

**MSS**

**MESTRADO EM  
SOCIOLOGIA E SAÚDE**

UNIVERSIDADE DO PORTO  
FACULDADE DE MEDICINA  
FACULDADE DE LETRAS

Ana Tenreiro de Avelar Fernandes Martins

**Voices on stigma: Injecting drug  
users and the impact of infectious  
diseases**

Porto, Outubro 2011

# **Voices on stigma: Injecting drug users and the impact of infectious diseases**

Dissertação de candidatura ao grau de mestre em Sociologia e Saúde apresentada  
à Faculdade de Medicina da Universidade do Porto

Ana Tenreiro de Avelar Fernandes Martins

Porto, Outubro 2011

Investigação realizada no Departamento de Epidemiologia Clínica, Medicina Preditiva e Saúde Pública da Faculdade de Medicina da Universidade do Porto e no Instituto de Saúde Pública da Universidade do Porto (ISPUP), sob orientação do Professor Doutor Henrique Barros.

Esta dissertação foi efectuada com base num projecto financiado pela Organização Mundial da Saúde – Europa, coordenado pela London School of Hygiene and Tropical Medicine, pelo Departamento de Epidemiologia Clínica, Medicina Preditiva e Saúde Pública da Faculdade de Medicina da Universidade do Porto e pelo ISPUP.

## **Agradecimentos**

Ao Professor Henrique Barros, por todas as oportunidades que me deu e que tanto me têm feito crescer.

À Dra. Susana Silva, pelo incentivo e encorajamento constantes.

À Cláudia Carvalho, pelos importantes contributos na área da epidemiologia.

A todos os entrevistados que se disponibilizaram a partilhar as suas histórias, o meu profundo agradecimento.

Aos meus amigos, que são os melhores do mundo. Um abraço gigante à Ana Juzze e ao Gil, pelas barreiras que me ajudaram a ultrapassar.

À minha Mãe, que é o meu pilar.

## Contents

|   |           |
|---|-----------|
| <b>Resumo.....</b>  | <b>1</b>  |
| <b>Abstract.....</b>  | <b>3</b>  |
| <b>1. INTRODUCTION .....</b>  | <b>5</b>  |
| <b>1.1. Illicit drug use: explanations for the addiction .....</b>  | <b>6</b>  |
| <b>1.2. Epidemiology of injection drug use and Infectious Diseases among<br/>People who inject drugs.....</b>   | <b>9</b>  |
| <b>1.3. People who inject drugs and infectious disease related stigma .....</b>   | <b>15</b> |
| <b>1.4. Framing the Portuguese legal context and the health services used by<br/>PWID in two Portuguese cities – Porto and Vila Nova de Gaia.....</b> | <b>19</b> |
| <b>2. AIMS .....</b>  | <b>25</b> |
| <b>3. METHODS.....</b>  | <b>27</b> |
| <b>4. RESULTS AND DISCUSSION .....</b>  | <b>36</b> |
| <b>5. CONCLUSIONS .....</b>   | <b>49</b> |
| <b>6. REFERENCES .....</b>  | <b>51</b> |
| <b>7. APPENDIX .....</b>  | <b>59</b> |
| Appendix no.1 - Geographic distribution of HIV, TB, HCV and harm reduction<br>services in Porto and Vila Nova de Gaia.....                            | 60        |
| Appendix no.2 – Informed consent sheet .....  | 61        |
| Appendix no.3 – Information sheet.....  | 63        |

## List of Figures

|  |    |
|--|----|
| Figure 1 – Prevalence of injecting drug use .....  | 9  |
| Figure 2 – HIV Infections per 100.000 population: PWID cases, 2009 .....   | 11 |
| Figure 3 – Number of cases infected with HIV who were notified (year of diagnostic) and categories of transmission in Portugal ..... | 12 |
| Figure 4 – Prevalence of Hepatitis C among PWID in Europe, 2008-2009.....  | 14 |
| Figure 5 – HIV, TB, HCV and drug treatment services and referral channels in Porto area..  | 23 |
| Figure 6 – Data analysis categories .....  | 34 |

## List of Tables

|   |    |
|---|----|
| Table 1 – Hepatitis C prevalence among PWID, 2009 .....                 | 14 |
| Table 2 – Interview participants' status and treatment experience ..... | 31 |

## Abbreviations

**AC** – Asymptomatic carriers

**AIDS** - Acquired immune deficiency syndrome

**APA** – American Psychiatric Association

**ARV** - Anti Retroviral Therapy

**BCG** - Bacillus Calmette-Guérin

**CAD** – Centro de Aconselhamento e Detecção Precoce do VIH (Counselling and HIV Early Detection Centers)

**CDP** – Centro de Diagnóstico Pneumológico (*Pulmonary Diagnostic Centre*)

**CTC** – Centro Terapêutica Combinada (Combined Therapy Centre)

**DOTS** - Directly Observed Treatment

**EMCDDA** – European Monitoring Centre for Drugs and Drug Addiction

**HCV** – Hepatitis C Virus

**HIV** - Human immunodeficiency virus

**IDT** - Instituto da Droga e Toxicodependência (*Institute for Drugs and Drug Addiction*)

**ISPUP** –Institute of Public Health of the University of Porto

**LSHTM** – London School of Hygiene and Tropical Medicine

**MSM** – Men who have Sex with Men

**NSP** - Needle and Syringe Exchange Program

**OST** - Opiate substitution therapy

**PNT** - Programa Nacional de Tuberculose (*National Programme Against Tuberculosis*)

**PWID** – People Who Inject Drugs

**SPTT** - Serviço de Prevenção e Tratamento da Toxicodependência (*Service for the Prevention and Treatment of Drug Addiction*)

**TB** –Tuberculosis

**TT** – Treatment Team

**WHO** – World Health Organization

## Resumo

**Introdução:** O fenómeno da adição de drogas é visto como um problema global nas sociedades contemporâneas. Pessoas que injectam drogas são particularmente vulneráveis a um número de doenças infecciosas como as que são transmitidas por via sanguínea (nomeadamente o VIH e a Hepatite C) e infecções respiratórias como a tuberculose. Pessoas que usam drogas e vivem simultaneamente com uma doença infecciosa (VIH, Tuberculose e Hepatite C) têm sido discriminadas devido à sua condição, criando-se um múltiplo estigma.

**Objectivos:** Esta investigação teve como objectivo principal analisar os significados e as experiências de estigmatização construídas pelas pessoas que usam drogas injectáveis e como objectivos específicos: 1) analisar o impacto de viver com uma doença infecciosa nos significados e experiências de estigmatização construídos pelas pessoas que usam drogas injectáveis; 2) explorar a hierarquia estigmatizante das doenças infecciosas construída pelas pessoas que usam drogas injectáveis.

**Métodos:** A investigação foi realizada no âmbito de um Rapid Assessment. Foi utilizada uma amostragem intencional no sentido de recrutar uma gama variada de utilizadores de drogas injectáveis com historial presente ou passado. Entre Dezembro de 2010 e Março 2011, os participantes foram recrutados por profissionais de saúde que trabalhavam em nove serviços de tratamento de VIH, Tuberculose, Hepatite e outros serviços de redução de riscos localizados na cidade do Porto e Vila Nova de Gaia, Portugal. Entrevistamos 30 participantes cuja média de idades foi de 40 anos (entre os 31 e os 52), a maioria dos quais eram do sexo masculino (26).

Identificamos um conjunto de categorias que entendemos concorrer para a construção da categoria central de análise deste estudo – estigma. Através de uma estratégia em rede, de interactividade crescente, abordamos dimensões capazes de apreender os impactos do estigma nos participantes. Os significados atribuídos a cada uma das categorias de análise acessórias constituem um quadro interpretativo através do qual conseguimos simultaneamente decompor e complexificar as percepções dos indivíduos.

**Resultados:** Os participantes descreveram uma multiplicidade de sentimentos provocados pelo momento de diagnóstico com o tempo, no caso dos sentimentos negativos identificados – raiva, medo e rejeição de si – a ser elemento auxiliador na familiarização com a doença. A neutralização foi, também, uma das formas de encarar o diagnóstico. Verificou-se que o processo de revelação foi gerido de formas distintas pelos participantes que, optaram por não revelar pelo medo da reacção que poderiam obter do outro, e os que contaram às famílias e amigos, tendo conseguido o seu apoio, ou não. Vários relataram discriminação

por serem portadores de doenças infecciosas, especialmente VIH, devido à falta de informação, ou menor literacia em saúde dos mais próximos e da sociedade em geral. A discriminação, afirmaram, ocorre igualmente nos contextos de saúde. Uma hierarquia das doenças infecciosas, em que o VIH assume predominância quando comparado com a Hepatite foi identificada nos discursos dos entrevistados.

**Conclusões:** O conhecimento das redes de sociabilidade dos portadores de doenças infecciosas sobre as condições de contracção e contágio das mesmas assume peso relevante como factor explicativo para a eliminação da estigmatização que recai sobre as pessoas que vivem com as infecções. Assim, o aumento da literacia em saúde constitui um factor vital para a redução da discriminação e estigma associado aos utilizadores de drogas e, cumulativamente, portadores de doenças infecciosas.

Verifica-se uma noção de hierarquização das doenças infecciosas, sendo que a percepção de maior gravidade é associada ao HIV. A hepatite C é, através de um imaginário social, assumida como consequência do uso/ consumo de drogas por via injectável, pelo que é mais facilmente aceite pelos indivíduos, assim como a noção de gravidade que lhes está associada. Desta forma, parece-nos existir uma grande possibilidade de intervenção através de políticas de redução de riscos para que esta realidade possa ser diferente no futuro.

## Abstract

**Introduction:** In the contemporary societies, the drug addiction phenomenon is seen as a global problem. People who inject drugs are particularly vulnerable to a number of infectious diseases such as blood-borne viral infections (namely HIV and HCV) and respiratory infections such as tuberculosis. People who use drugs and simultaneously live with infectious diseases (HIV, TB, HCV) have been discriminated against because of their condition, creating a multiple stigma.

**Aims:** This research aimed to analyze the meanings and experiences of stigmatization constructed by people who use drugs and as specific goals: 1) To analyze the impact of living with an infectious disease on the meanings and experiences of stigmatization constructed by people who use drugs;

2) To explore the stigmatizing hierarchy of infectious diseases constructed by people who use drugs.

**Methods:** The study was conducted under a Rapid Assessment method. A purposive sampling was done to recruit a varied range of people who had injected or still inject drugs. Between December 2010 and March 2011, participants were recruited by health professionals working in nine HIV, Tuberculosis and Hepatitis treatment centres and other harm reduction services located in Porto and Vila Nova de Gaia. We interviewed thirty participants with an average age of 40 years old (ranging between 31 and 52), most of whom (26) were male.

We identified a set of categories, we believe to be convergent in building the central category of stigma analysis. Through a network strategy, of increasing interactivity, we approach dimensions able to apprehend the impact of stigma in the participants. The meanings assigned to each one of the accessory categories of analysis constitute an interpretive frame from which we can simultaneously decompose and complexify the perceptions of individuals.

**Results:** Participants described a multiplicity of feelings provoked by the moment of diagnostic, with time, in the case of negative feelings identified – anger, fear and self-rejection – being the auxiliary element in order to familiarize with the disease. Neutralization was also, one of the ways to face the diagnosis. It was found that the development process was managed differently by the participants who chose not to reveal for fear of reaction they might get from another, and who told the families and friends, having succeeded in their support or not. Many reported discrimination for being infectious disease carriers, especially HIV, due to the lack of information, or lower health literacy from those closer and from society in general. Discrimination, they stated, occurs equally in healthcare settings. A hierarchy of

infectious diseases, where HIV assumes predominance when compared with Hepatitis C, was reported by the interviewees.

**Conclusions:** The knowledge of social networks on the conditions which one can contract the disease and the contagion of infectious diseases, assume a relevant weight as an explainable factor to the elimination of stigmatization by these same networks. Therefore, the increase in health literacy constitutes a vital factor for the reduction of discrimination and stigma associated to drug users and, cumulatively, carriers of infectious diseases.

A hierarchy of infectious diseases is notorious, being that the perception of greater severity is associated with HIV. HCV is, through a social imagery, assumed as a consequence of use/consumption of injectable drugs, so they're easier to be accepted by individuals, as well as the notion of severity associated to it. Thus, it seems to exist a great possibility to intervene through risk prevention policies in order to change the current situation.

