

*Accessibility and integration of HIV, TB  
and harm reduction services for people  
who inject drugs in Portugal*

**A RAPID ASSESSMENT**  
April 2012

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## **Keywords**

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## Abbreviations

<b>ART</b>	Antiretroviral therapy
<b>CAD</b>	Centro de Aconselhamento e Detecção Precoce da Infecção pelo VIH/SIDA ( <i>Centre for Advice and Early Detection of HIV/AIDS Infection</i> )
<b>CAT</b>	Centro de Atendimento a Toxicodependentes ( <i>Support Centre for Drug Users</i> )
<b>CDP</b>	Centro de Diagnóstico Pneumológico ( <i>Pulmonary Diagnostic Centre</i> )
<b>CTC</b>	Centro de Terapêutica Combinada ( <i>Combined Therapy Centre</i> )
<b>DOTS</b>	Directly-observed therapy short course
<b>ET</b>	Equipa de Tratamento ( <i>Treatment Team/Drug Treatment Centre</i> )
<b>HBV</b>	Hepatitis B Virus
<b>HCV</b>	Hepatitis C Virus
<b>IDT</b>	Instituto da Droga e Toxicodependência ( <i>Institute for Drugs and Drug Addiction</i> )
<b>IDU</b>	Injecting Drug Use
<b>IPT</b>	Isoniazid Preventive Therapy
<b>ISPUP</b>	Instituto de Saúde Pública da Universidade do Porto ( <i>Institute of Public Health, University of Porto</i> )
<b>Klotho</b>	Programa de Detecção Precoce e Prevenção da Infecção VIH/SIDA Direccionado a Utilizadores de Drogas ( <i>Programme for the Early Detection and Prevention of HIV/AIDS Infection for Drug Users</i> )
<b>LSHTM</b>	London School of Hygiene and Tropical Medicine
<b>LTBI</b>	Latent Tuberculosis Infection
<b>NSP</b>	Needle and Syringe Exchange Programme
<b>OST</b>	Opioid Substitution Therapy
<b>PLHIV</b>	People Living with HIV
<b>PWID</b>	People Who Inject Drugs
<b>PWUD</b>	People Who Use Drugs
<b>TB</b>	Tuberculosis
<b>MDR-TB</b>	Multidrug-resistant Tuberculosis
<b>SNS</b>	Serviço Nacional de Saúde ( <i>National Health Service</i> )
<b>TST</b>	Tuberculin Skin Test
<b>WHO</b>	World Health Organization
<b>XDR-TB</b>	Extensively Drug Resistant Tuberculosis

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## Executive summary

**Background:** 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 lack of documented strategies for the effective delivery of integrated HIV, TB and drug dependency treatment. Within a harm reduction framework, Portugal has made concerted efforts to move towards integrated service delivery. We aimed to document existing models of integrated TB and HIV care for PWID in Porto, Portugal.

**Methods:** We undertook a rapid assessment combining 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.

**Findings:** The 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 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.

**Recommendations:** Guidelines on integration of HIV, TB and drug dependency care should reflect the importance of: multi-agency collaboration, use of existing professional networks to develop mechanisms for expedited access to integrated care; uninterrupted provision of drug dependency treatment accounting for interactions with anti-TB and anti-retroviral therapy; a client-centred approach recognising service users' autonomy; and the key role outreach programmes can play in facilitating access. Recommendations specific to Porto include expansion of TB and HCV screening among PWID; improved health information systems; streamlined referral mechanisms; increased user involvement; renewed focus on HCV; tackling stigma in primary care; and addressing PWIDs' broader social care needs.

# Introduction

## *TB and the challenge of HIV-TB*

People who inject drugs (PWID) are vulnerable to multiple, overlapping health harms, reduced access to health care and social marginalisation [1, 2]. The high burden of HIV and hepatitis C virus (HCV) among this population has been widely documented [3-6] and evidence of harm reduction and HIV treatment interventions reviewed [5-7]. In the absence of national or regional surveillance data, studies in North America, Europe and Asia have documented high latent and active TB prevalence among PWID recruited in health care and community settings [8]. PWID are at increased risk of TB for a number of reasons [9]. Poverty, homelessness, overcrowding and imprisonment, harms to which drug users are vulnerable, are key social determinants of TB [1, 9, 10]. Co-infection with HIV also greatly increases the risk of progression from latent TB to active disease [11]. TB care typically involves repeated, regular contact with health services to which PWID may have poorer access and adherence [9]. TB treatment is further complicated by common co-infections (e.g. with HIV and HCV), and therapeutic interactions with opioid substitution therapy (OST) and anti-retroviral therapy (ART) [12]. Without appropriate drug dependency treatment, PWID suffer worse HIV and TB treatment outcomes than people who do not inject drugs [13-16]. Incomplete TB treatment can lead to morbidity, mortality, drug resistance and continued transmission [17].

For the past two decades, the World Health Organization (WHO)'s *DOTS* strategy<sup>1</sup> has formed the cornerstone of TB control [18], centred on direct and supportive observation of active TB treatment, high-quality diagnosis by microscopy, continuous treatment supply, standardised data collection and reporting, and sustained political and financial commitment to TB control. Despite successful reduction of TB prevalence and mortality, case detection rates have fallen short of international targets and the emergence of co-morbid HIV and TB has presented new challenges to control efforts [18]. In 2006, the *STOP TB Strategy* added a focus on TB-HIV care to be achieved through collaboration between HIV and TB services; intensified TB case-finding; provision of isoniazid preventive therapy (IPT) to people living with HIV (PLHIV) with latent TB infection (LTBI); TB infection control in health care and congregate settings; provision of HIV testing, counselling and prevention to TB patients; and provision of ART, cotrimoxazole and continuous HIV care for TB patients with HIV [19]. Integrated TB and HIV services are critical in determining TB-related health outcomes in PLHIV [20, 21], including the timely diagnosis and treatment of LTBI. TB prevalence is dramatically reduced, and IPT more effective, among PLHIV receiving ART [22-24]. Collaboration between HIV and TB programmes, co-location of services, training of staff across specialities and effective monitoring systems are likely to be critical to integration [25].

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## *Integration of TB, HIV and drug dependency care*

Effective strategies to deliver HIV, TB and drug dependency care in combination are urgently needed [2, 20]. Combined ART and OST have improved ART access, adherence and treatment outcomes among HIV and HIV-HCV co-infected PWID [26, 27]. Co-location with needle-and-syringe-exchange (NSP) and OST programmes has achieved good engagement in TB screening, prevention and treatment among PWID but there is a lack of documented examples of integrated HIV-TB care for this population [8]. Integration with TB care has been impeded by a lack of multidisciplinary care, an assumption among non-specialists that substance use and TB are too complex to be managed concurrently [28] and prolonged hospitalisation for TB treatment without concurrent drug dependency treatment [29]. In Eastern Europe and Central Asia, where the number of HIV cases among PWID has almost doubled since 2004 [30] and multidrug-resistant TB rates are among the highest in the world [31], poor access to OST poses a major barrier to integrated care [32, 33]. In the Russian Federation, Turkmenistan and Uzbekistan, OST remains prohibited. While pilot OST programmes and their scale-up have begun in other countries in the region, availability of OST remains highly restricted by the small number of treatment centres, high cost and user fees, long waiting lists, strict eligibility requirements, police harassment, unavailability of take-home doses and interrupted treatment supplies [33, 34].

## *Portugal as a European case study*

Portugal's drug policy and approach to integrated care is distinct from many other parts of Europe. In 2001, personal drug use was decriminalized, framing a move from a criminal justice approach to one of public health. Though people who use drugs (PWUD) remain subject to sanctions and are referred to a commission for the 'dissuasion of drug addiction', the main objectives are to explore treatment need and promote healthy recovery [35, 36]. Since decriminalization, rates of drug-related morbidity and mortality [36] and of injecting [37] have decreased dramatically. Though injecting drug use (IDU) was an important driver of the HIV epidemic in Portugal [38, 39], cases associated with IDU have declined dramatically over the past decade [39]. OST became widely available via drug treatment centres early on in the HIV epidemic and a subsequent pharmacy-based NSP is estimated to have prevented 7,000 new HIV infections per 10,000 PWID by 2002 [40]. TB rates in Portugal remain the highest in Western Europe (22 vs. <10/100,000 in most other countries) [41] and although rates of MDR-TB are low (1.5%), extensive drug resistance (XDR) poses a particular challenge to treatment (almost a third of all MDR-TB cases in Portugal are XDR) [42]. Though TB and drug treatment are typically delivered via specialist health programmes, concerted efforts have been made to integrate HIV, TB, drug dependency and psychosocial care through collaboration between treatment centres and support services for PWUD [43].

WHO has prioritised operational research to identify "the best delivery models of collaborative TB/HIV interventions for most at-risk populations" including PWID [44]. Conscious of the dearth of descriptive case studies of integrated HIV and TB service provision for PWID in Europe and elsewhere [8], we 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.

## Methods

### *Study setting*

Between November 2010 and March 2011, we conducted a rapid assessment of integrated HIV and TB services for PWID in Porto and Vila Nova de Gaia (Gaia), northern Portugal. These are the two most populated of 16 cities comprising the metropolitan area of Porto, with respective populations of 237,559 and 302,092 inhabitants. The two cities have independent local administrations but are geographically contiguous and inhabitants often live in one and work or study in the other. The district has one of the highest number of PWID attending drug treatment centres and is also one of the most affected by TB, with an incidence of 34 per 100,000 inhabitants in 2010 [42]. Porto and the surrounding area offer examples of varying models of HIV-TB care for PWID. Although TB and drug treatment is generally provided via specialist health programmes and HIV/HCV care in hospital-based clinics, Porto is unique in being home to the country's only dedicated combined treatment centre providing integrated, co-located HIV, TB and drug dependency treatment.

