HIV, TB and HCV services who are offered HIV, TB, HCV and OST treatment in one location
- % HIV, TB, HCV and drug treatment services with a protocol for adapting OST doses to account for interactions with HIV, TB and HCV treatment
- % PWID on OST and HIV, TB and HCV treatment whose OST dose is adjusted to account for treatment interactions

At the level of policy advocacy for improved OST accessibility, indicators may include evidence of:

- National and international bodies responsible for HIV, TB, HCV and drug treatment, as well as relevant civil society organisations, that declare their support for, and participate in, discussions with national governments to advocate for, improved availability and accessibility of OST and harm reduction programmes for PWID

8.3 Eligibility and appointments procedures

Process indicators can measure barriers to treatment access in regard to failure to meet eligibility criteria. Consultations and reviews of criteria between multidisciplinary groups can also be measured though such indicators. Examples of indicators that could be captured by meeting records are:

- % of PWID requiring HIV, TB or HCV treatment who are able to access it without abstinence requirements by service providers
- % of local services who have developed eligibility requirements in consultation with a variety of stakeholders, including drug treatment services

Service user experiences of appointments can be measured though a number of indicators, such as evidence of:

- % of PWID clients reporting being able to schedule appointments at times convenient to them
- % of PWID clients without an appointment who are able to be seen by a service provider on presentation at the service
- % of PWID clients reporting service waiting times of x minutes or less
- Flexible appointment schedules for PWID referred between HIV, TB, HCV and drug treatment services (as above)
- % PWID clients in HIV, TB, HCV and drug treatment services requiring HIV, TB, HCV and drug treatment care who report receiving timely referral and appointment (through 'fast tracking' and/or flexible referral appointments) (as above)

8.4 Client centred care and user involvement

Indicators of client-centred care need to capture the existence of relevant protocols as well as service user awareness and satisfaction with opportunities for individualised care. Examples include evidence of:

- Protocols within and across services enable flexible timing and location of HIV, TB, HCV and drug treatment, offering community and home-based care where required
- Protocols for take-home medication for clients who have the capacity, or social support, to manage their own adherence, if appropriate under national and international treatment guidelines for HIV, TB and HCV
- % PWID clients of HIV, TB, HCV and drug treatment services who are *aware* and *satisfied* of the range of locations in which they may receive treatment
- % PWID clients of HIV, TB, HCV and drug treatment services who are *aware* and *satisfied* of the availability of appointments

Indicators of PWID involvement in service planning might include:

- % PWID clients and representative groups invited to meetings to discuss design, delivery and evaluation of HIV, TB, HCV and drug treatment services
- % PWID clients and representative groups involved in the above discussions who are actively involved in the delivery and evaluation of HIV, TB, HCV and drug treatment services

8.5 Peer and social support

The development of peer education programmes addressing HIV, TB, HCV and OST awareness and literacy can be measured through process indicators relating to development of resources and training of peer educators, as well as contacts with PWID in the community. Indicators include evidence of:

- Health promotion resources developed in collaboration between treatment providers and peer educators
- % peer educators recruited and trained in HIV, TB, HCV and drug treatment awareness
- Extent of peer educator contacts with PWID to discuss HIV, TB, HCV and drug treatment accessibility
- % PWID clients of who have had peer education contact regarding HIV, TB, HCV and drug treatment access

Many PWID testing positive for HIV, TB or HCV and contemplating treatment may require extra home support to aid medication adherence, especially given associated side effects. Services can record the proportion of PWID embarking on treatment whose social needs are properly prior to commencing treatment. Further, they can monitor the proportion of individuals, requiring support, who are provided with the support they need. Examples of indicators that can be captured by clinical records include:

- Proportion of PWID commencing treatment whose social needs are audited by service providers
- Proportion of PWID who require support, provided with assistance such as subsidised home help, food vouchers and/or transport costs to attend appointments

8.6 Reducing stigma and involving mainstream services

Discriminatory policies and stigmatising attitudes or behaviour from service providers are important barriers to treatment for many PWID. However, it can be difficult to measure such issues as by their nature they tend to be covert. Process indicators can include the provision of anti-discrimination training for staff and specific measures taken to remove discriminating policies (such as the removal of abstinence-based eligibility requirements). Indicators to measure efforts to tackle stigma and the increased involvement of mainstream health services in PWID care might include the following:

- Representatives of specialised and mainstream health services, including prisons and pharmacies, participating in regular meetings regarding provision of integrated care for PWID
- % staff in mainstream health services trained in anti-discrimination and PWID healthcare needs
- % mainstream health services with an anti-discrimination policy which encompasses PWID
- % mainstream health services which operate policies which discriminate against PWID (e.g. relating to eligibility requirements regarding abstinence, housing situation etc)
- % PWID clients of services who report experiencing discrimination from staff in mainstream health services

8.7 Gender, language and culture

As with issues relating to stigma, the barriers preventing women from accessing treatment can be hard to measure and there may be many reasons why different groups of women are deterred from treatment and services. Indicators may include evidence of:

- % women accessing services who accept testing and treatment
- reasons for declining service access opportunity or referral

Process indicators can also be used to measure how well services cater for clients who have insufficient English to communicate with service providers. For example, an indicator that could be captured by clinical records may look like:

- % PWID clients who have insufficient English to communicate with the service provider offered an appointment with an independent interpreter within x days

8.8 Addressing wider social and welfare needs

Possible indicators regarding provision of social welfare care for PWID, and the wider involvement of social care services, might include evidence of:

- HIV, TB, HCV and drug treatment services having established and 'fast track' referral links with social services to secure access to housing and financial aid
- % PWID clients of HIV, TB, HCV and drug treatment in need of social care services who are referred
- % PWID clients of HIV, TB, HCV and drug treatment services who report unstable housing or homelessness
- % PWID clients of HIV, TB, HCV and drug treatment services who report unstable housing or homelessness and who are offered support or who are housed stably
- % PWID clients of HIV, TB, HCV and drug treatment services referred for financial aid, who receive the support to which they are entitled

- National agencies responsible for HIV, TB, HCV and drug treatment having established contingency funding strategies to ensure that access to HIV, TB, HCV and drug treatment is not compromised among PWID

8.9 Monitoring

Indicators for measuring improvements in service monitoring relate to measuring the coverage of screening programmes, as well as the delivery of health information and treatment services, including through integrated service provision. Example indicators may include:

- % PWID in HIV, TB, HCV and drug treatment with unknown or negative HIV/HCV/TB status who are screened for HIV/HCV/TB
- % HIV, TB, HCV, and drug treatment services with functioning health information systems to monitor service use, output, integrated care, and referrals
- Common indicators of service use, referral and integration established across HIV, TB, HCV, and drug treatment services

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