# 1. Introduction

## 1.1. Illicit drug use: explanations for the addiction

In the contemporary societies, the addiction phenomenon is seen as a global problem, being the health area, one that pays special attention to it. In a social point of view, although there are addictions that are socially accepted, others are subject to penalties (moral and/or criminal), which can be explained by the level of acculturation that many of those behaviours suffered over time. As an example, alcohol is commonly accepted in western societies, opposed to substances that appeared more recently, like heroin or cocaine, particularly with its injectable way of administration.(1)

The World Health Organization refers that an addiction consists “in a repeated use of a psychoactive substance or substances to the extent that the user (referred to as an addict) is periodically or chronically intoxicated, shows a compulsion to take the preferred substance (or substances), has great difficulty to voluntarily ceasing or modifying substance use, and exhibits determination to obtain psychoactive substances by almost any means”(2) So, the addiction is related with the exposure to a stimulus and a restatement of expositive behaviours to that same stimulus until – and after a phase of adaptation is surpassed – an addiction routine is established. Regarding drug dependency, the term “craving” applies, which is an irreprehensible desire to consume a drug or feeling its toxic effect. (3)Therefore, the matter it’s not only in the simple fact of consuming a product, but the presence of a need or an inner pressure that inevitably forces an individual to look for a drug and to consume it. To support what the World Health Organization has referred to, it can be said that the modifications caused by drug consumption, when perceived as pleasant or as a soothing effect regarding a physical or psychic unease, have a strong effect of positive reinforcement about its own consumption, which can become progressively more important in the scale of motivations of a drug addict, leading to a transgression of social and moral conventions previously respected, and modifications of patterns of behaviour and socialization. (4)

There are many approaches that try to explain the motives by which people become drug addicts.(5)

The first theoretical line relates to the neurobiological effects of drugs, explaining the dependence at a biological level. The “primary actions” in the brain are different according to the kind of drugs that are used. (5)Two major routes, however, are common to most drugs: the dopamine reward system, with the effects of cocaine being associated with an increase of the dopamine function (6) and the endogenous opioid system, which play an important part in drug uses. Exogenous opiates like heroin, work as opiate receptor agonists, causing a fast tolerance and dependence. The opiate receptors adapt very easily after chronic use of opiates, as seen in the need to use larger quantities to achieve pain relief or euphoria.(7)

With biologically biased analysis, the physiological conditions of individuals cannot be neglected as important locus to the differentiated occurrence of the consumption effects. However, not every individual is equally exposed to addiction, meaning that the incidence of addictive behaviours will be as big as an individual's proneness to certain stimulus or, the greater the correspondence between the stimulus and the need for satisfaction that the individual feels.(8)

One hypothesis regarding drug dependence is that the increased likelihood (vulnerability) to develop dependence on substances may be inherited. Referring to heroin, authors(9) explain heroin addiction vulnerability caused by an unspecified, possibly inherited, metabolic deficiency. Another theory on drug dependence is based on the concept of neuroadaptation (7) – referring to changes in the brain occurring in opposition to a drug's acute actions after repeated administration – and argues that tolerance to the effects of a substance and withdrawal when drug use stops, result from that conception.

Supported by the theories at biological level, a substance user, namely a heroin drug addicted, is considered a victim of physiological reactions, continuing to use the drug to protect himself from the affliction of withdrawal.(9)

The second approach is intimately related with the psychological dimension. The explanations are mainly centered in behaviour models and individual differences, and have often been based on concepts common to other behavioural syndromes that involve compulsive or impulsive behaviours, such as obsessive-compulsive disorder or gambling. (5, 9) One central aspect of drug dependence is the fact that the individuals have weakened control over their use of the substance. This can be translated in a continued use of the drug even though there is a willingness to reduce or stop the dependency, to use greater amounts than intended, or to use it for longer periods than intended. (10)

This way, addiction results from the close relation between powerful substances and individuals with little control over themselves. (8) Here lies the theory that as long a consumer chooses what to do and when to act, the addict is "forced" to do it, creating the identity of the person as an "addict". Some authors assume that the addiction leads to a process where the addict forms and maintains his own identity, meaning that if one stops with his practices, he stops being himself altogether.(11)

In contrast, arises the theory that drug-dependent persons do make rational choices in their continued use of drug substances. These theories aim to explain how people can become "knowingly trapped in a consumption pattern (...) and (...) once they realize that their current lifestyle is actually suboptimal, still continue to act the same way" (11).

Finally there is the sociocultural approach, explaining how cultural and environmental factors make drug dependence more likely.(5, 12)

In this model, even though it is given relevance to the argument of addicts' loss of control over themselves, it is decentered from neuropsychological conditions of an individual, considered only by itself, to assign centrality to the social constraints, to the environment, recognizing that social and cultural contexts influence the exposure to the addiction. (13, 14) This way, the focus is on social and situational conditions, which make the addiction more, or less likely. It is evidenced that the social contexts in which they developed and expressed the addiction are important.

The sociocultural theories emphasize the role of the community in which one lives, its history, institutions and traditions in the causes of drug addiction, namely heroin. The sociocultural environment states drug availability and its degree of access: A study has shown that an important factor in determining who may become addicted is the drug availability to certain groups (15) influencing also the continued use. Other author (16) found that, out of a sample of heroin addicts who stopped using it, over 50% did so because of heroin's unavailability in their community.

The Biopsychosocial model is a comprehensive model of addiction (5, 17) which aggregates genetic, psychological and sociocultural explanations. In 1987, the American Psychiatric Association admitted that dependencies on psychoactive substances were considered mental disorders, of bio-psycho-social nature. (18) The existence of this model recommends the existence of an interaction between product, consumer and environment. As an analogy, Cassel, in the field of epidemiology also recognized the emergence of a physical illness which can be a consequence between host, agent and environment. (19) Currently, the bio-psycho-social model of the causes of addictive behaviours forms the basis of most treatment responses to addictions. (5)

According to the presented theories, the biological, social and psychological dimensions of the substance use disorder, as well as the possible interactions between these dimensions, gain a prominent place on the main objective in order to realize that this is a changing concept and (re)constructed socially and culturally. The theoretical approaches reinforce that whether we approach a biologically biased analysis, whether we give more importance to conjunctural factors, we should assume that the addictive behaviour depends on external factors, as well as internal to the individual. (5, 12)

In a sociological point of view, different than the one presented by the "disease model", which sees dependency as a disease, that dependency can be seen as social alienation. (1). Anyway, nowadays it's no longer possible to think that addiction to psychoactive substances only concerns the individual itself. (20)

In the next sub chapter, we'll focus in the addiction phenomenon embodied by injectable drugs consumption, evidencing its own epidemiology. The infectious diseases associated to the use of injectable drugs will also be addressed.

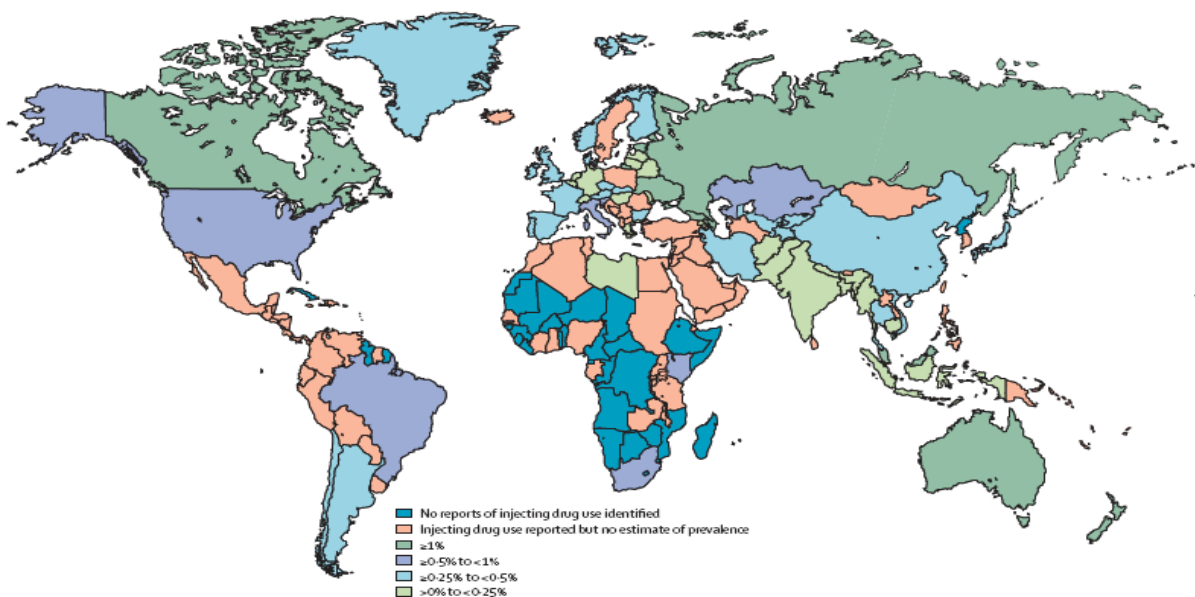
## 1.2.Epidemiology of injection drug use and Infectious Diseases among People who inject drugs

The use of illegal substances by injection – a method of administration where with the same amount of drug it is possible to get more intense and faster effects than by smoking – had its origin in the United States of America (USA), around the 1930s. Comparatively, in Europe the phenomenon took place later, having spread during the late 1950s. (21)

Only in the 1980s, with the rapid growth of heroin use by injection and with the spread of the human immunodeficiency virus (HIV), this behaviour became relevant as a central element of the drug problem in Europe, taking on the shape of a social problem. (21)

In 2009, the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) estimated that worldwide , the number of problematic drug users (described as injecting drug users or long duration/regular users of opioids, cocaine and/or amphetamines)(22), ranged between 15 and 39 million (0.3% to 0.9% of the population aged 15-64 years old).(23)

Figure 1 exemplifies the prevalence of injecting drug use world-wide, showing variations in different countries, China, USA and Russia having the largest number of PWID.



**Figure 1 – Prevalence of injecting drug use**

Source: Global epidemiology of injecting drug use and HIV among people who inject drugs: a systematic review

In Portugal, it was by the end of the 1980s and during the 1990s that the structure of intravenous consumption consolidated.(24) At that time, intravenous drug use became quite visible in some communities and the strong association of injecting drug use with the HIV epidemic was also noted. (21, 25)

National estimates show over a 50% decline in the number of PWID between 2000 and 2005, from 32,287 to in the region of 14,500 (13,395 – 15,972). In 2005, a national survey estimated that 6.2-7.4 per 1000 inhabitants aged 15-64 engaged in problem drug use) and 1.5-3.0 per 1000 inhabitants injected drugs. (26, 27) The positive evolution of the data seems to reflect the strategy of decriminalization of drug use, carried out in 2001 (24, 28) (see section 1.4 of this chapter).

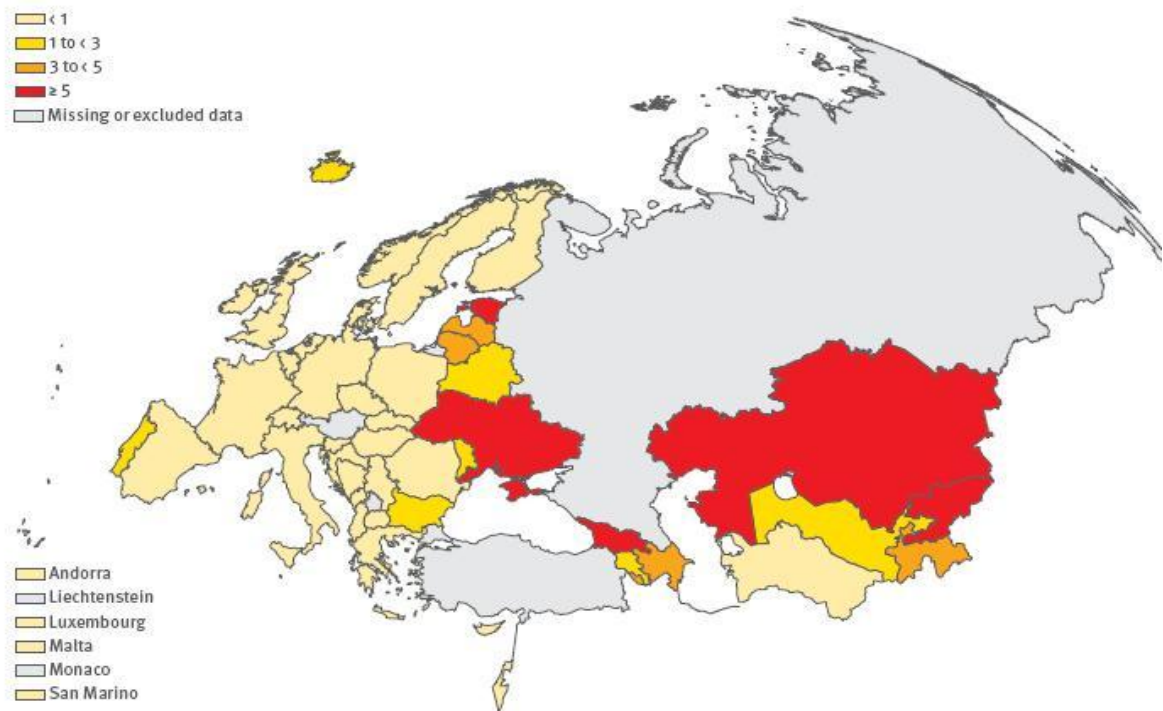
PWID are particularly vulnerable to a number of infectious diseases such as blood-borne viral infections (namely HIV and HCV) and respiratory infections such as tuberculosis. This risk relates to overlapping individual, social and structural factors. Besides risk behaviors associated with drug use itself (where the phenomenon of “polydrug use” or multiple drug use is included<sup>1</sup> (2, 29)), poverty, homelessness, overcrowding and imprisonment are key determinants for the acquisition of these diseases.(22) Also, active injecting drug use often reduces access and adherence to, and retention in, treatment programs, contributing for the higher morbidity and mortality rates observed among drug users, when compared to those who do not use drugs. (30)

We will now focus on epidemiological data referring to three infectious diseases commonly present in PWID, namely HIV, Tuberculosis (TB) and Hepatitis C Virus (HCV).