### *Data collection methods*

Rapid assessment constitutes a multi-method, action-oriented approach to research, prioritising timely response and intervention development, its inductive nature allowing assessments to be guided by emerging practical findings [45, 46]. Triangulation between multiple methods and data sources alongside data generation allows findings to be cross-referenced to develop a more complete picture of the issue under study [45]. There is an established body of work on rapid assessment in the field of drug use [47, 48] which accentuates the exploratory role of rapid assessment in circumstances where data are limited or unavailable.

During this rapid assessment, we undertook a mapping of HIV, TB, drug dependency treatment and harm reduction services and referral mechanisms in Porto; a review of routinely collected data on the epidemiology of HIV, TB and HCV among PWID and use of associated services; and semi-structured interviews with PWID, service providers and stakeholders involved in provision of HIV, TB and drug dependency care and harm reduction services. The rapid assessment team comprised sociologists, epidemiologists and medical doctors based at the Institute of Public Health (ISPUP), University of Porto, in Portugal and the London School of Hygiene and Tropical Medicine (LSHTM) in the United Kingdom. Prior to data collection, members of the assessment team met representatives of local services in the Porto area to: gain their approval and engage them in the assessment; assess feasibility of recruitment; inform interview topic guides; and establish availability of existing data.

### **Mapping**

In order to represent the geographic distribution of services, we undertook a mapping exercise of all HIV, TB, HCV and drug dependency treatment centres and support services for PWID, as well as key drug use sites, in Porto and Gaia. Information was derived from interviews with service providers and PWID, grey literature [49], searches of key 7 organizations' web sites [50-56] and existing knowledge of the research team. Locations were assigned using *Google maps* web mapping service and *ESRI ArcGIS* mapping software (v. 9.3).

## **Existing data review**

We collated data from national surveillance programmes, service provider records and existing research studies regarding HIV, TB and HCV epidemiology, service use and integration among PWID, locally and nationally. Specifically, we aimed to determine: (1) the number of PWID registered with HIV, TB, HCV and drug treatment services (including in prisons); and, among this population, the coverage of TB, HIV and HCV screening; prevalence and incidence of latent and active TB, HIV and HCV; and access to, uptake of and adherence to HIV, TB, HCV and drug dependency care.

We extracted HIV and HCV screening data from annual reports of the *European Monitoring Centre for Drugs and Drug Addiction* and the Portuguese *Institute for Drugs and Drug Addiction* (IDT) [57, 58]. We also reviewed HIV screening data from the national *Programme for the Early Detection and Prevention of HIV/AIDS Infection for Drug Users* (*Klotho*), an initiative introduced in 2007 to offer rapid HIV testing to PWUD at ETs and encourage timely referral for care and treatment [42, 59]. TB prevalence and treatment outcome data among PWUD were accessed from annual reports of the national TB programme. We also extracted data from IDT's annual activities reports from 2006 to 2010 [42, 43, 57, 60, 61].

Published studies were identified using automatic and manual literature searches. MEDLINE was searched to identify relevant studies published between 2000 and 2010, in Portuguese and English, using the following search strategy: ("HIV" OR "Tuberculosis" OR "Hepatitis C") AND ("Portugal" OR "Portuguese") AND ("prevalence" OR "incidence" OR "occurrence" OR "frequency") AND ("drug use" OR "injecting drug use"). Searches were cross-referenced against those of a concurrent literature review conducted by PG and TR [8] and via manual searches of relevant Portuguese publications (*Revista Portuguesa de Saúde Pública* and *Revista Portuguesa de Pneumologia*). We also accessed unpublished reports via personal communication with key informants at collaborating services.

## **Interviews with PWID**

We conducted 30 semi-structured interviews with individuals who currently or formerly injected drugs. We purposively selected participants to include those with and without experience of HIV and/or TB treatment, with and without experience of OST, with recent experience of imprisonment, and to reflect a range of ages, ethnicities, mono and coinfection status (HIV and/or TB, with or without concurrent HCV). Participants were recruited via HIV, TB and drug treatment centres and harm reduction outreach programmes. We aimed to sample purposively according to contrasting service/hospital sites in Porto to represent different models of HIV-TB care.

Interviews took place at HIV or TB treatment services, outpatient drug treatment centres (ETs) or in a nearby cafe. Written informed consent was sought from all participants, who were given as much time as they required to decide whether or not to participate. Interviews were conducted in Portuguese by social researchers from ISPUP, under the guidance of project coordinators at ISPUP and LSHTM. All interviews were audio-recorded with consent and lasted an average of one hour (range 27-137 minutes). Participants were offered light refreshments to thank them for their contribution to the study, as well as written information on local health and support services for PWUD. In this report, all participants' names have been replaced with pseudonyms to protect anonymity.

Interviews with PWID pursued key narrative themes in the individual's accounts of their TB and HIV treatment access and experience. Interviews were informed by a topic guide, developed in English and translated into Portuguese, before being piloted and revised accordingly. Topics explored included: HIV, TB and HCV treatment literacy; access to and experience of HIV, TB and HCV testing and treatment; navigation of administrative and other pathways into HIV and TB treatment; factors influencing HIV and TB treatment adherence; experience of drug treatment in relation to HIV, TB and HCV treatment; experiences of HIV, TB, HCV and drug treatment service referral, coordination and integration; expectations of the personal impact of treatment; social and structural factors influencing PWID lifestyles and treatment access, initiation and adherence; the role of self-help, informal support and civil society organizations in HIV, TB and HCV care; and perceptions of the future.

### **Interviews with Service Providers**

We also interviewed seven experts representing the following services: a pulmonary diagnostic centre providing TB care (*Centro de Diagnóstico Pneumológico*, (CDP)); a hospital-based HIV clinic; an outpatient drug treatment centre (ET); an outreach team providing mobile NSP, OST and psychosocial support (*GiruGaia*); a prison-based OST programme; and the North regional office of the IDT. Consent was gained from service providers and their organizations to name the services in which they worked.

We used a topic guide exploring the following areas: experience of working with PWID and services offered; testing and treatment access for PWID; experience of HIV, TB, HCV and drug treatment delivery; treatment adherence among PWID; mechanisms for referral between and integration of HIV, TB, HCV, drug treatment and other harm reduction services; social and structural factors influencing PWID lifestyles and treatment; the role of self-help, informal support and civil society organizations in HIV, TB and HCV care; comparison of treatment services for PWID in Porto with other parts of Portugal; and unmet health needs of PWID.

### *Ethics approval*

All elements of the rapid assessment were approved by the LSHTM and University of Porto Ethics Committees. Additional administrative approvals were sought from the relevant bodies in Porto.

### *Data analysis*

#### **Existing data review**

Prevalence, incidence and service use data were extracted from the above data sources and entered into Microsoft Excel (2010), recording each indicator's definition, numerator, denominator, data source and limitations. Indicators were based on available data and informed by the WHO *Guide to Monitoring and Evaluation for collaborative TB/HIV Activities* (2009) [49]. Data are reported descriptively, indicating trends over time, where available. Where both numerator and denominator data were available, percentages were calculated.

#### **Interview data**

Qualitative data were analysed thematically, identifying key areas which emerged within and across individual accounts. All interviews were transcribed verbatim. We coded data as we collected it to inform the direction of subsequent interviews, coding and case selection. We aimed to maximize internal reliability and reflection through comparing coding between

multiple researchers. Coding was undertaken in two linked phases. Our first-level coding drew upon a combination of *a priori* themes reflected in the study topic guide and inductive codes. Our second-level coding sought to break down first-level coded data into smaller units, moving from codes at the level of participant description to concept-driven categories, similar to the process of moving from 'open' to 'axial' coding in grounded theory. We maintained an audit trail of the coding process, including analytic memos, using Nvivo9 software (QSR International) to aid our analyses.

### **Triangulation**

Iteration between data from interviews with PWID and experts allowed us to build up a more complete picture of individual, social and structural factors shaping accessibility and integration of HIV, TB, HCV and drug dependency care in Porto. Data from interviews helped us to unpack and identify gaps in data on service use and access to testing and treatment in services. It also helped to elucidate (1) how referral mechanisms and linkages between services identified via the mapping exercise operate, both through formal channels and informal professional networks and (2) how these are perceived and experienced by service users.

### *Characteristics of interviewees*

#### **Socio-demographics**

We interviewed 30 PWID aged 31 to 52 (average 40), most (27/30) of whom were male, demographically reflective of the client population seeking drug dependency care at ETs (85% male and 59% aged 30+ in 2010 [57]). Just over half of interviewees lived with a partner or family members (n=14), seven lived alone in rented or state-provided accommodation, six lived in sheltered housing and three were homeless. Participants included current injectors (having injected in the last month) (n=10), those who had recently stopped injecting (between last month and the past 6 months) (n=3) and long-term former injectors (having stopped 6 months to 22 years ago) (n=17). Participants had injected for an average of 12 years (2 months – 26 years), typically heroin or heroin and cocaine ('speed-balling'). The experts interviewed included HIV and TB consultants, and a psychiatrist, nurse and outreach worker providing drug dependency and harm reduction services, with an average of 14 years of experience working with PWID (range 7 – 25).

#### **Infection status and treatment experience**

Table 1 shows participants' HIV, TB and HCV infection status, history and treatment experience, as well as current and prior OST and imprisonment. The majority of participants had experience of OST (n=26), all but two of whom were still on treatment. Eleven participants had experienced both HIV and TB treatment (preventive therapy or active TB treatment), in all cases concurrently. Others had experience of concurrent HCV and HIV treatment (n=2), HIV treatment only (n=7) or TB treatment only (n=1). Two participants were HIV-positive and treatment-naïve and 17 had HCV but no history of treatment. All participants diagnosed with latent or active TB (n=15) had received treatment. For this analysis we have included individuals with experience of HIV and/or TB only (n=25).