The global estimated prevalence of HIV in PWID is of 17.9%, corresponding to a number of people of 2.8 million, meaning that nearly one in five PWID lives with HIV infection.(23) In Europe, HIV infection remains of major public health importance, with a continued increase in the number of HIV cases diagnosed and reported. However, the predominant transmission mode varies by country and geographical and epidemiological area, with sexual transmission among MSM (men who have sex with men) dominating in some countries and heterosexual transmission dominating in others. In the East, the number of HIV cases has continued to increase substantially and injecting drug use accounts for the majority of the infections. (31)

---

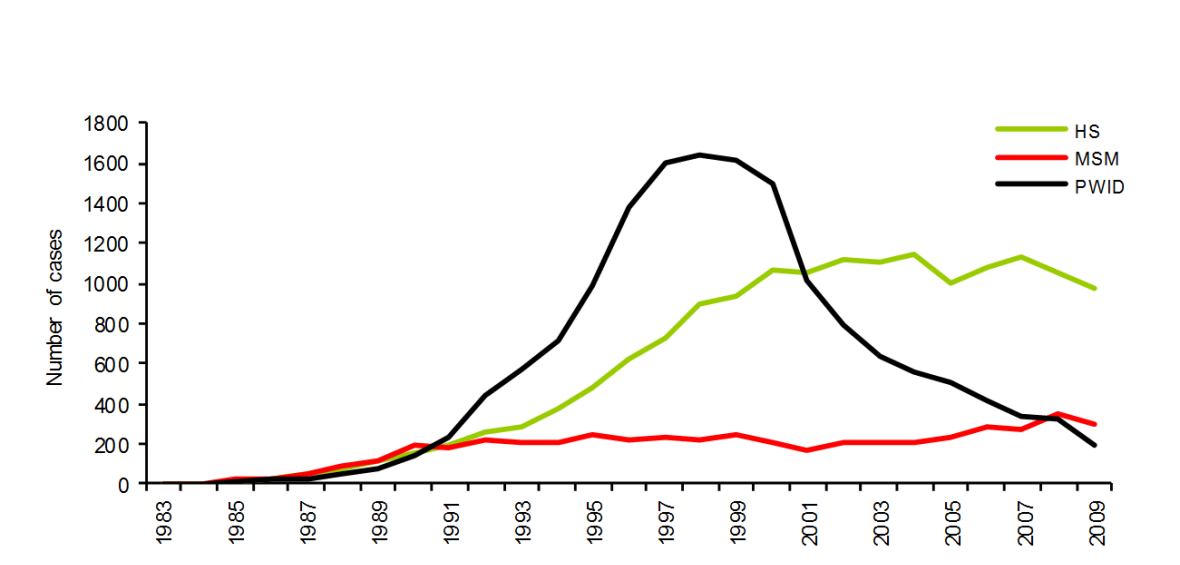
<sup>1</sup> Polydrug use is described by the use of more than one drug by one individual, often at the same time or sequentially, usually with the intent to enhance, accentuate or counteract the effect of another drug.



**Figure 2 – HIV Infections per 100.000 population: PWID cases, 2009**

Source: HIV/AIDS surveillance in Europe 2009 – ECDC

Injecting drug use has been an important driver of the HIV epidemic in Portugal, to date accounting for approximately 40% of cumulative cases (39 347 up to December 2010). In the cumulative total of reported AIDS cases, of symptomatic non-AIDS and Asymptomatic Carriers (AC), the addict population represented, respectively, 47%, 35% and 39% of the cases. However, the proportion and number of HIV cases associated with PWID notified to the national surveillance system has steadily declined over the past decade. (32)



**Figure 3 – Number of cases infected with HIV who were notified (year of diagnostic) and categories of transmission in Portugal**

Source: Data based in National Health Institute Dr. Ricardo Jorge

According to national surveillance data, 14.4% (n=147) of the HIV cases diagnosed and notified in 2010 were attributable to injecting drug use (all stages of infection included: AC, Symptomatic non-AIDS and AIDS). By comparison, during the same period, the heterosexual transmission was responsible for 60% (n=612) of the reported cases, and sex between men for 21.3% (n=217). (32) The district of Porto is the second most expressive in the cumulative total of reported cases of HIV infection association with drug addiction, recording 30% of cases, with only Lisbon surpassing this number (33%). Until the end of 2009, 83% of HIV infection cases resulting from situation of drug use were male, 94% of them aged between 20 and 44 years old. (33)

The continuous decline in the number of notified HIV infections associated with drug use is attributable in part to the implementation of harm reduction strategies, widely available in the country. (see section 1.4 of this chapter)

## **Tuberculosis**

PWID are at high risk of latent TB infection and are considerably more likely to develop active TB disease than the general population (34) and this is primarily due to high rates of incarceration, homelessness and poverty, all of which are factors that increase the risk of TB.(22) Among injecting drug users living with HIV, TB is a leading cause of mortality, showing that HIV infection dramatically increases progression to TB disease. TB-associated

mortality rates are several times higher among drug users living with HIV than among other people living with HIV. (34, 35)

As far as Portugal is concerned, until 2009, opportunistic infections represented 92.9% of the pathologies seen in drug users living with AIDS, with tuberculosis in the top of the list of infections. (32)

In 2009, the national TB programme (PNT) reported 587 cases of active TB among people who use drugs, representing 17% of national cases. Almost all drug users with TB (94%; 552/587) were aware of their HIV status and over half (57%) were HIV-positive. (36)

In 2010, 1.5% of first-visit drug treatment centres clients and 1.3% of repeat-visit clients tested positive for TB.(37) However screening rates were low (6% (1793/29,539)) among repeat visit clients and 6.4% (540/8444) among first-visit clients), TB type is not reported (latent/active, prevalent/incident) and data are not stratified by experience of (injecting) drug use. Although no national data are available specific to PWID, the Pulmonary Diagnostic Centre (CDP) in Vila Nova de Gaia, has published data specific to this population. Between 2005-2007, latent and active TB was diagnosed in 19% (96/495) and 12% (59/495) of PWID accessing the treatment centre, respectively. (38)

## **Hepatitis C**

HCV affects around 130-170 million people worldwide, representing 2.2%-3.0% of the global population.(39) Although HCV and HIV have different viral properties and clinical outcomes, they share parallel risks, and their epidemic follows a similar path. HCV is five times more widespread world-wide than HIV, probably because it is more infectious and has been present for longer in human populations. (23)

Infections, such as Hepatitis C, cause concern in terms of public health, giving rise to considerable morbidity and mortality among drug users, and being a major cause of liver disease with the potential for considerable ill health effects and premature death. (39) In developed countries, injecting drug use is the main route for the transmission of HCV. (23, 40)

As shown in table 1, the estimated prevalence of Hepatitis C among PWID worldwide is of 50.3% (range: 45.2% -55.3%), equivalent to 8 million people (range: 7.2 - 8.8 million), being known that the prevalence is also high among PWID in Europe. (23) From 28 countries with reported data, the average level of infection of HCV among injecting drug users is 47.0%, eight out of the 28 countries have prevalence rates above 60% and five over 70%. Africa and Oceania have the highest rates at 73.2% and 63.8% respectively, although the number of countries reporting rates from these two regions is very low. (27)

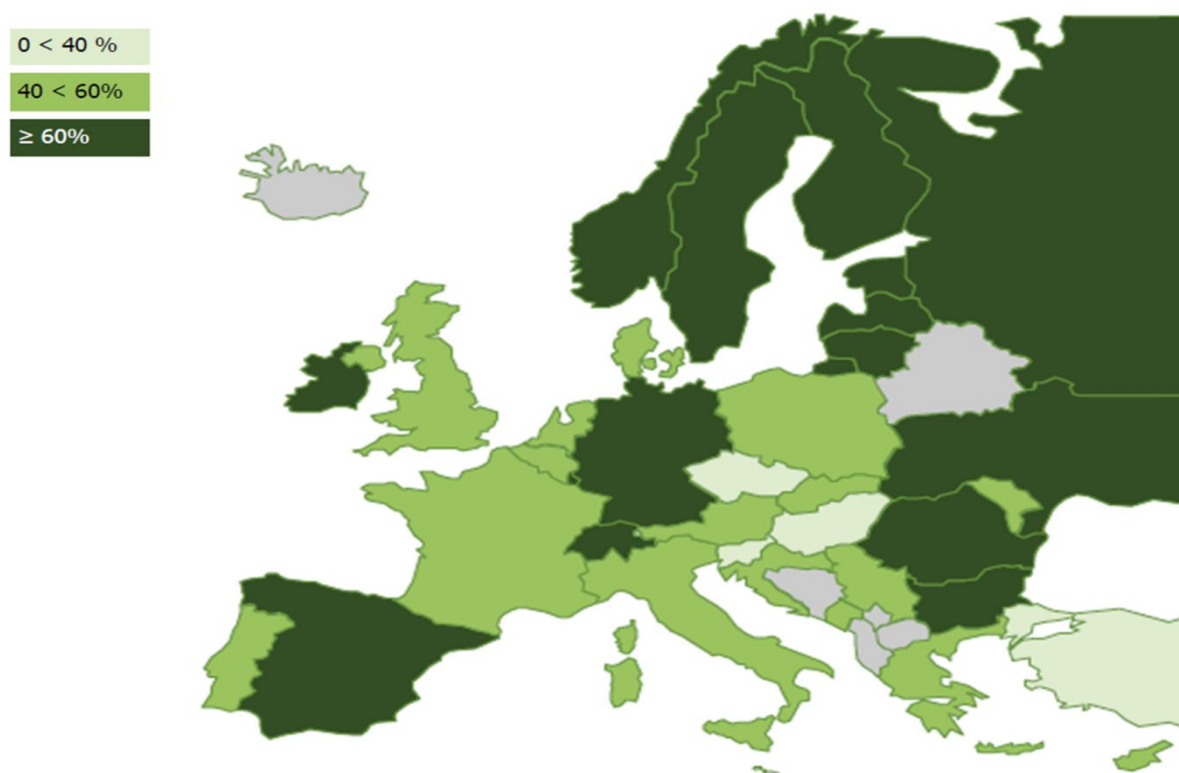
| Region   | HCV among PWID        |                   |
|----------|-----------------------|-------------------|
|          | Number of countries * | Prevalence (%) ** |
| Africa   | 2                     | 73.2              |
| Americas | 4                     | 58.4              |
| Asia     | 10                    | 50.6              |
| Europe   | 28                    | 47.0              |
| Oceania  | 2                     | 63.8              |
| Global   | 46                    | 50.3              |

**Table 1 – Hepatitis C prevalence among PWID, 2009**

\*Number of countries used in prevalence calculation (requires both an estimate of number of PWID and country-level prevalence. The total number of countries reporting prevalence is 51).

\*\* Country-level prevalence weighted by number of PWID.

Source: UNODC ARQ and UN Reference Group for HIV among injecting drug users



**Figure 4 – Prevalence of Hepatitis C among PWID in Europe, 2008-2009**

Source: ECDD and EMCDDA, 2011.

Regarding Europe particularly, and as shown in the picture above, between 2008 and 2009 17 countries including Portugal, reported HCV prevalence between 40% and 60%, while 16 countries reported an HCV prevalence of over 60%. Only 4 countries reported an HCV prevalence below 40% and 6 countries weren't included, didn't reported or have unknown values. (41)

In Portugal, HCV prevalence among TT clients is reported annually by IDT (42-44). Data comparison is limited by differences in the proportion of PWID, which is not specified, and testing uptake over time. Although HCV prevalence among existing TT clients has declined over the past 4 years (from 54% in 2006 to 50% in 2008 to 42% in 2010) screening coverage also declined from 39% to 15% over the same time period, which IDT consider partly attributable to the transition to an electronic data collection system.(37, 43, 44)

Among new TT clients, there is no clear directional trend, prevalence having initially decreased from 42% in 2006 to 33% in 2008, but in 2010 reaching levels above 2006 estimates (48%). As for existing clients, screening rates have declined considerably (from 32% in 2006 to 21% in 2008 and 17% in 2010). (37, 43, 44)

We will now focus on stigma, central element of this thesis, which is felt both in practices of drug consumption and in the infectious diseases we just analyzed.

### **1.3. People who inject drugs and infectious disease related stigma**

Stigma is a social process resulting from experience, perception or anticipation of a negative social judgement about a person or group.(45) It occurs when a person has an attribute that makes him/her less desirable or acceptable in the conceptions of others, i.e. which "discredits" an individual. It may affect the interactions between the individual and the rest of society, given that these interactions are shaped by the mutual awareness of the presence of stigma, simultaneously affecting the self-image of the individual to whom a label is attached.(46)

Throughout history, the condition of being an ill person has been associated to stigma. The leper was viewed as having been struck with a divine punishment for inappropriate moral conduct, cholera sufferers were associated with lazy people who had vices, and people with syphilis were "rejected" by doctors who were reluctant to treat them, for fear of contamination. (47) Therefore, in the case of people who live with a disease, the diagnosis acts as a classification tool of medicine (48), and is part of the process of labelling individuals (49) and functions as a cultural expression that society is prepared to accept as normal.(48) Upon making the diagnosis, a sphere of power is therefore opened that dictates

the discipline of normality, organising individuals into ill or healthy, pure or impure subjects.(50) The diagnosis makes individuals take on their status of being socially undesirable and encourages people to hide their condition from others in an attempt to maintain “normality”. (51, 52) In this situation, when individuals try to control the information about themselves, avoiding disclosure of their status and consequently stigmatisation from others, they are described as “discreditable”. (46)

Scambler makes a distinction between enacted stigma and felt stigma (51): the former refers to the cases of discrimination in relation to people who possess the attribute and who therefore have less acceptance from others; the latter refers to the fear of enacted stigma, also incorporating the feeling of shame associated to the attribute the individual possesses, insofar as the condition is outside what Goffman called “the norms of identity or being”.(46) In both cases the notion is at play that the stigmatised attitudes of others can have a deep impact on the life of individuals. (53) The negative feelings and thoughts which arise from identification with the stigmatised group and the possible impact this will have in the eyes of others may lead individuals to avoid contact with others and to self-stigmatise themselves. (54)

The affected person’s experience of feeling discriminated against by others, the attitudes in relation to this person, the perceived or felt stigma, the self or internalised stigma and society’s discriminatory practices are therefore points that can assess the stigma and health-related stigma. (55)

In many communities, illicit drug use and users are highly stigmatised, with stigma affecting negatively drug users’ mental and physical health (56) (57)

However, the stigmatisation is not equal: studies show that the use of a given substance is more stigmatised if it is injected rather than being inhaled or smoked. Reported that among drug users, crack and injection drug users had a greater social stigma than non-injected cocaine or heroin users. (59)

This may be linked to the fact that injecting oneself is seen as a violation of the functionality of the natural body orifices, such as the mouth or the nose, and hence is viewed as an act of transgression. (60) Following on from this perspective, the use of injecting drugs involves “the drawing back of blood”, which is considered a symbolically polluting substance, which upon entering the vein perturbs the standard distinctions between the exterior and the interior of the cultural processes. (61) The negative effects of the stigma in relation to PWID derive from public perceptions that have an impact on the way injected drug use is perceived and treated. (62)

In contrast to the injecting drug users, who carry visible signs (on their arms and other parts of the body, which are pierced and often contain abscesses), there is an invisible nature of most of the infectious diseases that enables management of the stigma, given that despite being “embodied stigmas” they are not immediately visible. (58) However, people who use drugs and simultaneously live with infectious diseases (HIV, TB, HCV) have been discriminated against because of their condition, with research on the means of transmission showing that contracting the disease (HIV or HCV) through injecting drugs is more stigmatised. (63, 64) Though, literature shows that stigmatisation of people who live with infectious diseases is a social phenomenon that involves individual and social judgements, and affects the well-being of the individuals in question, influencing their choices about the disclosure of their serological state to others. (65-67) The fact that one is a carrier of an infectious disease, which is associated with injecting drug use, makes it difficult to find employment. (68)

### ***Approaching infectious diseases related stigma – The case of HIV, HCV and TB***

The evidence shows that there is a hierarchy of infectious diseases, with studies revealing that the stigmatisation felt by the carriers of multiple diseases is more intense in the case of HIV, owing to the stereotypes that society creates and the enacted stigma experienced by the carriers. The fear of physical and moral contamination is revealed with the perception of the danger brought by the stigmatised group. (53) In this context, Herek tells us that the social imaginary of non-infected people when they interact with an infected person, or when they talk about the disease, leads to an awareness of their own mortality.(69) At the same time, the disease carriers themselves view the HIV stigma as more prejudicial for their well-being in comparison to the stigma attached to being HCV carriers, for example. (70)

Stigma may be symbolic, as in when a moral judgement is made. For example HIV/AIDS sufferers may be viewed as blameworthy just like PWID, unlike those ‘innocently infected’ by blood transfusions (71)

In a focus group carried out with people who live with HIV, TB and Severe Acute Respiratory Syndrome (SARS), the group related to HIV, concluded that it was much more common for people with HIV/AIDS to maintain secrecy as they regarded AIDS a highly stigmatized disease. All agreed that HIV-related stigma is rooted in biased publicity about the nature of the disease, judging it from a moralistic point of view. Actual and anticipated rejection by others left people with HIV/AIDS open to feelings of self-hatred, humiliation and withdrawal. (72) In this sense, some authors have attempted to map the trajectory of the HIV

stigma, in which one of the phases is the diagnosis. Faced with a changed identity, the individuals feel threatened with the decisions they have to wrestle over as regards disclosing the disease. Another of the phases is when the disease lies dormant and the carriers can live in a state that alternates between health and illness, i.e. when the disease does not yet manifests symptoms and it is possible to hide being seropositive. In this case, the enacted stigma can be avoided, but the self-stigma can come to the fore. (73).

A study on the stigmatisation within the population that injects drugs reveals that the users that are not infected with HCV make moral judgement on those who are infected, viewing them as irresponsible, “not caring” and having “fewer morals”, (74) in this way, the perceived stigma relative to hepatitis C derives from a link society makes between the virus and injecting drug use, given that the injecting practices can be viewed as unhygienic and antisocial. In the field of HCV, authors saw it as a liminal illness experience, oscillating between trivial and serious, normalised and stigmatised, public and personal.(64)

A systematic review relative to the tuberculosis stigma identified feelings of shame, owing to the conception of TB as a “dirty disease” and fear. (75) The stigma comes from the idea that TB is a “death penalty” and is considered a dirty disease, associated with bad habits and immoral practices. (76) In the specific case of tuberculosis, the stigma may lead to social isolation. (77)

In contrast to the injecting drug users, who carry visible signs (on their arms and other parts of the body, which are pierced and often contain abscesses), there is an invisible nature of most of the infectious diseases that enables management of the stigma, given that despite being “embodied stigmas” they are not immediately visible. (58)

In terms of health care settings, elements like fear and prejudice are seen as barriers to an effective aid given by healthcare professionals in patients who live with HIV infection: In a study conducted to HIV patients, the level of stigma was related to the way by how the disease was acquired, reporting a higher level of stigma among drug users. Studies also report that the level of discrimination and stigmatization in people who live with Hepatitis C was widespread in health care environments, resulting from stereotypes of IDU. (63)

Along these lines, the phenomenon of multiple stigmatisation (53, 78) emerged with the stigma seen as a multi-layered structure, where more than one state considered deviant occurs simultaneously.

As mentioned in this sub-chapter, drug consumption is an attribute that makes its users to be less desirable in the eyes of the society. The prohibition laws contributed for this to happen, with stigmatization being described as socially and structurally produced, reproduced and sanctioned by those same laws. On this track, the last chapter of this

introduction will address the legal framework relating to illicit drugs in Portugal, focusing in the decriminalization of these drugs.

#### **1.4. Framing the Portuguese legal context and the health services used by PWID in two Portuguese cities – Porto and Vila Nova de Gaia**

The first approach to the decriminalization of illicit drugs in Portugal has its roots in 1976, a time when drug use took high proportions and care institutions were facing several difficulties.

Without ceasing to be considered a crime, the Portuguese Parliament considers the making the drug use illicit raises delicate legal problems. According to this legal framework, drug users were seen as patients suffering from a disease leading to “a weakening and even to the enslavement of the will and, therefore, should be immune (...) to an imputation of guilt” (authors’ translation) (79) . In this sense, there is the intention to substitute the punitive model by the biomedical one, with the clinical treatment of drug users, pointing out to the failure of the means of criminal justice as a way of managing the problems created by drug use.

The highlight of the inadequacy of the current punitive system, in favour of a “careful review of the criminal act consisting in the drug use that would best fit within a set of norms” emphasizing the treatment of drug users, is the gateway to the process of reflection on drug use and its (de) criminalization. In 1993, the biomedical model is consolidated, bringing on a health point view, with the Portuguese Parliament considering drug users as people with medical needs “and that everything should be done to treat them, because of them and also because of the other citizens” (80)

In the year of 99, public discourse based on the humanistic principle, recognize the full human dignity of those involved in the phenomenon of drugs and justify the position against criminalization “because it is not the absolutely necessary mean or even suitable to address the problem of drug use and its effects”. (81)

Actually, drug use is prohibited and illegal in Portugal, but since July 2001, the consumption, purchase and possession for personal consumption of illicit substances aren’t considered crimes, but administrative offences, if the quantity doesn’t exceed the amount corresponding to an average individual consumption for a period of 10 days (This amounts in practice to 0.1 g heroin, 0.1 g ecstasy, 0.1 g amphetamines, 0.2 g cocaine or 2.5 g cannabis) (82-84)

Several Commissions for Dissuasion of Drug Addiction (composed by a jurist and other members with an appropriate curriculum in the drug addiction area, such as social

workers and medical professionals) (85) are responsible for conducting the infringement proceedings and deciding the most appropriate penalties to be applied to drug users. These commissions cannot require drug users to resort to proper health facilities, focusing on the principle that voluntary compliance is an essential requirement for recovery (86) but penalties can be suspended if they accept to begin a therapeutic treatment. (87, 88)

At the moment, Portugal is the only country within the European Union that decriminalizes illicit drug use.(24) The public's opinion is that the Portuguese legal framework is primarily concerned with health and well-being. One of the goals of decriminalization is to eliminate the stigma associated with criminal prosecution and drug use.(85)

In terms of provision of health services for PWID (see figure 5), there are in the city of Porto and V. N. Gaia four outpatient drug treatment centres (Treatment Teams - TT), coordinated by the Institute for Drugs and Drug Addiction (IDT) – whose major responsibility is to promote the reduction of the use of licit and illicit substances and the decrease of addictions - and the Ministry of Health. Devoted to drug, alcohol and tobacco treatment, they also offer psychological and social care to individuals, being often the entry point to the treatment system. (89) On admission, each patient's situation is assessed and a therapeutic project is designed by a multidisciplinary team of medical doctors, nurses, psychologists and social workers (health professionals mention that prior to the decriminalization of drugs, in order to preserve their identity and feeling afraid of social control, there were cases when drug users wouldn't even give their full name to the technicians of the harm reduction services).(90)

TTs offer methadone, buprenorphine and naltrexone. Treatment is initially delivered under daily supervision but may subsequently be dispensed weekly, depending on assessment of individual circumstances. In cases of hospitalization, imprisonment, or in which proximity or co-location of treatment is considered likely to facilitate adherence, opiate substitution therapy (OST) can also be delivered in other settings such as hospitals, CDPs, health centres, community pharmacies, mobile outreach units and prisons. In these situations, treatment is organised in coordination with TTs and supervised by health professionals at the point-of-delivery service. All TT clients are expected to be offered screening for HIV, TB and HCV on admission and subsequently according to clinical assessment. (91)

Since 2007, rapid HIV testing has been available onsite under the *Klotho Programme* designed as public health intervention targeting people who use drugs, aiming at the early detection of the infection amongst drug users and their early referral to treatment, thus increasing their quality of life and life expectancy. (92).

For TB screening and treatment, patients are referred to a CDP – there is one in Porto and another in V.N. Gaia. HCV screening is prescribed onsite but performed at a private clinical laboratory (hired by the National Health Service), in the client's preferred location. Those with positive HIV or HCV results are referred to hospital-based clinics for care and treatment. Through collaboration with CDPs and HIV treatment clinics, antiretroviral and anti-tuberculosis therapy may also be provided under direct observation (DOTS) at TTs. This collaboration however is not formally established and is dependent on the health professionals' own diligence in finding an individualized strategy for the patient. (91)

As far as pharmacies are concerned, in 1993 appears a national syringe exchange programme (NSP) promoted by the *National Coordination for HIV/AIDS via the partnership with the National Association of Pharmacies* (93). The main goal was the prevention of the transmission of HIV infection among PWID, with the distribution of sterile material<sup>2</sup> (94) and the collection and destruction of used material. In the beginning it was limited to community pharmacies, later expanding to mobile outreach units and governmental and non-governmental organizations. (95, 96)

In 1998, the Service for Prevention and Treatment of Drug Addiction (SPTT), the Pharmacists Order and the National Association of Pharmacies signed a cooperation protocol aiming at supporting the Programme for the Administration of Methadone in Pharmacies. (97) In 2001, the programme expanded to the administration of Naltrexone and, in 2004, to Buprenorphine. These programmes are aimed at patients already included in replacement therapy programmes in TT, being selected by them. (97) In the cities of Porto and V.N. Gaia, the cooperation between pharmacies and Oriental, Ocidental and Gaia TTs was carried out. The fact that it allows patients to continue the treatment in their area of residence or of work, allows the patients' private life and social integration to be easier.(97)

Other services available for drug users are the outreach teams that provide methadone and combined HIV/TB treatment programmes, in conjunction with TTs, HIV and TB treatment services, providing daily treatment at a fixed location and time. In Porto and V.N. Gaia there are four. Simultaneously they make needle exchange (NSP), rapid HIV testing and referral for TB/HCV screening and treatment. The outreach teams usually have patients that are current and former PWID with minimal social support, with significant social care needs and those who have had difficulty adhering to drug treatment in the past.(91)

CDPs (in Porto and Vila Nova de Gaia) are autonomous units providing TB preventive, diagnostic and treatment services. (38) These centres also offer BCG (Bacillus

---

<sup>2</sup> In the beginning, the "AIDS Prevention" kit consisted of a sterile syringe, a disinfectant wipe, a condom and a leaflet. In 1999, it was added the vial of bid stiller water and the filter, and in 2007, two containers and two packages of citric acid.

Calmette-Guérin) vaccination and HIV screening, via rapid testing (since 2008). CDPs can be accessed through self-referral or via TTs, outreach teams, or other health and social services. CDP clients who are drug dependent are offered general medical support and referral to an OST programme, at a TT or via outreach. If the patient agrees, co-located TB and OST is arranged.