**Table 1: Interview participants' status and treatment experience**

Pseudonym	Age	HIV		TB		HCV		OST	Prison ever
		Status	Treatment	History	Treatment*	History	Treatment		
Miguel	37	Positive	Current	Current active	Current	No	-	None	Yes
Jesualdo	-	Negative	-	Current active	Current	Yes	Past	None	-
Américo	43	Negative	-	Current latent	Current	Yes	None	Past	-
Helder	44	Positive	Current	None	-	Yes	Past	Current	-
Jacinto	37	Positive	None	Current active	Current	Yes	Past	Past	-
Jorge	52	Positive	Current	Past active	Past	No	-	Current	Yes
Fátima	43	Positive	Current	Past active	Past	Yes	None	Current	-
Edgar	40	Positive	Current	None	-	Yes	None	Current	-
Mário	39	Positive	Current	Current latent	Current	Yes	Current	Current	Yes
Maria	35	Positive	Current	Current active	Current	Yes	None	Current	-
Joel	43	Positive	Current	Current active	Current	Yes	None	Current	Yes
Alberto	40	Positive	Current	None	-	Yes	None	Current	Yes
Jerónimo	49	Negative	-	None	-	No	-	Current	-
Nuno	32	Positive	Current	None	-	Yes	None	Current	Yes
Amilcar	45	Positive	Current	Past active	Past	*	*	None	-
Ivo	39	Positive	Current	None	-	Yes	Current	Current	-
Justino	42	Positive	Current	None	-	Yes	None	Current	-
Ricardo	40	Positive	Current	Past active	Past	Yes	None	Current	Yes
Sara	36	Positive	None	None	-	Yes	None	Current	-
Juliano	40	Negative	-	None	-	Yes	None	Current	-
André	43	Positive	Current	None	-	No	-	Current	Yes
Márcio	34	Positive	Current	Current active	Current	No	-	None	Yes
Juvenal	42	Negative	-	None	-	Yes	Current	Current	-
Óscar	46	Negative	-	None	-	Yes	None	Current	Yes
Jeremias	35	Positive	Current	Past active	Past	Yes	None	Current	-
Rafael	31	Negative	-	None	-	Yes	None	Current	Yes
Marcelo	40	Negative	-	Past latent	Past	Yes	Past	Current	Yes
Fábio	40	Positive	Current	None	-	Yes	None	Current	-
Julião	35	Positive	Current	Past active	Past active	Yes	None	Current	Yes
Patrícia	42	Positive	Current	None	-	Yes	None	Current	Yes

\*Preventive therapy or active TB treatment

## Findings

### *1. Drug dependency, TB, HIV & HCV service delivery: the system in Portugal*

In Portugal, TB and drug dependency care are delivered via specialist programmes with their own administration, financing and staff, while HIV and HCV care is hospital-based. Coordinated by the IDT and Ministry of Health, a network of free, public services offer OST and other substance use treatment, and psychological and social support, largely via outpatient drug treatment centres (ETs). Autonomous pulmonary diagnostic centres (CDPs) provide TB screening and diagnosis, prevention (IPT) and treatment (DOTS) under the national TB programme [43]. Specialized HIV and HCV care is provided in hospital-based outpatient clinics, dispensing treatment via hospital pharmacies. Community pharmacies and mobile outreach teams linked to ETs deliver NSP and a small-scale OST programme. Outreach teams aimed at the most vulnerable and socially marginalised PWID also offer psychosocial support and a link to other health and support services. HIV, TB, HCV and drug dependency care are linked through a combination of integrated screening programmes, referral mechanisms and informal arrangements for co-located treatment, through collaboration between pulmonary diagnostic centres (CDPs), HIV and HCV outpatient clinics, ETs and outreach programmes.

#### **Drug dependency care services: OST, HIV testing & referral for TB/HIV care**

OST has been widely available via public ETs (formerly known as *Centros de Atendimento a Toxicodependentes* (CATs)) since 1987. A multidisciplinary team of doctors, nurses, psychologists and social workers develop client-tailored care programmes. OST is initially supervised daily, although take-home doses may subsequently be dispensed weekly depending on individual assessment. OST can also be provided in other settings including hospital wards, prisons, primary health care centres, CDPs, community pharmacies and via mobile outreach teams, under the supervision of an ET, although this depends on locally arranged initiatives in the absence of a formal protocol. Short-term medically-assisted withdrawal treatment is available at inpatient public and private detoxification units, and longer-term, abstinence-based care via therapeutic communities [62]. These services are typically accessed by referral from an ET. Private centres are publically subsidized, free-of-charge to clients and follow IDT's treatment principles. Day-care centres provide occupational, educational and training activities for vulnerable PWUD with scarce or no family support, as well as offering daily-observed OST.

All centres are expected to offer HIV, TB and HCV screening to new clients and then according to clinical assessment, although no written national protocol exists. Onsite rapid HIV testing has been available at ETs since 2007 under the *Klotho* Programme [35, 63]. Although HCV screening is prescribed onsite, service users must select a private laboratory (contracted by the National Health Service (SNS)) at which to be tested. For TB screening, clients receive a written referral form and are asked to attend a CDP, before returning their results to the ET at their subsequent appointment. Patients admitted to a detoxification unit or therapeutic community are also screened for HIV and HCV (blood is collected onsite and sent to a private laboratory) and are accompanied to the nearest CDP for TB screening. Clients with positive HIV or HCV results are referred to hospital-based

outpatient clinics for care and those with TB are treated at their local CDP. In collaboration with CDPs and HIV clinics, ART and TB treatment can be delivered at ETs and inpatient detoxification centres/therapeutic communities, although this approach is not formally established and depends on staff efforts to develop individualized care strategies.

#### **TB services, with scope for co-located DOTS and OST**

CDPs deliver TB screening, preventive therapy, and DOTS-based treatment for active disease [59]. Screening comprises a symptom questionnaire (regarding history of fever, night sweats, cough, weight loss, fatigue), tuberculin skin testing (TST), and a chest X-ray to exclude active TB. The decision to provide IPT to clients with LTBI is based on an assessment of the risk of developing active disease, anticipated adherence and comorbidities [64]. DOTS is delivered via nurse home-visits or inpatient hospital care during the initial 2-week infectious period, at which time patients are required to wear a protective mask. Once the risk of transmission has been ruled out, treatment is relocated to the CDP, under the observation of a nurse. CDPs are staffed according to local TB burden and can be accessed directly or by referral from ETs, outreach teams or other health and social care services. Drug-dependent clients are referred to an ET or outreach team and offered co-located DOTS and OST, if desired. CDPs have also offered rapid HIV testing since 2008 and refer clients to hospital-based outpatient clinics for HIV care.

#### **HIV testing**

Rapid HIV testing is offered routinely at ETs, outreach teams and CDPs but is also available at hospitals and public primary health care centres (requested by the general practitioner and performed at an SNS-contracted private laboratory). Free anonymous HIV testing is available at designated testing centres (CAD), one located in each district. Clients with a reactive result are referred to an SNS-contracted private laboratory for confirmatory testing and onward to HIV clinics for care if confirmed.

#### **Hospital-based HIV and HCV care**

HIV and HCV care is delivered by hospital-based outpatient clinics. ART has been widely available since 1987, is initiated at a CD4 count below 350 [63] and dispensed monthly by hospital pharmacies, in conjunction with three to six monthly consultations with an HIV specialist (Service Provider and PWID interviews). HCV treatment is also dispensed by hospital pharmacies, typically on a take-home basis. All new HIV clinic clients are offered onsite TB screening (TST, X-ray and other imaging/microbiological diagnostics if needed) on enrolment and then according to history of exposure. Those with latent or active TB are referred to their local CDP for IPT or treatment. Clients initiating TB treatment in hospital are referred to the CDP on discharge.

#### **Pharmacy-based NSP, OST and pilot HIV screening/DOTS programmes**

In 1993, the National Coordination for HIV/AIDS and the National Association of Pharmacies introduced a pharmacy-based NSP, in which just under half (n=1360) of Portugal's pharmacies now participate [65]. Since 1998, a number of community pharmacies have also offered supervised methadone for ET clients (with the addition of naltrexone in 2001 and buprenorphine in 2004), aimed at minimising disruption to clients' lives and improving adherence [66]. Pharmacies do not provide screening for HIV,



TB or HCV but often informally advise clients to attend ETs or CDPs for testing. A pilot intervention in Gaia involving community pharmacies in DOTS has since been ruled against due to pressure from the national body of nursing to retain treatment within health care settings [67]. Results of a pilot study of pharmacy-based rapid HIV testing in Southern Portugal are not yet available [68].

### **Outreach-based NSP, OST and combined HIV/TB treatment**

Since its inception, the national NSP has expanded to include publically and NGO-funded mobile outreach teams [69], known locally as ‘street teams’, and has moved from one-for-one exchange [69] to distribution of harm reduction kits (containing sterile syringes, safe injecting equipment and condoms) [69]. By 2007, approximately 13 million kits had been distributed. Outreach teams provide rapid HIV testing and referral for TB and HCV screening, vaccinations, health education and psychosocial support. Some also supervise OST, HIV and TB treatment in the community in conjunction with ETs and treatment services. Shared protocols between national health and social services, NGOs and private services facilitate provision of food aid and shelter, and financial support is accessed via social assistance.