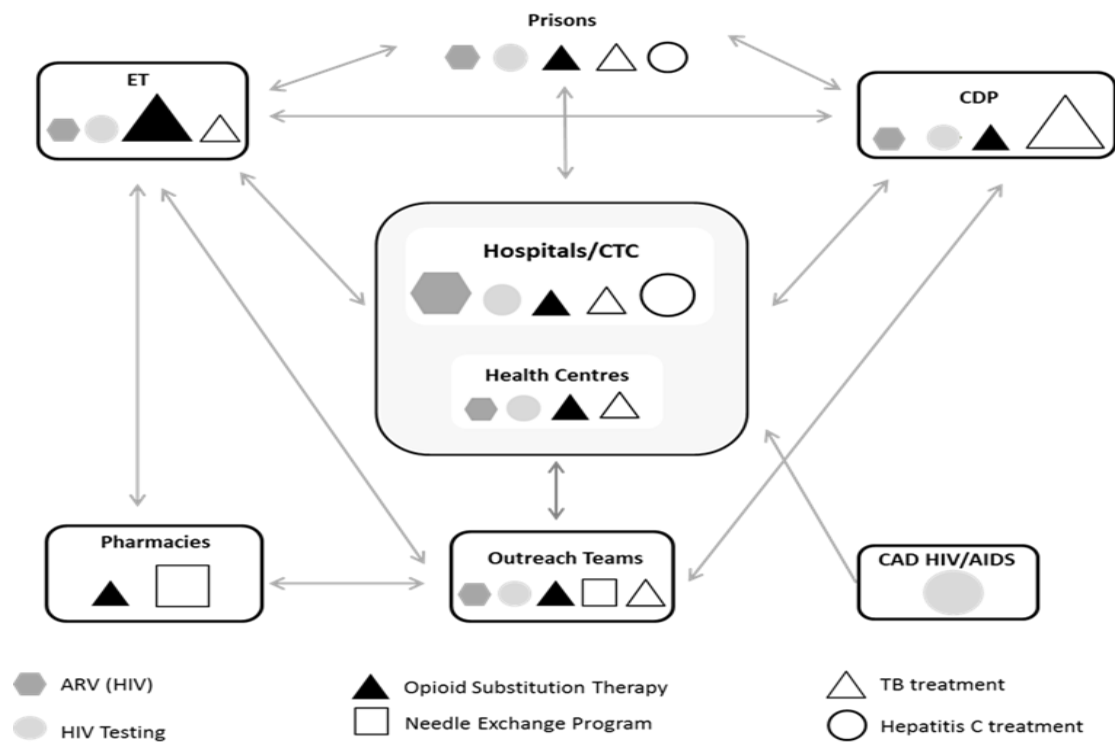
As well as being offered routinely via drug treatment services and outreach teams, HIV testing can be sought at specific centers for Counselling and HIV Early Detection Centers (CAD), located in each district. Testing is voluntary, confidential, anonymous and free of charge, accompanied by pre and post test counselling. Those with positive results are referred to hospitals for treatment. (94)

HIV and HCV-related care is delivered free of charge via hospital-based outpatient clinics. Since 1987, anti-retroviral therapy (ART) has been freely and widely available in Portugal. Initiation of treatment is recommended at a CD4 count below 350, in accordance with European and national clinical guidelines (98).

HCV care is delivered via hospital-based infectious disease and/or internal medicine and/or gastroenterology treatment centres, and treatment is dispensed by hospital pharmacies and is usually home based. At *Combined Therapy Centre* (CTC) in Porto, however, PWID must typically take interferon (as a weekly subcutaneous administration) onsite. The CTC, located at Joaquim Urbano Hospital, diverges from this model, offering integrated, co-located outpatient care for HIV, TB, HCV and drug dependence. (99)

In prisons, OST is provided under a protocol with the IDT and HCV treatment is also available. Drug-free units were established to provide spaces separate from communal areas where drug-dependent prisoners could seek treatment (100)

For PWID without secure accommodation, sheltered housing and OST are provided by *Casa Vila Nova*, in Porto, in collaboration with TTs and outreach teams. (101)



**Figure 5 – HIV, TB, HCV and drug treatment services and referral channels in Porto area**

Source: A rapid assessment of the quality and accessibility of integrated TB, HIV and harm reduction services for people who inject drugs in Portugal [forthcoming]

As previously shown, the decriminalization of drug use in Portugal has been articulated with a biomedical model, having risen during the issue of drugs and drug-related diseases becoming a relevant social problem and with the perception that criminalization was exacerbating that problem instead of solving it.<sup>(85)</sup> With an underlying approach to public health, evidence shows its successful results, namely: the decrease in the number of drug users, and the decrease of drug use related infectious diseases. (28, 32, 33) It would not be exaggerated to think these successes were partial, since other factors (psychological, socially and cultural) may be taken into account in the construction of a complementary approach to the addiction, solely and exclusively as a disease.

Beyond that, the notion of social hazard, with the idea of (moral and physical) contamination (102, 103) of the healthy by the patient continues to exist though, among health care providers; in some health facilities, for example, there is a glass between the patients and the nurses, so there is no contact between them. While safeguarding hygiene, this physical barrier also shows that stigmatising procedures within drug users' treatments still exist.

To the best of our knowledge, there is no study that allows us to understand how the legal framework has changed the social cultural aspects. There was a restructuring in the

health field, but we do not know to what extent there was a change in mentalities and if it was beneficial to patients in treatment as far as the stigmatization processes are concerned.

## **2. Aims**

We aimed to analyze the meanings and experiences of stigmatization constructed by people who use drugs.

The specific aims were:

- To analyze the impact of living with an infectious disease on the meanings and experiences of stigmatization constructed by people who use drugs;
- To explore the stigmatizing hierarchy of infectious diseases constructed by people who use drugs.

# 3. Methods

## ***Rapid Assessment***

A Rapid Assessment is a multi-method, action-oriented approach to research, prioritising timely response and intervention development. Its inductive nature allows assessments to be guided by emerging practical findings, and the triangulation between multiple methods and data sources allows findings to be cross-referenced and situated socially, culturally and economically, developing a more complete picture of the issue under study.(104)

In the context of a research project coordinated by Professor Tim Rhodes (London School of Hygiene and Tropical Medicine, UK) and Professor Henrique Barros (University of Porto Medical School and Institute of Public Health of the University of Porto, Portugal), and funded by WHO, a Rapid Assessment was conducted between November 2010 and March 2011 in Porto and Vila Nova de Gaia with two general objectives: 1) to understand the accessibility and quality of tuberculosis and integrated tuberculosis and HIV services and delivery systems for people who inject drugs; and 2) to develop guidance on models of integrated care.(91) It had six specific objectives: 1) to examine patterns of tuberculosis and HIV service use among PWID, including prisons; 2) to describe experiences of TB and HIV treatment access and delivery from the PWID service users and HIV and TB treatment providers perspective; 3) to explore social contextual factors influencing engagement in and adherence to TB and HIV treatment among PWID; 4) to assess relationships between TB and HIV treatment systems, by examining mechanisms for coordination, referral and integration of services; 5) to describe the TB and HIV treatment related social support and care needs of PWID and the role of local community-based organizations in treatment advocacy, support and provision; and 6) to develop guidance regarding models of “best practice” in the provision of integrated TB and HIV services for PWID.

In order to meet these objectives, multiple data sources, in combination with multiple methods of data collection, were used, namely the following ones: a review of routinely collected data on the epidemiology of TB, HIV and HCV among PWID and use of associated services; a mapping of current TB, HIV and other harm reduction services and referral mechanisms in Porto; semi-structured interviews with TB and HIV treatment and harm reduction service providers; and semi-structured interviews with PWID and users. This thesis relied on the latter.

Ethical approval was obtained by LSHTM and Hospital de S. João Ethics Committees.

## ***Data collection***

In a total of 16 HIV, TB, HCV and other harm reduction services located in Porto and Vila Nova de Gaia (see appendix no. 1), ten were contacted with the goal of representing different treatment models, including co-location and integration of HIV, TB, HCV and drug treatment services. The geographic proximity, the volume of patients they care for and the previous professional contact between the research team members and those from these services were the base for the selection.

Of the services contacted, nine collaborated on the identification of potential participants, in particular: one drug treatment centre; two hospital services (Infectious Diseases Service of the Hospital S. João and the Combined Therapy Centre of the Hospital Joaquim Urbano); two HIV and TB treatment centres (Pulmonary Diagnostic Centres in Porto and Vila Nova de Gaia); two outreach teams and a sheltered housing for people who use drugs (Casa Vila Nova).

While the demands of researchers are many times considered by services as a work overload(105) the majority of the above mentioned services responded positively to our requests, maybe benefiting from previous contacts between them and the research team in well succeed finalized projects.

Currently or formerly people who had injected drugs were recruited by health professionals working in these services, namely doctors, nurses, psychologists and social workers. A purposive sampling was done to recruit a varied range of participants, taking into account the following aspects: having or not TB and/or HIV treatment access and experience; diversity of previous experiences of opioid substitution therapy and imprisonment; variety of ages, co-infection status (with TB and Hepatitis C) and length of time with HIV diagnosis.

We interviewed 30 PWID with an average age of 40 years old (ranging between 31 and 52), most of whom (26) were male. 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 injecting between 6 months and 22 years ago) (n=17). Participants had injected for an average of 12 years (2 months – 26 years).

Table 1 illustrates participants' HIV, TB and HCV status, history and treatment experience, as well as current and prior experience of opiate substitution therapy (OST) and imprisonment. Eleven participants had experience of both HIV and TB treatment (latent and active), 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 infected and treatment naive and 17 had HCV but no treatment experience. All participants diagnosed with latent or active TB (n=15) had experienced treatment. Three of the participants were, at the time of the interview, homeless.

**Table 2 – Interview participants' status and treatment experience**

| Pseudonym | Age | HIV status | HIV treatment | TB history     | TB treatment   | Active HCV history | HCV treatment | OST     | Prison ever |
|-----------|-----|------------|---------------|----------------|----------------|--------------------|---------------|---------|-------------|
| Miguel    | 37  | Positive   | Current       | Current active | Current active | None               | -             | -       | Yes         |
| Jesualdo  | -   | Negative   | -             | Current active | Current active | Past               | Past          | -       | -           |
| Américo   | 43  | Negative   | -             | Current latent | Current latent | Current            | None          | Past    | -           |
| Helder    | 44  | Positive   | Current       | None           | -              | Past               | Past          | Current | -           |
| Jacinto   | 37  | Positive   | None          | Current active | Current active | Past               | Past          | Past    | -           |
| Jorge     | 52  | Positive   | Current       | Past active    | Past active    | None               | -             | Current | Yes         |
| Fátima    | 43  | Positive   | Current       | Past active    | Past active    | Current            | None          | Current | -           |
| Edgar     | 40  | Positive   | Current       | None           | -              | Current            | None          | Current | -           |
| Mário     | 39  | Positive   | Current       | Current latent | Current latent | Current            | Current       | Current | Yes         |
| Maria     | 35  | Positive   | Current       | Current active | Current active | Current            | None          | Current | -           |
| Joel      | 43  | Positive   | Current       | Current active | Current active | Current            | None          | Current | Yes         |
| Alberto   | 40  | Positive   | Current       | None           | -              | Current            | None          | Current | Yes         |
| Jerónimo  | 49  | Negative   | -             | None           | -              | None               | -             | Current | -           |
| Nuno      | 32  | Positive   | Current       | None           | -              | Current            | None          | Current | Yes         |
| Amílcar   | 45  | Positive   | Current       | Past active    | Past active    | *                  | *             | None    | -           |
| Ivo       | 39  | Positive   | Current       | None           | -              | Current            | Current       | Current | -           |
| Justino   | 42  | Positive   | Current       | None           | -              | Current            | None          | Current | -           |
| Ricardo   | 40  | Positive   | Current       | Past active    | Past active    | Current            | None          | Current | Yes         |
| Sara      | 36  | Positive   | None          | None           | -              | Current            | None          | Current | -           |
| Juliano   | 40  | Negative   | -             | None           | -              | Current            | None          | Current | -           |
| André     | 43  | Positive   | Current       | None           | -              | None               | -             | Current | Yes         |
| Márcio    | 34  | Positive   | Current       | Current active | Current active | None               | -             | None    | Yes         |
| Juvenal   | 42  | Negative   | -             | None           | -              | Current            | Current       | Current | -           |
| Óscar     | 46  | Negative   | -             | None           | -              | Current            | None          | Current | Yes         |
| Jeremias  | 35  | Positive   | Current       | Past active    | Past active    | Current            | None          | Current | -           |
| Rafael    | 31  | Negative   | -             | None           | -              | Current            | None          | Current | Yes         |
| Marcelo   | 40  | Negative   | -             | Past latent    | Past latent    | Past               | Past          | Current | Yes         |
| Fábio     | 40  | Positive   | Current       | None           | -              | Current            | None          | Current | -           |
| Julião    | 35  | Positive   | Current       | Past active    | Past active    | Current            | None          | Current | Yes         |
| Patrícia  | 42  | Positive   | Current       | None           | -              | Current            | None          | Current | Yes         |

The sample size was determined by reaching the point of data saturation, that is, we recruited new participants until no new themes emerged from the interview data (106, 107).

Between December 2010 and March 2011, three trained interviewers - two women and one man – based at Institute of Public Health of the University of Porto, under the supervision of project coordinators based at *Institute of Public Health of the Porto University* (ISPUP) and the London School of Hygiene and Tropical Medicine - conducted 30 semi-structured interviews to PWID, 17 of which were carried out by the author of this thesis.

Researchers faced three main typical responses from the potential participants during the recruitment process: first, participants who immediately had consent to be interviewed (n=11), saying that they had already participated in other studies and deconstructing the widespread idea that over-researching can often lead to difficulties in initially recruiting people to projects and retaining that participation (108); second, those who had accepted to be interviewed without having participated in previous studies (n=15); third, those who had used indirect strategies (109) so they wouldn't perform the interview, having cancelled or postponed it (some more than once) or just did not show up at the time and place agreed (n=7) (110).

In a total of 33 PWID contacted by the interviewers, 26 readily accepted to participate in the research. Their availability can be related with the fact that the recruitment was done inside treatment settings(111, 112); however, interviewers always explain that the project was independent of the health service. At the same time, evidence shows that PWID reasons to participate in researches are due to altruism, personal satisfaction and seeking information or assistance, among others.(113)

In the recruitment of PWID it is essential to maximize opportunities when they appear (114). According to this facilitative approach, when a PWID agreed on participation, the interview was scheduled as soon as possible, always in accordance with his/her availability and in the most suitable place for the interviewee. In this study, interviews were conducted in the services facilities (n=28) and in coffee shops (n= 2).