### **Prison health services: OST, onsite screening & referral for treatment**

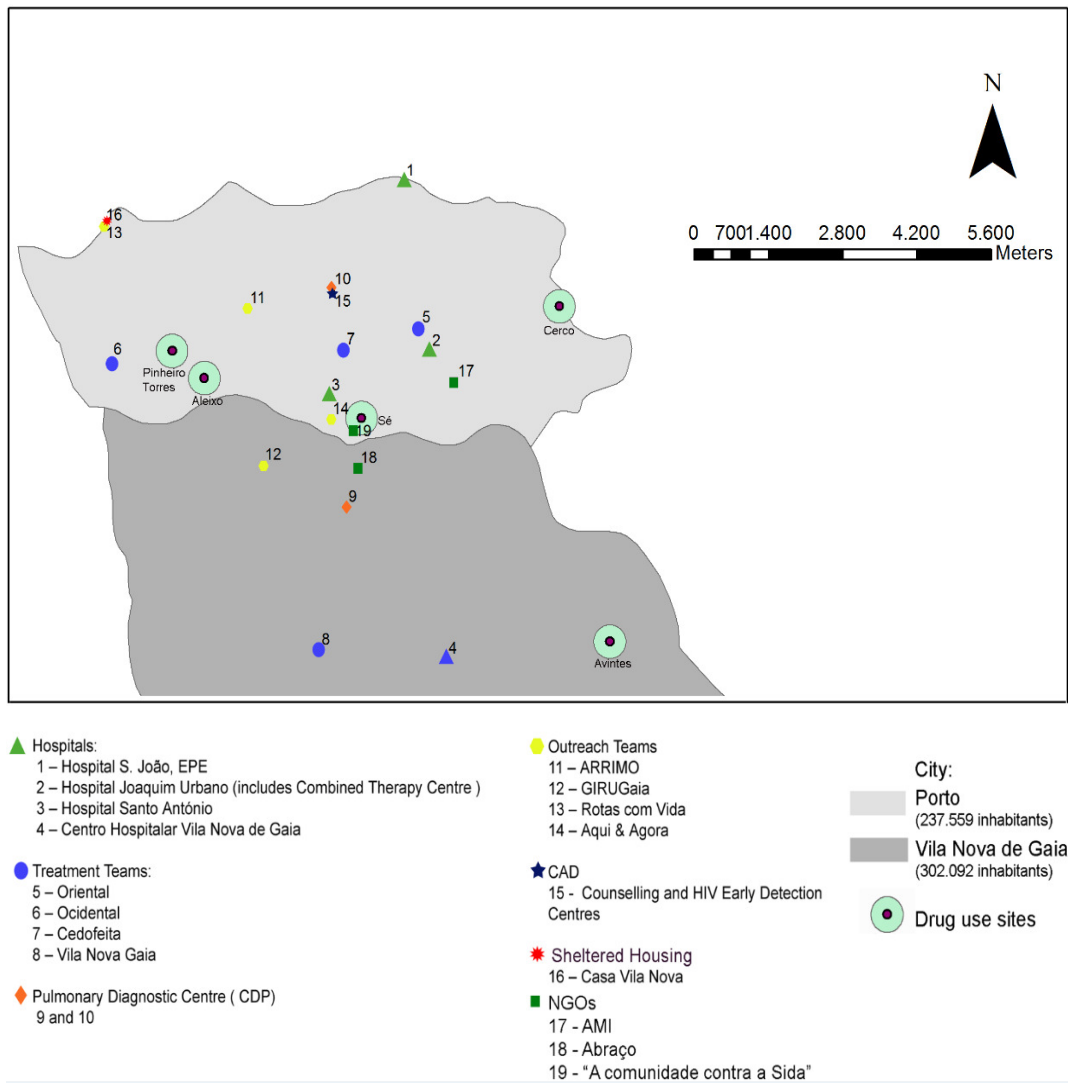
On admission, all new prisoners receive HIV, TB, HBV and HCV screening and are referred to civilian treatment centres where necessary, accompanied by prison guards. Treatment is dispensed by hospital pharmacies and CDPs but is administered via direct observation in the prison setting. In 2006, a national action plan to prevent infectious disease transmission in prisons prioritised access to condoms, NSP and OST [70]. All prisons offer OST onsite [71]. In 2007, a pilot NSP was implemented in two prisons in which inmates could request sterile injecting equipment at prisons’ health facilities. However, to date, no prisoner has used the service. While some argue that this suggests an absence of injecting, the lack of guaranteed anonymity and fear of subsequent sanctions has been posited as an important factor and new strategies for prison-based NSP are under study [70, 72].

Rates of drug use and injection have decreased considerably in Portuguese prisons over the last decade, the proportion of prisoners in 2001 and 2007 reporting having used drugs in prison falling from 47% to 36% and those injecting from 11% to 3% [73]. For one interviewee, temporarily switching from injecting to smoking while in prison was a strategy to avoid the extensive needle-sharing that he had witnessed 12 years earlier: *“In jail one syringe is shared by around by 10 or 15 people. Till it’s totally knackered ... I preferred to smoke”* (Márcio, male).

## ***2. The treatment system in Porto and Gaia***

In Porto and Gaia, there are four ETs, two CDPs, one HIV testing centre (CAD), and four hospitals providing HIV and HCV care (Figure 1). Several outreach teams provide mobile NSP and OST close to key drug use sites, screening and treatment referral and psychosocial support. A number of NGOs also coordinate support groups for PLHIV. For PWID without secure accommodation *Casa Vila Nova* provides sheltered housing, entry to which is contingent upon HIV and TB screening and initiation of OST. Collaboration with ETs and outreach teams allows OST to be supervised on-site, obviating the need for daily attendance at ETs (service provider and PWID interviews).

**Figure 1: Map of HIV, TB and drug treatment services in Porto and Gaia\***



\*Urban areas only. For clarity, health centres and community pharmacies are not depicted.

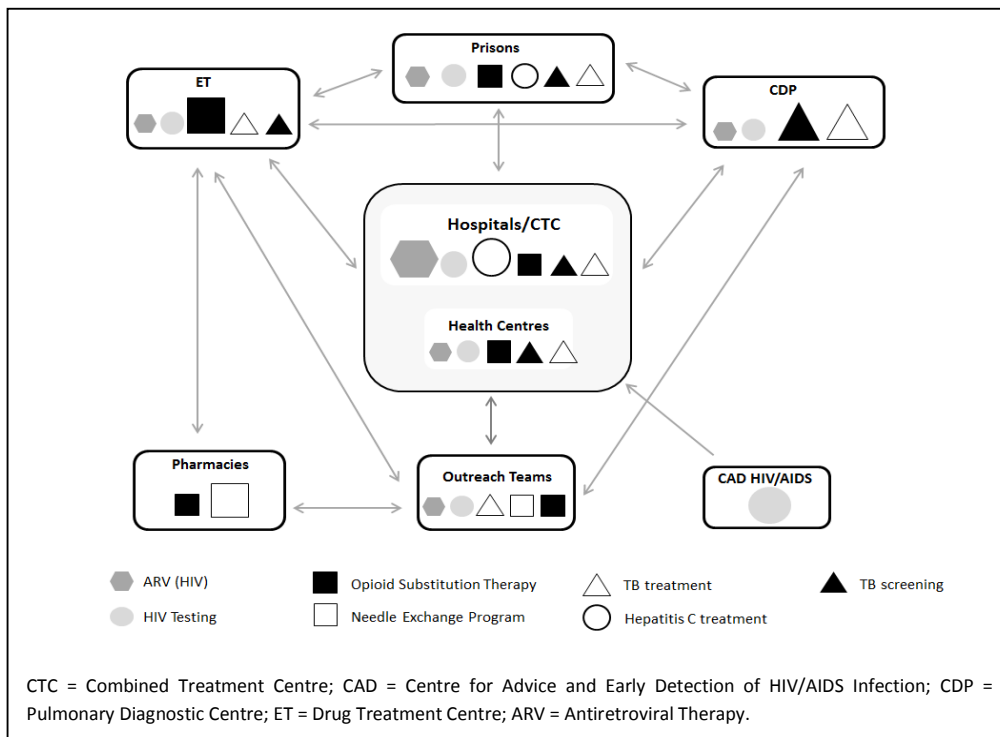
### **Models of integrated drug treatment, HIV & TB service provision**

This assessment identified two distinctive models of integrated HIV, TB and drug dependency service provision. The Combined Therapy Centre (CTC) at Joaquim Urbano Hospital provides integrated outpatient HIV, TB, HCV and drug dependency care in a dedicated care centre (‘combined model’) [74] (Figures 1 & 2). The CTC was set up in 1998 to address poor adherence to concurrent treatment among PLHIV on OST, with considerable success. ART, OST and TB treatment are delivered daily under direct observation, managed by a multidisciplinary team of infectious disease specialists, psychiatrists, psychologists, social workers, nurses, and ‘social mediators’ under combined care protocols, enabling co-located and integrated care from the outset. HCV treatment is also delivered onsite, in contrast with take-home medication in other centres across the country (JU & IDT service provider interviews). An outreach team provides home-based treatment for those who are physically unable to attend consultations. Incentives to encourage HIV and TB treatment adherence include provision of travel passes, daily

snacks and informational/recreational facilities (computer and internet access, reading materials and sporting activities). This programme requires daily visits to the CTC. Clients achieving suppressed viral load, good treatment adherence and a stable lifestyle can be transferred from the CTC to the hospital’s adjacent outpatient HIV service, receiving ART supplies monthly (for those in drug treatment or with active TB, ETs provide daily/weekly OST and CDPs deliver daily DOTS). However, this transfer has rarely occurred in practice (service provider interview).