Participants must voluntarily agree to participate, without physical or psychological coercion, and their agreement was based on full and open information.(115) Participants' written consent (see appendix no. 2) was obtained after they were given an information sheet on the study's description (see appendix no. 3).

The sensitive nature of the topic and the characteristics of the population have defined the terms with which the protocol was written, safeguarding the health, security and the well-being of the interviewers.

The shortest interview lasted 27 minutes and the longest 137 minutes, with an average duration of 60 minutes. The interview guide included questions on the following areas (without hierarchical order of importance):

1. HIV, TB and HCV treatment literacy;
2. HIV, TB and HCV testing and treatment access and experience;
3. navigation of bureaucratic and other pathways into HIV and TB treatment;
4. factors influencing HIV and TB treatment adherence;
5. experience of drug treatment in relation to HIV, TB and HCV treatment;
6. experiences of HIV, TB, HCV and drug treatment service referral, coordination and integration;
7. expectations of the personal impact of HIV, TB and HCV treatment;
8. social and structural factors influencing PWID lifestyles and HIV, TB and HCV treatment;
9. the role of self-help, informal support and civil society organizations in HIV, TB and HCV care;
10. perceptions of the future.

All topics of the interview contributed to the categories of analysis in which we've supported in this study.

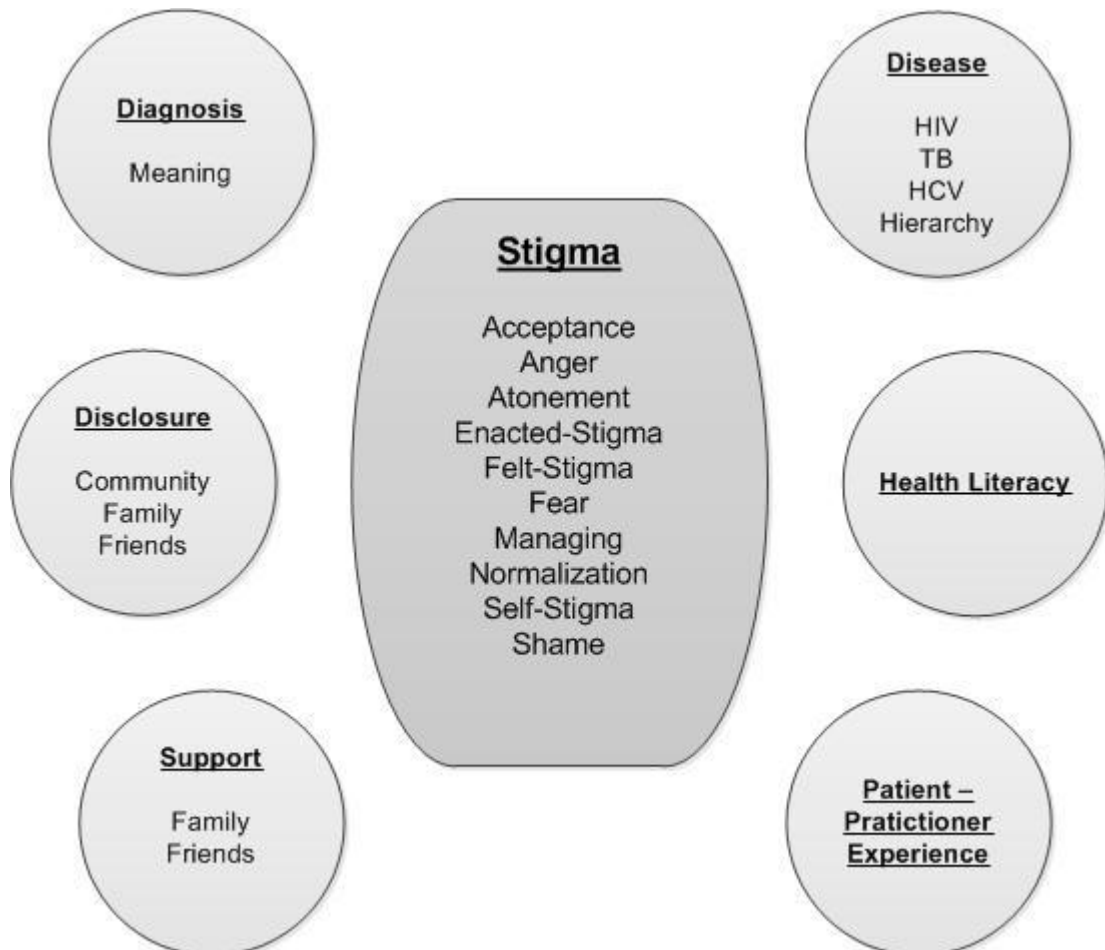
At the end of the interview a snack was offered to each participant, being clear that it was just a way to thank their participation, and information on local health and support services for people who use drugs and for people living with HIV, TB and HCV was provided.

All the interviews were digitally recorded and transcribed verbatim. Transcripts of the interviews were checked for transcription accuracy by the respective interviewer and were then translated into English by professionals. Field notes were added to the transcripts.

### ***Data Analysis***

Data were analyzed thematically by two independent researchers in order to identify key themes which emerged within and across individual accounts, accepting our *a priori* interests. Data were coded as researchers collected them to inform the direction of subsequent interviews, coding and case selection. 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.(107) As the analysis evolved, themes were discussed with two senior researchers. In the case of conceptual difference, it was reflected upon and resolved by further joint debate.

In accordance with the objective of this master's thesis - to analyze the impact of living with an infectious disease on the meanings and experiences of stigmatization constructed by PWID - two core themes were explored. The first one concerned stigma perceptions and experiences, constructed by the participants at a micro, meso and macro perspective; the second one – the hierarchy of infectious diseases (VIH, TB, HCV) as far as stigma is concerned. We identified a set of categories, we believe to be convergent in building the central category of analysis in this study – stigma. Through a network strategy, of increasing interactivity, we approach dimensions able to apprehend the impact of stigma in the participants. The meanings assigned to each one of the accessory categories of analysis constitute an interpretive frame from which we can simultaneously decompose and complexify the perceptions of individuals.



**Figure 6 – Data analysis categories**

Analysis was performed with NVIVO 9 qualitative analysis software (QSR International). The findings are reported with verbatim quotes from interview transcripts, using pseudonyms, in order to ensure anonymity and confidentiality.

# **4. Results and Discussion**

Based on the meanings and experiences of stigmatisation constructed by the interviewees, we adopted three analysis levels. A micro level that explores the individual's reflections as a carrier of an infectious disease and the impact of living with this condition; a meso level, which focuses on the perceptions formed and experiences of individuals deriving from interaction in socialising networks – such as the family, peer groups and health professionals; and a macro level, based on the meanings apprehended and realities experienced by the actor, resulting from a dialectic relationship – acting in society means being exposed to the construction of society's representation of the individual.

### ***Diagnosis: the multiple feelings on PWID***

At the micro level, i.e. the direct impact on the individual, the moment of diagnosis triggered different feelings and reactions to obtaining first-hand knowledge that s/he was a carrier of an infectious disease.

#### *Anger, fear and self-rejection*

Anger was the feeling cited by seven of the interviewees at the moment they found out they were carriers of an infectious disease. In four of the participants, infected with HIV the anger came simultaneously from awareness of the irreversible nature of their clinical condition, which was viewed as an early death sentence, and the negligence in undertaking risk behaviours which left them exposed to contamination. In other words, the moment of diagnosis constitutes a first confrontation with an altered identity (70) where, similarly to what's referred in other investigations, reactions flow, like disbelief, numbness and denial, followed by anger, acute turmoil, disruptive anxiety and depressive symptoms (45)

*“Anger, anger and desperation, I don't even know. I just wanted to die back then.”* (Sara, HIV)

*“Very strong anger. Anger. A lot of anger. But why? With myself as well, because why didn't I take precautions? But what do you feel now when you think about your diagnosis? Fury, fury, doctor, for doing what I did and a person can't take it back.”* (Nuno, HIV)

Protective sexual practices without disclosure from the individuals that live with HIV is very common, however, other studies refer that the percentage of individuals who maintain unprotected sexual intercourse without revealing their condition is very small (113). Put in perspective issues regarding moral responsibility are raised by HIV carriers in the moment of the disclosure about their HIV status to sexual partners. (114, 115)

The reality encountered exposed three interviewees, who were female, and their anger took on a particular form given that they were infected with HIV through sex with

partners who had hidden the fact they were carriers of the virus. Placing the blame on the other partner emerges as a form of atonement in relation to the anger at being put in a situation of no return, the consequences of which, unknown at the time, would from then onwards have an impact on their own lives / identities.

*“I think he should have told me that, it wasn’t because he was HIV positive that I, that I would not stay with him but I think I had the right to know, right! At least I could take precautions. There are many ways that we can protect against the illness, and that’s something he never did. He always denied to me that he was, that he was HIV positive.” (Patricia, HIV)*

Five interviewees also reported feelings of fear and self-rejection – as carriers of an infectious disease there was a believe that the new clinical condition dictated a short-term future.

*“How did you react when you found out? My world... [Silence] the whole world fell on me! Why? Because few survive HIV” (Joel, HIV).*

The rejection emerges as a reactive attitude to the discovery of a new, contaminated self, inciting a disconnection between one’s self perception and the clinical reality. The short time span between the stimulus (diagnosis) and the reaction (rejection) led to the latter being expressed in extreme attitudes like the denial in assuming the need of treatment and the thought of death (suicide) as a solution. Clearly, the identity of the individual enters in a process of reconfiguration (70).

*“I wanted to kill myself and I didn’t accept it”(Ricardo, HIV).*

#### *Taking a different path - neutralization*

On the other hand, it is pointed out the neutralization of the disease in nine of the interviewees, both in the case of diagnosis of HIV, and HCV or TB. In other words, the diagnosis of the disease did not cause negative impacts, and was accommodated by the force of knowledge that the individuals had as regards the clinical conditions they had acquired.

*“What did I feel at the moment I was infected with HIV? I didn’t feel anything special. I knew it was a chronic illness. It was not like 20 years ago, when it was a death sentence. At the moment this is no longer the case.” (Ivo, HIV)*

When opinion moved on to their everyday lives with the illness, the notion of triviality and decomplexification gains ground in the discourses of the interviewees, and references are even made to situations when they forgot they were carriers of the disease. The thesis of normalization points, therefore, to the triggering of processes of crystallization in the social

structure of the position occupied by the individuals in stigmatization. (116) The disease turns out familiar, it gets vulgarized.

*“I have to live with it. It’s something I even forget I have, I have a normal life. And quite honestly you look at me and you don’t say I have it. Thank God, they can look at me and never say I had the (sic) HIV. It’s something I have but I forget that I have it.” (Jacinto, HIV)*

*“And what did you felt in the moment you were told you had Hepatitis C? Nothing. I don’t worry about that, there you go again with the diseases, I don’t worry, I don’t worry, I have nothing to worry about. I feel at ease... I have the disease inside, what I need to do is recover from it, I don’t have to be thinking about that every day.” (Jesualdo, HCV)*

The temporality assumes special importance as an element of normalization of portability (117, 118), where time appears as a central factor in the progression of the disease’s trajectory because it induces a certain notion of *habitus*.(119)

*“I got to a point where I forgot the disease; I put the disease behind me. I did what the doctor told me: ‘pretend you don’t have a disease, if you don’t get that out of your head, you will go out faster’ and I put it behind me, I forgot about it, until today, I just keep going, I always take the right medication.” (Miguel, HIV)*

The idea that they had to carry on with their lives outweighed the possibility of being straight-jacketed by the reality of an infectious disease, with some participants shifting from an initial refusal of diagnosis to an acceptance and normalisation of living as carriers. This trajectory – nonlinear – towards an accommodation of the disease strengthens the argument that these are individuals experiencing spoiled identities (120)The normalization shown by the interviewees should, though, be problematized to a more complex level. We should not neglect the instrumental power which assists the individual of choosing between public and private presentations of the lived experience. Having reached the moment where they face the disease as “no big deal”, the diagnosis should always be perceived as a moment, coproducer of symbolic violence in the lives of the marginalized. (61)

*“I felt bad for some time, in the beginning. Now I carry on with my life as if...I try to carry on with my life, right, you know, of course that, I have to forget about the subject, you can say that. Of course if it (the subject) is brought up or if I am somewhere where this theme comes up, of course, it makes me think about everything.” (Julião, HIV)*

#### *Self – Stigma*

Another phenomenon detected in the interviewees’ discourses is linked to self-stigma (54), the internalisation of stigma not through reflection of the interaction with others, but

through the self-appraisal as a marginal, inferior self, coming from the image constructed by the individuals themselves and which may, at the extreme, condition their social practice. A biographical “disruption” and “loss of self” is triggered by the onset and diagnosis of chronic disorder (45, 121). So much so that some of the interviewees revealed that they had been accepted by their peers when they told them about their condition, nevertheless the structure of their interactions had been changed by the endogenous mechanisms that had led to the need to distance themselves, and discomfort in their socialising networks. It was found that the attachment of a label to themselves, reduces the involvement in situations where the individuals, some way perceived as potential negative interactions, leading them to imposed exclusion. (59) That creates the effect of looking glass self (122) - internalization of negative judgments about themselves.