The second ‘collaborative model’ is a less formalised but widespread client-centred approach in which multiple and existing health programmes work together to achieve co-located treatment delivery at a location convenient to the patient. This approach relies on informal referral networks and outreach teams often act as mediators between multiple treatment services. Although HIV, TB, HCV and drug dependency care are typically delivered by separate services (figure 2), collaboration between CDPs, HIV/HCV clinics, ETs, outreach teams, sheltered housing and clients allows delivery of individually-tailored treatment in one health care or community setting, or at home. “16We [CDP] have 6 patients in the day hospital, 1 in the health centre, 10 having home treatment and 5 who basically pick when it is most convenient for them to do the treatment. We have no one being treated by the street [outreach] teams [at the moment], we don’t but we could.” (CDP provider). Since adopting this approach, CDPs have seen marked improvements in TB screening coverage, treatment adherence and cure rates.

**Figure 2 HIV, TB and drug treatment in Porto: services and referral channels**



Symbol size represents the relatively primacy of that activity within each type of service.

An NGO-supported outreach programme, *GiruGaia*, also offers a combined therapy programme, supervising daily methadone, HIV and TB treatment in the community, in collaboration with ETs, HIV clinics and CDPs. The programme serves current and former

PWID with minimal social support, significant social care needs and those who have had difficulty adhering to OST (outreach provider interview).

### *3. Access to and uptake of testing and treatment services*

#### **Drug dependency treatment service use**

Rates of injecting drug use have declined considerably in Portugal over recent years. Between 2000 and 2005, the estimated number of PWID more than halved (from 32,287 to approximately 14,500) [37], a trend reflected in interviews with PWID and experts (“*They’ve fundamentally changed in terms of method of [drug] use. It’s now mainly smoked*” (outreach provider)) and ET service use data. In 2010, just half (3120/6233) of new ET clients sought drug-related care and only 7% reported having injected in the past month, compared with 36% in 2000 [57]. Among those attending for drug or alcohol-related care, heroin/other opiates were the most common primary substance used (44%), followed by alcohol (30%), cannabis (13%) and cocaine (11%). In total, 37,983 people attended ETs across the country in 2010, 40% in the Porto area. ET services were most commonly sought by clients themselves (41%), followed by referral from other health facilities (21%) and social or criminal justice services (18%). In 2010, 85% of clients received their first consultation within two weeks of initial attendance [57]. Admissions to public therapeutic centres have remained fairly constant over the past two years: in 2010, 124 patients were admitted, representing a 84% occupation rate compared with 82% in 2009 [57]. Admissions to detoxification units declined by 10% over the same period, with 1489 patients treated in the 4 public units in 2010 [57].

#### **HIV, TB and HCV: screening uptake and results**

Although national surveillance data do not capture rates of infectious diseases among PWID, screening data from drug dependency treatment services and CDPs provide estimates of HIV, TB and HCV prevalence among PWUD (though often not stratified by history of IDU). Between 2007 and 2008, almost three-quarters (74%) of new ET clients reporting IDU were unaware of their HIV status, compared with a fifth (21%) of existing clients [35]. Provision of targeted rapid HIV testing at ETs resulted in high screening rates among new and existing PWID clients (Table 1) [57]. Reported screening coverage was similarly high among inpatient clients at detoxification units and therapeutic communities, although no raw data were available (Table 1) [75].

The proportion of ‘reactive’ rapid HIV tests among PWID was over twice as high in new ET clients than existing clients, although attendance for follow-up confirmatory testing was low (Table 1). Of the half attending for confirmatory tests almost all tested positive. This suggests that the ‘reactive’ rate is a good indicator of real prevalence but also that up to 50% of cases remained unconfirmed. In 2010, 10% of *GiruGaia*’s clients enrolled in the outreach-based combined therapy programme had confirmed HIV although, again, this is likely to be an underestimate due to reluctance to take up hospital-based confirmatory testing (Outreach provider interview). HIV prevalence was highest among inpatient drug treatment clients, although it is not reported whether data relate specifically to those with prior negative or unknown status.

**Table 1: HIV Screening in Drug Dependency Treatment Facilities in Portugal**

Setting	Year	Population	Screened	HIV testing method	HIV-positive
ETs ( <i>Klotho programme</i> )*	2009	6456 existing clients (PWID)	87% (5609)	Rapid test + confirmatory blood test	1.4% reactive†
		1149 new clients (PWID)	85% (977)		3% reactive†
Detoxification units	2010	2424 service users	92%	Blood test	11%‡ [75]
Therapeutic communities	2010	4499 service users	87%	Blood test	12%‡ [75]

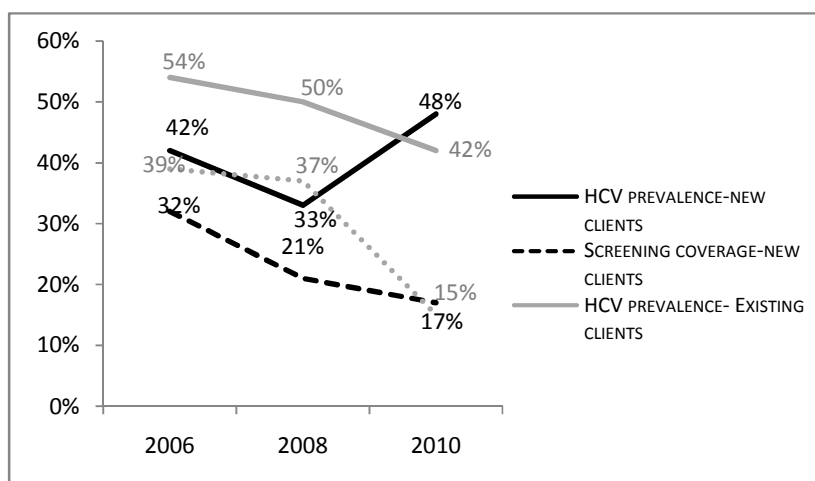
\*Clients with unknown HIV status/prior negative result

†0.5% & 1.2% confirmed (new and existing clients). However, almost all attending for confirmatory testing were positive; prevalence is therefore likely to be close to “reactive” rate; ‡ No raw data available

In 2009, the national TB programme reported 587 cases of active TB among PWUD (94% confirmed), representing 17% of cases nationally. In the same year, prevalence of MDR- and XDR-TB was over twice the national rate: 2.3% of TB cases among PWID were MDR-TB and, of these, 61% were XDR-TB. Almost all PWUD with confirmed TB were aware of their HIV status and over half (57%) were HIV-positive [76]. No equivalent data were available on TB screening or status among HIV clients. In 2010, prevalence of TB among ET clients was reported as between 1.3 and 1.5% (among existing and first-visit clients, respectively) [57], however data are not stratified according to TB type (latent/active) or experience of drug use and screening coverage was very low (6%: 1793/29,539 repeat-visit clients and 540/8444 first-visit clients). No data were available on the proportion of ET clients referred to CDPs for screening who took up referral appointments. TB screening coverage in inpatient units was reported to be almost universal (98% in detoxification units and 93% in therapeutics communities), although test results data are not available. The only data available on TB screening specific to PWID is derived from a study published by the CDP in Gaia [43]. Between 2005-2007, subsequent to a collaborative intervention to improve case detection and treatment among PWUD, latent and active TB was diagnosed in 19% (96/495) and 12% (59/495) of PWID accessing the CDP, respectively, via a combination of active screening and passive referral. At the time of this assessment, one of *GiruGaia*'s clients had suspected active TB and was awaiting confirmation, and another was receiving IPT.

The results of ‘selective’ HCV screening (offered to PWUD considered at risk of infection) provides an estimate of prevalence among ET clients, although data are not stratified by history of IDU [57, 60, 77]. Over the past four years, reported prevalence among existing ET clients has declined by approximately 20% while no clear directional trend emerges for new clients (Figure 3) [57, 60, 77]. However, reported screening rates have also decreased considerably (attributed partly to transition to an electronic data collection system) [57, 60, 77], making it difficult to assess the precision of these estimates. HCV testing coverage was higher at inpatient drug dependency treatment facilities (95% and 89%, respectively, in 2010) [57], although prevalence data are not reported.

**Figure 3: Trends in HCV prevalence among ET clients<sup>1</sup> across Portugal (2006-2010)**



<sup>1</sup>Including but not limited to PWID

### Treatment uptake and outcomes

By the end of 2010, 21,110 ET clients were enrolled in OST, 77% receiving methadone (n=16,287) and 23% buprenorphine (n=4823) [57]. Approximately 4847 clients left methadone treatment that year, the majority of their own accord (2089/43%) and 14% (683) with medical release, although a small proportion were excluded (82/1.7%). Just under half (226/498) of enrolled pharmacies were delivering OST, supervising methadone for 714 clients, compared with 579 clients in 2008. In 2009, 8.3% (202) clients were medically released from the programme following dose reduction [58, 66]. The same year 472 prisoners enrolled in OST, an increase of 24% compared with the previous year and the highest uptake in the past decade [75]. In 2010, 60 of *GiruGaia's* 75-80 outreach clients were receiving methadone in the community.

In 2009, 5357 PWID were receiving HIV care via hospital-based outpatient clinics in Portugal, 33% in the Porto region. However, this is likely to be a significant underestimate since data were only available from half of the hospitals. Nationally and in the Porto region, PWID represented approximately a third of all patients receiving HIV care (34% and 35%, respectively) [63]. Among drug dependency treatment service clients who had acquired HIV through IDU, 23%-69% were receiving ART, the lowest rate representing new clients at ETs and the highest rate daycare centre clients (raw data not available) [78]. In 2010, 182 ET clients across Portugal (including but not limited to PWID) were receiving ART at ETs [57].

In 2009, three-quarters (440/587) of PWUD with active TB in Portugal completed DOTS. Four per cent (n=23) remained in treatment, 8% (n=46) interrupted therapy, 4% (n=23) were lost to follow-up and 9% (n=53) died. In 2010, 105 clients were receiving both OST and DOTS at ETs nationally [57]. The only data available on adherence, completion and TB-related mortality among PWUD were published by the CDP in Gaia [43]. Between 2001 and 2003, 82 cases of active TB were identified among PWUD, over a third (35%; 29) of whom did not complete DOTS and 18% (n=15) died [43]. In order to improve TB case detection and access to care, a collaborative approach was initiated, involving hospitals,

the public health department, ETs, homeless shelters and outreach teams, encouraging referral to CDPs for TB screening. Compared with the period prior to this intervention, the number of PWID screened for TB increased almost four fold (from 125 to 465) and treatment outcomes improved, with non-adherence falling from 48% (n=39) to 24% (n=14), and deaths from 18 to 14% [43].

No data were available on the number of PWID receiving HCV treatment, nationally or regionally, nor is the unmet treatment need known since prevalence data were not disaggregated according to chronic and spontaneously-cured cases.

#### *4. The role of integrated drug dependency, TB & HIV care in access to services*

Client preferences to receive integrated treatment via the 'combined' or 'collaborative' model depended largely on the proximity of treatment services and the desire for health-facility or community/home-based care. The quality of care, commitment and communication skills of staff at the CTC were highly valued by clients (*"I don't think I have ever found anything like it in the whole country. I think they are extremely dedicated. They know how to talk to us"* (Jacinto)). However, for those who no longer used drugs or were not engaged in OST, being surrounded by young, active PWUD was an emotionally-difficult reminder of their former situation and thus made this an unappealing setting for care: *"I see many people there [CTC] who's on methadone and they're there falling to pieces ... it's hard for me to see these people like this, this young youth, because I've already gone through all this ... I started missing them [appointments] and it was then ... I went there to the hospital [Santos Silva] ... you don't see so much misery here as you see up there."* (Miguel)

The 'collaborative model', on the other hand, involved less bureaucracy, more timely access and the opportunity to receive treatment at or near one's home, facilitated by outreach teams. Provision of integrated care, particularly via the latter model, was shaped by four key factors: the nature and extent of collaborative networks and shared protocols; the central involvement of outreach teams; provision of uninterrupted OST; and flexibility over treatment location.

##### **Collaborative networks and shared protocols**

Collaboration between disciplines, organisations and individual service providers was central to achieving effective TB and integrated HIV, TB and drug dependency care. Cross-specialty training and monthly meetings between a CDP, outreach team and ET helped to develop mutual understanding of services' practices and their clients' needs. Communication between centres, as well as an understanding of referring services' practices and capacity, was key to facilitating co-located treatment:

*"Collaboration at CDP is great ... 'How is tomorrow looking? Are you very busy? Can I send a patient over that I think needs to be tested ... the patient takes this dose [of methadone] ...' because we stock up CDP with methadone ... 'If you can, colleague, will you give him the dose tomorrow so that he doesn't have to come here to take it and that way he only goes to one place?'"* (ET provider)

Formal referral between HIV clinics and other treatment centres was hindered by bureaucracy, a lack of awareness of appropriate referral services among clinic staff and an

absence of shared protocols. Informal professional networks with colleagues in TB and HIV services, on the other hand, facilitated flexible access to appointments, which proved particularly important in getting outreach clients into services:

*“Dr R. [CDP], [she’s] excellent, she’s always ready to see an urgent case ... And then, at the Hospital Santos Silva, Dr MM ... she’s given us, for some years now, those two consultations a week [reserved for GiruGaia clients], which is excellent. Whether we go or not, we have them reserved for us, those two hours.”* (Outreach provider)

The capacity to arrange timely referrals and co-located care thus depended heavily on individual providers’ efforts to collaborate with colleagues in other treatment and support services.

### **The central role of outreach services**

Recognition of outreach teams’ potential to facilitate prompt, active referral to CDPs, without the need for patient documentation, motivated regular communication between services and a move away from solely fixed-site treatment delivery. Outreach teams’ capacity to supervise combined treatment in community settings, in collaboration with ETs, CDPs and HIV clinics, was key to facilitating treatment adherence and attendance at follow-up consultations:

*“It’s still them who give me the methadone and the pills [ARVs]. It’s them who tell me to go to the appointments in Santos Silva Hospital. I do my whole treatment with them, because if I kept it there would be days when I would[n’t] take the pills and this way I do.”* (Joel)

These services were a crucial link to health and social care, particularly for PWID lacking support networks. Their location in the community, minimal documentation requirements and, in the case of *GiruGaia*, capacity to provide an immediate minimal dose of methadone prior to a psychiatrist consultation expedited access to OST, as well as HIV and TB screening and treatment. Outreach teams offered essential help navigating multiple treatment services, particularly for those with unstable living situations or were still using drugs. Accompanying clients to services, both early on and in cases of urgent care, providing vital support for those with financial difficulties and reduced capacity for self-care:

*“I was in a very bad way, I was dying, I was on my last legs and that street team, which hands out syringes and food here ... they picked me up because I didn’t have enough strength to get myself to hospital ... they took me to the Hospital Santo António first, I stayed there, they put a mask on me right away.”* (Ricardo)

Outreach services were therefore central not only to case detection, treatment access and engagement but also provision of ongoing support to the most socially marginalized PWID.

### **Uninterrupted OST**

Early on in experiences of combined care, achieving the appropriate methadone dose and combined HIV/TB treatment schedules required considerable experimentation, with the involvement of multiple service providers. When unsuccessful, the resulting withdrawals made continuation of HIV/TB treatment unbearable. Only on reaching a critically weak condition was treatment resumed, typically under hospitalisation:



*"I ended up having 14 defenses [CD4 cells] left. Dr M. said, 'I don't know how you are still standing' ... the tuberculosis medication reduces the effect of the methadone, it is a horrible withdrawal ... I felt bad the first time when he told me it, 'No, I won't take anything'... He admitted me and [only] then I started taking all the medication [ART & DOTS] properly." (Maria)*

This was a particular concern for clients admitted to hospital who feared withdrawals due to perceived difficulty securing methadone treatment or interaction with HIV or TB treatment. In more recent years, however, established communication between ETs, treatment providers and outreach teams has facilitated monitoring of treatment interactions and appropriate adjustment of OST, both of which have proved fundamental to engaging PWID in concurrent HIV, TB and drug dependency care.

### **Flexibility over treatment location**

Access to take-home medication had important implications for engagement in multiple treatment courses. While provision of take-home supplies made adherence easier, frustration was expressed by those who had to attend services daily and felt insufficiently trusted to adhere to treatment themselves. Meanwhile, the possibility to attend a treatment centre near one's home or workplace, and to transfer to a more conveniently-located service, improved attendance at HIV and TB services, emphasizing the value of a geographically flexible system of treatment delivery and integration. Co-located care, whether achieved through the 'combined' or 'collaborative' model, was highly valued. The opportunity to receive home-based DOTS and OST in combination was critical to adherence for immobile or physically weak clients:

*"They bring it [TB treatment] to my home. If I had to come here I wouldn't do it, and I would have to take two types of transport, or else get out at the town hall and then walk here. Even now I don't feel well, I have already gained 9 kg in weight ... She [the nurse] brings the tuberculosis one and the methadone ... I rarely came here to take it ... I had missed 3 or 4 [days] ... I came when I saw that I had to come or when I felt alright." (Maria)*

Provision of ART at CDPs or ETs was more 'sporadic' (service provider interview) and treatment delivery often continued in separate centres, although monthly dispensing of HIV treatment precluded the need for daily attendance at HIV clinics.

## ***5. Other factors shaping engagement in drug dependency, TB & HIV services***

The scope for integrated care was affected by a number of factors relating to service accessibility more broadly. The extent of social network and outreach support; recognition of client autonomy; patient-provider relationships; timing of testing and treatment provision; clients' treatment literacy; and the availability of broader social care played key roles in shaping access to HIV, TB and drug dependency care.

### **Social network support**

Information on where and how to seek care from ETs was often derived through familial and community networks. Knowing individuals who worked within the health system or social services allowed bureaucracy to be navigated and access expedited:

*“A woman that I know ... she met me in the street ... she looked at me and took a fright ... ‘What is this?’ I said like, ‘Well I already went to Santo Antonio Hospital, Sao Joao, they don’t say anything, I went to Santo Antonio and they tell me nothing, what am I gonna do? And she [said], ‘Do me a favour, when you get there to Santo Antonio, call for Célia! ... Do something, say my name three times ... you’ll see how they will send you to Joaquim Urbano hospital, Wood Lane.’” (Jeremias)*

Practical and moral support from friends and relatives was an important impetus for TB and HIV care-seeking, although a reluctance to attend health services often delayed attendance until reaching a point of critical weakness:

*“I’d already been at home for 3 months, a very strong cough and I had fever ... the girl I was living with, she said, ‘Ó, Miguel.’, go to the hospital’, and I [said], ‘I won’t go to the hospital, I don’t like it’ ... I got up, took my brother’s car ... went to the hospital, I was immediately hospitalized ... the doctor told me I had tuberculosis, if it [had] lasted kind of, a week [longer], I would pass away.” (Miguel)*

Familial support, however, was far from universal. For some, long-term drug use or disclosure of HIV status had culminated in exclusion from the family home and estrangement from parents, siblings and sometimes children. While peers could share concerns and exchange information on services, those who no longer used drugs were reluctant to spend time in environments in which others continued to do so, including support groups for PLHIV, for fear of ‘relapsing’. A lack of network support could result in a sense of isolation and fatalism, ultimately leaving vulnerable and physically weak individuals reliant on self-care:

*“I’ve already, already been a kind of a month or so without taking the medication [ART] ... Because there were some family problems and I lost my mind and it was, ‘I won’t take anything else, when I die, I die’, then I thought, ‘No, let me keep it on’.” (Miguel)*

The vital role of network support, and the implications of its absence for care-seeking and treatment adherence, points to the importance of social as well as health care interventions to engage PWID in HIV and TB care.