This scenario was equally observable in the need to protect others as regards objects the individuals could have touched/used. The idea of the physical contamination of the healthy subject by the carrier arises here, accentuating the pure/impure dichotomy. (99)

*“Was it easy or hard to get access to those services? Man! It was easy. But in my head it was hard. What kind of barriers did you feel? I felt paranoid, like those people were superior, that they were. I felt inferior to others because I had the disease.” (Justino, HIV)*

*“Then I told them, I got a virus, HIV, and they “What? And it’s because of that that you’ll despise us” and I “no, but I don’t feel well near you.” (Miguel, HIV)*

*“I know that if I drink from this bottle, then if my son drinks from it he won’t get infected, but I avoid it. I avoid it, avoid it. I take every care because as much as I don’t want it, I don’t want my children to get it, for the love of God! And they, thank God, are clean.” (Edgar, HIV)*

In the case of tuberculosis, the isolation of the patient so it won’t infect the healthy is perceived as a negative consequence of the disease, more than the use of a mask.

*“Do you think that rather than because of the illness it was the fact you had to wear a mask? That’s it, to be wearing the mask, it was not needed to be wearing the mask, just to know that I will go there and just my air, also you know, I’m harming someone perhaps” (Julião, TB)*

Related only with PWID condition and it’s physical marks, we identified another situation where self-stigma is present. Two of the interviewees referred to the state of their teeth as an element that produces stigmatization.

*“I don’t go to clubs because of my complex with my teeth. I don’t go to a bar, I don’t talk to certain, let’s say, certain girls because of my teeth. This hinders a person very much. It’s an impediment. A barrier even.” (Fábio, HIV, HCV)*

### ***(Non) Disclosure: a way to manage stigma***

Broadening the field of analysis to the sphere of interaction, the inclusion of the individual in multiple fields of action, the moment of disclosure and the assumption of the condition as a carrier of an infectious disease, in socialising networks, was a landmark moment in the projection and reconfiguration of their identities. The moment of disclosure brings together the formulation of different judgments about how and whom to reveal, and at the same time already requires the adjustment to new roles that individuals have to play (123)

As found in some researches, the participants created their own ways of managing how they disclosed their condition, opting for non-disclosure, disclosure only some time after being diagnosed and selective disclosure, with a view to minimising the negative impacts on their identities. (64) In fact, stigma may affect the moment of disclosure(124) since, the individual always looks upon himself to formulate the best concept of personal identity (46)

From another prism, they alternated between a front region (in which they adapted their identity to the context and interaction partner) and backstage (where they assume their true condition) (120) We found that the fear of the reaction of others (felt stigma) and the unpredictability in the feedback they are going to obtain led the interviewees to adopt different attitudes, reflecting the weight of the structure, the power of labelling that is characteristic and which the individuals do not know when and how such will be mobilised.

*“Of course I don’t tell them right away: I have tuberculosis, because people would be like: Christ! I tell them I caught a virus in my lungs and that’s it.”* (Maria, TB)

Justifying what was previously exposed, in the case of an interviewee that takes anti-retroviral medication, the apprehension that the partner witnesses the pill ingestion – which is dubbed by Goffman as “stigma cues” (46) , because that could act as “clues” for others leading them to suspect a somewhat undesirable alterity about the individual in question – and the dominant expectations that the reaction of the partner would be negative, appeared to be the central element in the decision of not revealing the individual’s health condition, contributing to the decision of keeping the disease in anonymity.

*“...there are people who make a mountain out of a molehill. For example, I remember going out with a guy and he started spending more time in my house, and I had to take my medication in secret, right. Why? Because if he saw that, there is always that curiosity to find out what it is, it’s normal, except that people like to, when they see you taking all these tablets every day, it’s normal to ask isn’t it? And would you hide it? Sure. And I ended up*

*telling him because that way I didn't, as long as I took precautions, I am not obliged to tell of my health problems, because that is my fear, my greatest concern is how people are going to react. Because there are people who actually react well, but there are others who don't.*" (Patricia, HIV)

However, three interviewees manage this from other point of view - the positive management of the stigma. These are cases in which the individual adopts a reactive stance, projecting the growth of their (re)integration in socialising networks.

*"If we tell the truth, tell the truth and are sincere with the people we most love, automatically the effect will be for them to automatically talk to us more naturally and to accept the news more naturally. And that is why I never hid the fact that I am seropositive. Because I believe that it's a way of discriminating and not showing your face, and automatically you are discriminating against yourself. If you are scared of saying it, these people will discover. And that will make it worse"* (Edgar, HIV).

Thirteen individuals stated that they had decided to disclose their condition to their families, and had received a positive reaction to this new reality. Furthermore, they described the attitudes of the socialising networks as a support to face up to the challenges of reconstructing their practices, habits, and new image of themselves.

*"How do people react? They are saddened, aren't they? They said they were there and I could count on them if necessary."* (Ivo, HCV)

*"But exactly concerning your disease, did people support you? Yes, they did, they gave me, look, they gave me, they only didn't give me a house to live in because they didn't have it, or else they would also have given it to me. They didn't put me aside, although they knew about my disease."* (Miguel, HIV)

The connection through affection, in these cases, seems to have much more influence on the facilitating attitude adopted by the families. We believe this can be put forward as one of the explanatory factors that helps to neutralise the stigma, whether self or hetero imposed by the condition of being a carrier of an infectious disease.

*"How did people react? They don't react badly. If there is friendship between people, if there is understanding, people don't react badly. They try to help. And how did they try to help? Psychologically, through affection, man!"* (Justino, HIV)

However, from the participants in our study we collected three reports of opposite situations, i.e. non-acceptance, lack of support, or even cases of rejection, when disclosing their condition. Among these, one situation is pointed out in which a family member

eliminated the name of the carrier from an official document, in a symbolic affective and legal cutting away from the interviewee. This enhances that families play a significant role in the individuals' experiences, once they have the potential to impact positively or negatively on the circumstances surrounding them and transform their social reality. (125)

*"In fact there were people that moved away from me, but I called them losers anyway."*  
(Fábio, HIV)

In tandem with the rejection, in a line which contemplates family networks but also broader relationship networks, sixteen of the interviewees turned their discourse in another direction – discrimination – which we adopted in our analysis as enacted stigma (51). The studied population is particularly vulnerable to discriminatory attitudes and, hence suffering a high degree of stigma because they are perceived as being to blame for their predicament and at fault morally. This means they are less likely to benefit from the altruistic tendencies of others. (126)

The experiences of discrimination were perceived in interactive situations where the fact the interviewee was a carrier of HIV or an injecting drug user became apparent. Discrimination, to Link and Phelan (65) while triggering the affixing of labels as "junkies", "deviants" and "scum" leads to them being seen as one of "them" not one of "us", resulting in social exclusion.

The main reasons cited by the interviewees for such situations they were involved in had been a lack of information of the interaction partners about the means of transmission, and consequently the adoption of behaviours of repulsion and detachment. This made it impossible to retain or cultivate socialising networks.

*"It wasn't a question of being difficult to live with the disease, but it was difficult to socialise. In every way. We can't be with somebody and be open with him/her, we are seropositive, we are discriminated against"* (Edgar, HIV).

*"Before they used to think that only us, homosexuals, were HIV positive you know, or we had to be a junky. And these are usually the two things that make most of society already discriminate against you, you know what I mean. And have you ever felt discriminated against? Me? I think anyone with this problem has. I don't believe that there is anyone who hasn't felt it, it's difficult, it's very difficult at least to convince me, now..."* (Julião, HIV)

In parallel, witnessing situations of discrimination, in which one doesn't have direct interference, may justify the decision to maintain hidden the condition of being a carrier of infectious disease, as it happened with one of the participants.

*“I see attitudes adopted, like, being in the neighbourhood with my friends, as happened once. They are getting on with their lives, trafficking I don’t know what, and some miserable bloke turns up, wanting to buy, and they turn to him and say: ‘get out of here junky, you miserable seropositive, you so-and-so.’ You understand, me there, listening... It affects you, doesn’t it? And I’m thinking to myself: ‘you don’t know what I’ve got, talking to an innocent bloke who you know has it, because he said or the guy went nuts.’ Then I get thinking ‘well, if they talk to him like that imagine if they knew that I had it!’ They wouldn’t speak to me like that. I guarantee you they wouldn’t speak to me like that, but it wouldn’t be the same, no it wouldn’t doctor. It wouldn’t be the same.” (Nuno, HIV)*

### **Health contexts and enacted stigma**

Another relevant dimension for the analysis of the impacts of the enacted stigma is the individual’s interaction with the health professionals, mainly because on these professionals lie most of the expectations of the participants regarding support, expertise, and access to health services (127, 128)

Among the eleven participants who talked about their relationship with these professionals, seven of them stated they felt discriminated against when using health services. With the exception of two interviewees (who experienced discrimination for being injecting drugs users), the other five participants are HIV carriers. The situations that the interviewees considered examples of discrimination involved instances when the expected interaction did not coincide with the standards observed, supporting the argument that exists a disconnection between what the individual expects to obtain, and the trivialization of the patient’s needs. Deep down, an incongruity between the experience lived by the patient and the interpretation the health care professional gives to it. (61)

The interviewees refer situations involving lack of attention concerning their clinical situation, or clinical state that led them to the health service, and the adoption of a distant attitude. One of the interviewees stated that the disease could not be transmitted by touch, suggesting that he experienced a situation of repulsion or absence of physical contact by the health professional. One of the participants also stated that there was a degree of negligence by the health professionals in relation to the needs of a drug user, and that in the situation he experienced he was not well served. Another research (129)exposes this same reality of lack of convergence between the expectations of the patient and its own experiences of treatment and counseling given by the health care professional.

*“Oh such and such a nurse seems to be grossed out by me! That is discrimination. I think all that is discrimination. The doctors should think a bit, if there is no contamination from touching people why do they discriminate against people like that?!”* (Ricardo, HIV)

*“At that time I wasn’t seropositive yet, but I was received with discrimination and a certain disdain.”* (Edgar, HIV)

*“At the hospital they didn’t give me the due attention that sometimes they have to give to a drug addict, normally. A person that is a drug addict, and it goes down really badly, a person is many times rejected, set aside.”* (Fábio, HIV)

Four of the participants had diametrically opposite perceptions. Similarly to a study of patients living with HIV infection, (130) their relationships with the health professionals and healthcare institutions never entailed discriminatory behaviour. Instead, they are contexts where there was deep knowledge about the condition of the infectious disease carrier, so they were contexts where the participants felt they were made welcome, and were comfortable, and were not treated with many of the labels that are attached to them in other contexts.

*“People are open and here it is easier. There isn’t the stigma of the diseases, everybody knows about the issues involved in the diseases.”* (Edgar, HIV)

*“We’re not treated like sick people there, we’re treated like people. They look at us. 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, HIV)

*“Do you think that the access is the same for everyone? Usually I think it is. But each case is a case you know, I think, I don’t know. But you never felt... Discriminated? Put to a side and that? No way.”* (Julião, HIV)

### **Social imagery and the hierarchy of infectious diseases**

Discrimination owing to lack of knowledge about the diseases leads to the emergence of a socially constructed imagery where the representations are (re)configured. In line with what is assumed by the principles of normalization discussed above, individuals tend to feel closer, more familiar with, what and those whom, associate positive mental representations (131) Therefore, five of the interviewees showed that their beliefs derived from a previously instituted scenario of the interpretative background of the condition as a carrier of an infectious disease. As an example, one of the interviewees said that he did not need anti-retroviral medication as a sign of his healthy condition.

*“Since they told me that it wasn’t necessary to take it at that time because my defences were very high. I had the defences, it wasn’t necessary to take the medication, so I got it into my head “oh I don’t want it!” that was the idea in my head, “I don’t want to take the medication, I’m fine as I am!” (Ricardo, HIV)*

Six participants mentioned a relevant aspect. As carriers of Hepatitis C their discourse showed they believed in a hierarchy of infectious diseases, in which Hepatitis is pushed into second place by HIV. However, the intersection of these two epidemics and the amount of population which carries both requires an additional analysis on how they perceive and deal/manage the duplicity of stigmas associated to them. (67)

*“But do you think that, remember how you felt when the doctor told you that you had hepatitis C? To me this is like normal hepatitis. The worst was the AIDS! In my head the worst was the AIDS” (Ricardo, HIV, HCV)*

In contrast to HIV, Hepatitis C is accepted as a consequence – now internalised – or a condition of the consumption by the injecting drug user showing that there is thus a causal link between the virus and the act of injecting (56). An example of that, in this imagery, is the notion that some interviewees have about the use of lemon juice in the preparative ritual that precedes consumption.

*“It is not a very serious thing, it is something which drug takers are usually expected to catch sooner or later isn’t it, they end up having it” (Marcelo, HCV).*

*“I already knew this was likely to happen because of the lemon and everything, this smashes everything. It was very likely and most drug addicts, almost all of them have it.” (Nuno, HCV)*

The common stereotypes associated to the experience of stigmatization related to the portability of HIV are necessarily more pervasive and detrimental to their well-being and lives compared to the HCV stigma. However, we should also refer another perspective which assures that, even though complying with a hierarchy – established either by imagetic, or by the experiences of stigma of individuals – HIV and HCV are associated to PWID, and for that matter, either one or another have a stigmatizing potential. (67)

Only two interviewees assumed TB had a more negative impact than HIV, because it is a disease easier to spread.

*“Do you think people have a portrait of people who have Tuberculosis? I don’t know. I think it’s even worse. I think it’s worse. Is it worse than with HIV? I think so, if it’s known that a person has TB it is worse. Why? Because I think so. Because I know that TB is easier to get. It’s easier to catch.” (Márcio, HIV, TB)*

“But what were the reactions of people, like close people that saw you with a mask? *Some were really bad. Them knowing you have HIV is bad enough, if they see that you have TB*” [it’s worse ]. (Maria, TB)

### ***Health literacy***

In addition to the concept of imagery – where the interviewees’ representations are sustained – we add another. The hiatus between the correct method of dealing with the illness and the (discriminatory) behaviours experienced by the interviewees are reflected in the World Health Organisation’s definition for literacy in health. In these cases, the competencies of the citizens identified as people who are literate in health (132) outline the adoption of informed behaviours, grounded decision making in health, in the heart of the community, at the workplace, in the use of the health system.