### **Client individuality and autonomy**

Although friends and relatives sometimes supported initial care-seeking, the decision to initiate OST was widely presented as a matter of self-responsibility, requiring individual desire to enact change (*“Methadone is everywhere ... You’re only not on methadone if you don’t want to [be] because it’s very easy.”* (Sara)). Attending services simply to please partners, relatives or peers were often unsuccessful or short-lived, while the few who had ‘recovered’ without treatment took pride in their sense of self-achievement (*“I did, I banged my head on the wall and that was that.”* (Jacinto)).

Engagement in HIV, TB and HCV services was characterised by varying degrees of client autonomy and service provider direction. Some PWID, particularly those who were actively using drugs and had difficulty managing a routine, placed importance on being ‘told’ to attend services:

*“I’ve got my sister who is more than a mother to me, right. But you see it’s not enough... I have got to have someone who is like ... ‘you must go to your appointment’... on my own if I*

*have to do it, I won't go! I won't! It's not that I don't have the will, I do! It's just that one day a person is withdrawing... you go down again, you start using again."* (André)

Others emphasized the role of individual responsibility and self-care, even in the context of supportive outreach services (*"I never went alone, always accompanied by people who wanted what's best for me. But ... it is only me who can want to change, nobody else can change me."* (Ricardo)), resonating with service providers' emphasis on the need to recognise clients' autonomy. Negotiation between PWID and service providers was apparent in a number of ways. Screening was mandatory in order to access sheltered housing and *GiruGaia's* outreach-based combined therapy programme. In ETs, convincing clients to accept screening required provision of sufficient information regarding its importance, though clients who were actively using drugs tended to prioritise withdrawal avoidance over less immediate health and social care needs:

*"It was also a two year struggle but we were able to get all our patients to be tested for everything here when they enrolled ... before they can begin any treatment that is the condition that we impose, we 'impose', I mean we ask people to collaborate and we explain how important it is ... to get the tests done and for them to be collaborative, they have accepted it ... they end up accepting it well."* (ET provider)

Typically, service providers emphasised engaging clients who miss appointments rather than refusing treatment, though persistent non-attendance at Joaquim Urbano hospital could result in warnings of HIV treatment interruption and the need to seek care in an alternative setting (JU provider interview). In the case of DOTS, negotiated 'adherence strategies' between patients and staff, including information on where the client could be located in the community if (s)he didn't attend an appointment, facilitated collaborative follow-up.

The individually-tailored nature of care, with careful negotiation between clients and service providers, was a recurrent theme across service user and provider accounts. However, there was no discussion of service user involvement in wider service design, planning and delivery.

### **Patient-provider relationships: care and felt stigma**

The relationship between PWID and the provider they viewed as their 'doctor' – typically a practitioner within a specialist treatment centre and/or someone with whom (s)he had a family link - was central to feeling valued within services, particularly where social networks were lacking. This linked closely with service providers' emphasis on recognising clients' individual needs and circumstances. Feeling known and treated equally helped clients feel accepted in specialist treatment centres:

*"We go there after so many years and people know me. [They say], 'Hi, how are you, everything alright?' ... It's these little details ... do you see? ... They don't look at us as sick people ... we're treated like people ... They have their lives outside, they have their friends outside, right, but they look at us like we look at them. There's no distinction."* (Jacinto)

Nonetheless, feared and enacted discrimination in general health care services remained a concern, despite considerable progress over recent years. Though many participants had positive relationships with doctors in hospital-based HIV clinics (*"[Santos Silva hospital]*

*has a doctor who is amazing, she doesn't do more because she can't*" (Miguel)), behaviour of other staff in these settings, embedded within mainstream hospitals, left some PLHIV feeling stigmatized ("*There are people who are working there, who are nurses, who seem to be disgusted to touch us ... That is discrimination.*" (Ricardo)). Outreach teams had noticed marked improvement in the way their clients were received by treatment services when referred or accompanied by outreach staff. However, this was not always sufficient to overcome clients' fears of embarrassment and stigma, in one case with fatal consequences:

*"Not long ago ... a young guy died ... in the terminal phase and that guy died saying that he never had any diseases at all ... Why? ... He smelled bad ... he was ashamed to go to the hospital ... many times the street team took him to the hospital and he'd arrive and run away because people would look at him ... 'what a smell'."* (Ricardo)

The welcome absence of discrimination in specialized treatment centres juxtaposed with continued experience of stigma in mainstream services highlights the importance of improving sensitivity of frontline health staff to PWIDs' needs and circumstances. Although collaboration with wider health services had improved over recent years, there was recognition of the need for increased involvement of general practitioners in the management of HIV, TB and PWIDs' other health needs.

#### **Timing of testing and treatment provision**

##### *Service capacity and eligibility*

Accounts of long-term PWID and service providers reflected dramatic changes in access to drug treatment services over the past two decades. ETs were initially heavily oversubscribed resulting in year-long waiting lists and, in some cases, overnight queuing outside centres. Although referral between ETs remains bureaucratic, requiring a client to attend the original centre in person to request a transfer, concerted investment in services and human resources has cut waiting times considerably in recent years. Access to TB services had also improved and was now typically timely ("*I arrived [at the CDP] on Friday, I came home on the weekend, on Monday I was seen by a lung doctor and on Tuesday I already had the bus pass to go there every day*" (Joel, male)). The capacity of HIV, TB and drug treatment services to offer testing and treatment without client identification facilitated prompt access to care:

*"We [CDP], not long ago, had a drug user who was homeless and had no identification card, no national insurance number, nothing, and he was seen, did all the tests and began treatment and in the meantime got all his documentation."* (CDP Provider)

However, restricted opening hours remained a barrier to attending services for treatment and consultations, particularly for those in employment with conflicting work schedules:

*"The second time that I had the tuberculosis was when I stopped taking the retroviral medication. I am sure that if I hadn't stopped I wouldn't have caught this. I stopped in the summer ... I would come home at 5 or 6 in the morning to be at the appointment at 8 or 9 which she would book. Sometimes I couldn't get up, I would fall asleep and not go."* (Maria)

Accessing initial HIV consultations by referral from an ET or a primary health care centre could take a month, though this was generally considered an acceptable waiting time by service providers and users. Initiating HCV treatment took considerably longer, in part

linked to the requirement to abstain from substance use during treatment, a particular barrier for outreach clients, many of whom actively used drugs.

### *Missed opportunities for HIV testing*

Although provision of HIV screening was typically prompt, a number of accounts highlighted missed opportunities for early diagnosis. Some long-term PWID received their first HIV test and diagnosis on entry into prison. While this highlights the effectiveness of prison-based screening, it reveals potential gaps in routine screening within the wider health system. For the few interviewees who had sought HIV testing in primary care services, a drawn-out referral process and feared unavailability of OST impeded access. Shortages of diagnostic supplies were very rare but on these occasions restricted capacity to offer rapid HIV testing at ETs, leaving service providers frustrated and concerned about clients' resulting sense of abandonment:

*"Once I had a dramatic situation, I think it is dramatic to not have [rapid test] kits for the HIV test ... actually this really marked [affected] me ... the patient had a risk behaviour and I wanted to test him but I didn't have the tests ... I was furious at the fact that I am the staff member who he had a relationship with, the person he came to, who he unburdened himself with, and I didn't have the kit! ... you feel like your hands and feet are tied ... I asked the committee to never let it happen again."* (ET provider)

A recent interruption in the supply of HIV diagnostic kits from the IDT temporarily reduced *GiruGaia's* capacity to provide rapid testing, however collaboration with the local CDP secured access to interim screening and a subsequent loan of test kits (outreach provider interview). A longer-term barrier was outreach teams' reliance on a fixed-site location for screening to ensure a sufficiently private and hygienic setting.

### **Treatment literacy**

Literacy around the purpose and value of HIV and TB treatment had important implications for uptake. Although most PWID began ART as soon as advised, feeling healthy and having difficulty accepting the diagnosis, coupled with a prior lack of treatment need, could delay initiation until reaching a point of critical weakness:

*"When they told me it was HIV ... I asked, "What is HIV?" HIV is AIDS. I wanted to kill myself and I didn't accept it ... I had the defenses, it wasn't necessary to take the medication, so I got it into my head, "Oh, I don't want it! ... I'm fine as I am!" ... In 2008, I was really forced to take it or else I would have died."* (Ricardo)

Information on the relative benefits of combined HIV-TB treatment could facilitate early initiation, although the perception that current drug use rendered ART 'pointless' could hinder uptake. Engagement in DOTS and, to a lesser extent, IPT was widely viewed as mandatory, underpinned by an awareness of its preventive role which could also protect family members and avoid prolonged future treatment:

*"I had to take preventative medicine. There were five pills, five Rifater or something, on an empty stomach in the morning, they actually made me quite ill but I had to take them ... it's like this, while I was taking it I had no problems of catching it [TB], you see, or developing it, but if I hadn't taken it nothing might have happened ... [or] it would've be well worse, I would have had to be treated for a lot longer."* (Marcelo)

Service providers, however, noted difficulties justifying preventive treatment to 'healthy' individuals.

In contrast with HIV and TB, HCV was characterised as ubiquitous, inevitable and 'normal', and therefore perceived as either not requiring treatment or being untreatable ("You can't do anything after you have it!"). Peers' negative accounts of treatment side-effects together with required abstinence from substance use often deterred or delayed uptake, echoing outreach teams' concerns:

*"It is not a very serious thing, it is something which drug takers are usually expected to catch sooner or later ... by listening to other people who had it and had done treatment, [it] is a bit painful, [their] hair fell out ... I was afraid of ... the physical tiredness, vomiting, sickness, changing sleep patterns ... so I was always postponing the treatment."* (Marcelo)

Service providers emphasized the need for renewed efforts to treat HCV among PWID, harnessing existing HIV and TB delivery systems, but also through better integration with drug treatment services and at the CTC, where a shared protocol was due to be developed.

#### **Addressing broader health and social care needs**

Interview accounts highlighted the importance of addressing broader health and social care needs to facilitate treatment adherence among PWID ("We cannot expect a patient that doesn't have food to adhere to a medication ... it is also important to secure other forms of social support." (São João Hospital provider)). Securing additional care, such as dental treatment, had been an important strategy used to motivate TB adherence. However, waning availability of support for health and social care in the face of government cuts was making it increasingly difficult for outreach teams to secure housing, social security benefits and other care for their clients:

*"Dental treatments are completely off the list, housing support ... [is] very rigid and almost none of our applications has been accepted because right now ... we are then left with hostels or a shelter in Porto, Casa Vila Nova ... we refer them to some community canteens [soup kitchens], we give them some food ourselves, and that's it ... financial aid for medicine, transportation, housing... most of them have been cut."* (Outreach provider)

This highlights the increasing vulnerability of PWID in this setting and the extent to which they depend on the support of drug treatment and outreach services.

## Discussion

This rapid assessment documented two models of integrated HIV, TB and drug dependency care for PWID. The first 'combined' model involves co-located, integrated provision of all services within a designated care centre. Shared patient management protocols and a co-located team of specialists facilitated provision of multidisciplinary care from the outset but this approach 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. 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.

Common factors facilitating integration included: collaboration, training and case management across specialties; development of informal professional networks and communication channels to minimize bureaucracy and expedite referrals; an adaptable, responsive approach to treatment delivery and location; uninterrupted provision of OST accounting for interactions with HIV/TB treatment; client-centred care involving patients in setting adherence strategies; the capacity of outreach teams to reach marginalised PWID and navigate access to multiple health services; provision of transport and food, and facilitated access to wider health and social care. Key remaining challenges to integration included bureaucratic formal referral channels; absence of written guidelines and shared protocols on integrated care; poor data collection between and within services, particularly in relation to indicators of integration; threats to funding for drug treatment and outreach services; and a lack of sensitivity and involvement of primary care staff in addressing the health needs of PWID.

Many of these factors resonate with the experiences of pilot integrated HIV-TB programmes for PWID in Ukraine [79]. In Portugal, the decriminalisation of drug use and widespread availability of OST, and more flexible conditions of its provision, remove important structural constraints and allows study of integration on a wider scale. The absence of accounts of police intervention in this assessment contrasts with experiences of PWID in Ukraine [79] and Russia [29], where harassment and arrest of OST clients posed a major barrier to treatment access and integration. Different settings require context-specific approaches to integrated care for PWID, adapted to local health systems and political environments. This assessment documents a model of collaborative HIV, TB and drug dependency care delivered through existing vertical delivery systems, offering an alternative to the 'one-stop shop' approach which poses financial, logistical, managerial and human resource constraints to health systems in some settings [80].

In Porto, the scope for integrated care was also shaped by a number of factors relating to service accessibility, including social network and outreach support; recognition of client autonomy; patient-provider relationships; timing of testing and treatment provision; clients' treatment literacy; and the availability of broader social care. The importance of social outreach interventions in reaching PWID is widely recognised [81, 82]. This assessment illustrates the pivotal role outreach services can play in facilitating access to

and integrated delivery of HIV-TB and other health care, when integration into one facility is not possible or optimal. The role of social support in prompting care-seeking also suggests scope for network interventions in this setting. Peer education among PWID has been shown to improve IPT adherence [83], reduce HIV-related risk behaviours [84], increase ART adherence [85] and engage clients in HCV care within a multidisciplinary care centre [86]. A client-centred approach, recognising clients' individuality and involving them in decisions regarding their care, is likely to foster trust and engagement in services and ultimately facilitate integration. However, there is a need for wider client involvement in the design, planning and delivery of harm reduction, drug dependency treatment and HIV-TB services, in order to maintain and improve the quality and accessibility of care. This approach has proved highly successful in Australia among other settings [87]. The potential for pharmacy-based DOTS to engage PWID in treatment in the community, which has proved successful in Spain [88], also warrants further attention in Portugal and elsewhere.

HCV treatment was 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 are important barriers to treatment uptake, as documented in other settings [89], and need to be addressed to improve access to HCV treatment among PWID. Provision of OST in combination with HCV and HIV-HCV care improves treatment uptake, adherence and outcomes [26, 27].

PWID form a large minority of PLHIV and a significant proportion of TB patients in Portugal. Although rates of MDR-TB are low in Portugal relative to the rest of Europe [41], the high proportion of extreme drug resistance among these cases, both in PWID and the wider population [90], poses a threat to TB control and warrants further attention. Targeted HIV testing in drug treatment centres and collaborative TB-service-led efforts to increase TB case detection have improved screening coverage among PWID [43], and the vast majority of PWID 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. There is a clear need for increased focus on TB within drug treatment and HIV services, improved data-sharing mechanisms between services, and expanded infectious disease surveillance among PWID, in order to improve provision and monitoring of integrated care.

### *Study limitations*

Scarce data on screening and treatment specific to PWID limited the extent to which service integration could be assessed quantitatively. This was itself, however, an important finding of the assessment resulting in key recommendations for improved data collection and information sharing across services.

PWID we interviewed were on average older than those seen in drug dependency treatment services, were all Portuguese and of white ethnicity, many had stopped injecting drugs, and all were in contact with health or support services. These accounts therefore do



not capture experiences of younger, current injectors not in contact with services. Injecting drug use in Portugal appears to have declined considerably in recent years but many former injectors remain on methadone treatment and in need of HIV and TB treatment. This study allowed us to explore this cohort's experiences of HIV, TB and drug dependency care and how these have changed over time. Recruitment via outreach services enabled us to interview a number of more marginalised PWID with complex health and social care needs.

Interviews with providers reflected distinct services agreeing to participate in this assessment. Individuals working collaboratively with other agencies may have been more inclined to take part and may not be reflective of all such treatment centres in the area or indeed the rest of Portugal. However, purposive inclusion of experts from services representing different modes of service delivery and integration enabled us to explore contrasting models of HIV and TB service provision for this population.

## *Implications for practice and intervention*

### **Developing guidelines on integration**

There are two models identified in this rapid assessment that could 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. The relative advantages and disadvantages of each model need to be considered and discussed with PWID when establishing the most appropriate integrated service delivery for each individual. The development of local, national and regional 'good practice' guidelines building on these experiences, emphasizing the importance of context-specific approaches, is likely to increase the consistency and scope of integrated care in Portugal and elsewhere. These guidelines need to reflect the importance of: multi-agency collaboration, harnessing existing professional networks to develop mechanisms for expedited and integrated access to services; uninterrupted provision of drug dependency treatment accounting for HIV-TB-OST treatment interactions; a client-centred approach recognising clients' autonomy; and the key role of outreach programmes to ensure access for the most marginalised PWID.

### **Improving integration of services in Porto**

#### *Expanded TB and HCV screening*

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.

### *Improved health information systems*

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 the HIV, TB and other health-related needs of this population.

### *Streamlining referral mechanisms*

This assessment has documented positive examples of informal communication channels between treatments and outreach services working with PWID. However, written referral procedures and the requirement for clients to attend an ET in person before being referred to a second centre are important barriers to referral. Efforts to reduced bureaucracy and streamline referral mechanisms are key to ensuring efficient and timely delivery of care.

### *Client-centred care and user involvement*

The findings of this assessment illustrate the feasibility of client-centred care for PWID, through recognition of individual needs and circumstances. Flexibility over take-home medication for those who have the capacity, or social support, to manage their own adherence is likely to reinforce trust between client and provider. Ensuring clients have a stake in their own care is likely to improve engagement in services, provided that their sense of agency is recognised and valued. Involving clients and PWID representative groups in service design, delivery and evaluation would help to sustain and enhance the quality and accessibility of care. Peer-based health promotion regarding TB symptoms and available treatment, drawing on narratives of preventive and public health benefits, could also help to encourage TB care-seeking among this population.

### *Renewed focus on HCV*

Poor access to and uptake of HCV treatment among PWID warrants 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. Better integration of HCV into HIV, TB and drug treatment services is likely to facilitate this approach but will require financial and political commitment.

### *Tackling stigma and increasing the involvement of primary care*

The potential for wider involvement of primary care in HIV and TB care, in close collaboration with specialised treatment services, warrants consideration. 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. Felt stigma in mainstream health services, and the relatively more positive reception of clients referred from outreach teams, highlights the need and potential for specialist services to work with primary, secondary and tertiary care centres to improve understanding of PWIDs' health care needs and challenge discrimination.

### *Ensuring access to social care services*

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. Financial cuts to government benefits and funding for drug user support services have already begun to be experienced by PWID, treatment and support services. The proposed closure of the only ET in Gaia raises concerns regarding the accessibility and integration of services in this area. Integrated care relies heavily on NGO-funded outreach programmes which may be particularly susceptible to fluctuations in funding. It is critical that these concerns be considered and funding strategies developed to ensure that access to HIV, TB and drug dependency care is not compromised among already-marginalised people who use drugs in Portugal.

### *Conclusion*

Integration of HIV, TB and drug dependency treatment services offers clear benefits to the accessibility and quality of care for PWID. Widespread access to OST in specialised health care and community settings, the involvement of outreach teams, a client-centred approach and effective multi-agency collaboration are key to delivering effective combined care. Beyond integration of treatment services, social interventions which involve social support and promote dignity are key to ensuring access. Portugal's experience is set within the context of a harm reduction framework and decriminalised personal drug use. The availability, scale-up and flexible provision of OST, engagement with civil society organisations and the capacity, resources and will for inter-service collaboration at local and national levels will strongly influence the scope for integrated care in other settings.

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