In fifteen interviewees, traits of illiteracy were identified in two different directions. Four of the interviewees revealed, themselves, lack of knowledge about the diseases which they were carriers of, both at the moment of diagnosis, and in situations of managing the disease in their everyday lives.

“What does it mean in Portugal for somebody to have HIV? *It’s complicated, very complicated. Why? Because of the stigma. A lot of people know what it is but they do not find out what HIV really means. They know only superficially. Indeed, I myself see this fault in myself (...) Innocently, I didn’t know whether I could infect a brother of mine through a fork.*” (Edgar, HIV)

From another viewpoint, one could identify scenarios of illiteracy in their peers in the discourses of eleven participants, aligned with the notion of hygienic degradation rituals (67, 133) according to which, in interaction situations with the carriers of infectious diseases, the non-contaminated individuals avoided physical contact, or when this was not possible, adopted excessive precautionary measures, even though contact was sporadic.

“*In my mother’s house I wouldn’t even ask for a glass of water. My brother slept on the sofa, they threw his clothes away and I just said to my sister: “Why are you going to throw the clothes away? Throw the sofa away too. He slept on the sofa. What’s the problem? You guys are retards.” It made me sad when I saw things like that, or he’d pick something up and another person would too but just with the tips of their fingers and then put it down, but not picking it up where he had picked it up. I’d see things like that, cutlery or dishes.*” (Fátima, HIV)

“*This happens; especially you have an example here which is the owner of the café in front who has cups for the users from here and other cups for the normal customers.*” (Ivo, HIV)

Nevertheless, we point out that seven of the interviewees perceived an evolution in the way society looks at carriers of infectious diseases. The main progress was found in the available information and subsequent way of interaction, corroborating the idea that a correlation exists between the rising levels of knowledge on diseases and the decreasing levels of stigma associated to them. (134)

*“But you were telling me you think that is different now, that people are... Yeah yeah, they are, it’s totally different now, people are better informed about the illness. Before being HIV positive was like a seven headed monster. At least I, I’ve noticed that. What do you notice the most? That we are better accepted, right, in society because before if anyone knew they just looked down on you, you know what I mean! It was difficult.”* (Patricia, HIV)

We should also refer to one of the cases in which literacy is clearly shown, both by the interviewee and by the family unit he belongs to. In this case, prior knowledge of the disease minimised the impacts at the moment it was disclosed.

*“And how do you think your family reacted when they found out? Um, there wasn’t really a problem because I explained it, it’s like this; my sisters have enough culture and age to know what it is, that it wasn’t a problem, my mother is a little bit more...I told her what I was, that there wasn’t a problem, with cutlery or anything, that you couldn’t catch it like that, only if it was blood on blood, so they accepted it and everything. A trivial thing.”* (Marcelo, HIV)

### ***Limitations of the study***

There are, at least, two limitations in this study, which relate with the purposive sample which was used. Despite our efforts to recruit a wide range of participants, the people who agreed to participate may differ in significant ways from those who did not participate. So, if an individual wasn’t seeking medical care or services of support, he/she did not had the chance to be recruited to collaborate in the study. The underrepresented female gender (four women within thirty participants) on the other hand, may be explained by the lower number of women who use injectable drugs compared to men in equivalent situation – sources refer that the users of Treatment Teams were mainly from the male gender, above 80%. (135)

It’s important to note that data cannot be generalized, because it was not used a representative sample of Portuguese people who inject drugs – so, we are aware that others might’ve had different experiences from the ones perceived by the participants of this study. However, we believe that the sample used represents a frequently ignored picture of illicit drug use and it promotes a more complex debate about this phenomenon.

# 5. Conclusions

- Even though everyone experienced stigmatization, the way to deal with those experiences is different. For some interviewees, the option to assume the disease which they carry is a reality they do not consider, including amongst their closest family members. Other interviewees decided to reveal their condition so they could receive family support. In either scenarios, the knowledge of social networks on the conditions which one can contract the disease and the contagion of infectious diseases, assume a relevant weight as an explainable factor to the elimination of stigmatization by these same networks. Therefore, the increase in health literacy constitutes a vital factor for the reduction of discrimination and stigma associated to drug users and, cumulatively, carriers of infectious diseases.
- A hierarchy of infectious diseases is notorious, being that the perception of greater severity is associated with HIV. HCV is, through a social imagery, assumed as a consequence of use/consumption of injectable drugs, so they're easier to be accepted by individuals, as well as the notion of severity associated to it. Thus, it seems to exist a great possibility to intervene through risk prevention policies in order to change the current situation.

# 6. References

1. Ricou M. A dependência: Doença ou Alienação Social? . In: Nunes R, Ricou M, Nunes C, editores. Dependências Individuais e Valores Sociais FMUP-UEP Porto Gráfica de Coimbra 2004.
2. WHO. Lexicon of alcohol and drug terms Available from: [www.who.int/substance\\_abuse/terminology/who\\_lexicon/en/](http://www.who.int/substance_abuse/terminology/who_lexicon/en/).
3. Ribeiro JS. Dependência ou dependências? Incidências históricas na formalização dos conceitos. Toxicodependências 1995;3.
4. Silveira JP, Pádua JM. Os utentes do Centro de Atendimento a toxicodependentes de Xabregas e a sua passagem pelo sistema judicial-penal. . Acta dos ateliers do Vº Congresso Português de Sociologia Universidade do Minho - Braga2004.
5. Teeson M, Teeson M, Degenhardt L. Addictions: Psychology press; 2002.
6. Spealman RD, Bergman J, Madras BK, Melia KF. Discriminative stimulus effects of cocaine in squirrel monkeys: involvement of dopamine receptor subtypes. J Pharmacol Exp Ther. 1991 Sep;258(3):945-53.
7. Koob GF, Le Moal M. Drug abuse: hedonic homeostatic dysregulation. Science. 1997 Oct 3;278(5335):52-8.
8. West R. Theories of addiction. Addiction. 2001;96:3-13.
9. Furnham A, Thomson L. Lay theories of heroin addiction. Soc Sci Med. 1996 Jul;43(1):29-40.
10. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 4th ed. Washington, DC American Psychiatric Association; 1994.
11. Elster J, Skog O-J. Getting hooked: rationality and addiction: Cambridge University Press; 1999.
12. West R. Theories of addiction. Addiction. 2001;96(1):3-13.
13. Schaler JAOCP. Addiction is a choice: Open Court Publishing; 1999.
14. Heyman G. Addiction: A disorder of choice: Harvard UP; 2009.
15. O'Donnell J. The rise and decline of a subculture. Social Problems. 1967;15.
16. Schasre R. Cessation patterns among neophyte heroin users. International Journal of the Addictions 1966;1(2).
17. Griffiths M. A 'components' model of addiction within a biopsychosocial framework Journal of Substance Use 2005;10(4):191-7.
18. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 3rd ed.(revised). Washington, DC American Psychiatric Association; 1987.
19. Cassel J. The contribution of social environment to host resistance. The fourth wade Hampton frost lecture. . American Journal of Epidemiology. 1976;104(2):107-23.
20. Negrão F. Direitos fundamentais e Exclusão Social In: Nunes R, Ricou M, Nunes C, editores. Dependências Individuais e Valores Sociais. FMUP-UEP Porto Gráfica de Coimbra; 2004.
21. Ribeiro JS. Dependência ou dependências? Incidências históricas na formalização dos conceitos. Toxicodependências. 1995;3.
22. EMCDDA. Guidelines for testing HIV, viral hepatitis and other infections in injecting drug users. Luxembourg: The Publications Office of the European Union; 2010.
23. UNODC. World Drug Report: United Nations Publication; 2011.

24. Greenwald G. Drug Decriminalization in Portugal - Lessons for creating fair and successful drug policies CATO Institute; 2009.
25. EMCDDA. Trends in Injecting Drug Use. Luxembourg: Publications Office of the European Union; 2010.
26. Balsa C, Vital, C., Urbano, C., Pascueiro, L. II Inquérito nacional ao consumo de substâncias psico-ativas na população geral, Portugal 2007. Lisboa: IDT 2008.
27. EMCDDA. Relatório anual 2010: a evolução do fenómeno da droga na Europa. Luxemburgo: Serviço das Publicações da União Europeia; 2010.
28. Negreiros J, Magalhães A. Estimates of the Prevalence of Problem Drug Use - Portugal 2005: IDT; 2005.
29. EMCDDA. Polydrug use. Annual report on the state of the drugs problem in the European Union and Norway 2002.
30. WHO. Available from: <http://www.who.int/mediacentre/factsheets/fs104/en/index.html>.
31. ECDC, OMS-Europa. HIV/AIDS surveillance in Europe 2009. Estocolmo: Centro Europeu de Prevenção e Controlo das Doenças; 2009.
32. Nucleo Vigilancia Laboratorial de Doenças Infecciosas. Infecção VIH/Sida - A situação em Portugal. Lisboa 2010.
33. IDT. Activities Report 2009 - The Situation of the Country on Drugs and Drug Addiction 2010.
34. Deiss RG, Rodwell TC, Garfein RS. Tuberculosis and illicit drug use: review and update. Clin Infect Dis. 2009 Jan 1;48(1):72-82.
35. WHO, UNODC, UNAIDS. Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users: an Integrated Approach. Evidence For Action Technical Papers Geneva: WHO; 2008.
36. National Programme to Fight Tuberculosis (PNT). Point of the Epidemiological Situation and Performance. 2010.
37. IDT. Activities Report 2010. 2011.
38. Duarte R, Santos AS, Mota M, Carvalho A, Marques A, Barros H. Involving community partners in the management of tuberculosis among drug users. Public Health. 2010;125:p.60-2.
39. Lavanchy. D. The global burden of hepatitis C. Liver International. 2009;29:74-81.
40. Aceijas C, Rhodes T. Global estimates of prevalence of HCV infection among injecting drug users. Int J Drug Policy. 2007 Oct;18(5):352-8.
41. ECDC., EMCDDA. Prevention and control of infectious diseases among people who inject drugs. Stockholm: ECDC; 2011.
42. Institute for Drugs and Addiction (IDT). Activities Report 2010 2011.
43. Institute for Drugs and Addiction (IDT). Activities Report 2006.
44. Institute for Drugs and Addiction (IDT). Activities Report 2008.
45. Scambler G. Health-related stigma. Sociology of Health & Illness. 2009;31.
46. Goffman E. Stigma: Notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice Hall; 1963.
47. Valdiserri RO. Editorial - HIV/AIDS Stigma: an impediment to public health. American Journal of Public Health. 2002;92:341-2.

48. Jutel A. Sociology of diagnosis: a preliminary review. *Sociol Health Illn.* 2009 Mar;31(2):278-99.
49. Goode E, Ben-Yehuda N. *Moral panics: the social construction of deviance.* Cambridge: Blackwell Publishers; 1994.
50. Maynard RJ. Controlling death - Compromising Life: Chronic Disease, Prognostication, and the New Biotechnologies *Medical Anthropology Quarterly.* 2006;20(2):212-34.
51. Scambler G, Hopkins A. Being epileptic: coming to terms with stigma. *Social Health Illness.* 1986;8:26-43.
52. Scambler G. Sociology, social structure and health-related stigma. *Psychol Health Med.* 2006 Aug;11(3):288-95.
53. Lloyd C. *Sinning and Sinned Against: The stigmatisation of problem drug users.* London UK Drug Policy Commission 2010.
54. Luoma JB, Twohig MP, Waltz T, Hayes SC, Roget N, Padilla M, et al. An investigation of stigma in individuals receiving treatment for substance abuse. *Addict Behav.* 2007 Jul;32(7):1331-46.
55. Van Brakel WH. Measuring health-related stigma--a literature review. *Psychol Health Med.* 2006 Aug;11(3):307-34.
56. Ahern J, Stuber J, Galea S. Stigma, discrimination and the health of illicit drug users. *Drug Alcohol Depend.* 2007 May 11;88(2-3):188-96.
57. Link BG, Struening EL, Rahav M, Phelan JC, Nuttbrock L. On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *J Health Soc Behav.* 1997;38:177-90.
58. Harris M. Injecting, Infection, Illness: Abjection and Hepatitis C Stigma. *Body & Society.* 2009 December 1, 2009;15(4):33-51.
59. Flom PL, Friedman SR, Kottiri BJ, Neaigus A, Curtis R, Des Jarlais DC, et al. Stigmatized drug use, sexual partner concurrency, and other sex risk network and behavior characteristics of 18- to 24-year-old youth in a high-risk neighborhood. *Sex Transm Dis.* 2001 Oct;28(10):598-607.
60. Bjerg O. Drug Addiction and Capitalism: Too Close to the Body. *Body & Society.* 2008;14(2):1-22.
61. Douglas M. *Purity and Danger: an analysis of concepts of pollution and taboo.* London: Routledge and Kegan Paul; 1966.
62. Tindal C, Cook K, Foster N. Theorising stigma and the experiences of injecting drug users in Australia. *Aust J Prim Health.* 2010;16(2):119-25.
63. Habib SE, Adorjany LV. Hepatitis C and injecting drug use: The realities of stigmatisation and discrimination. *Health Education Journal.* 2003 September 1, 2003;62(3):256-65.
64. Treloar C, Rhodes T. The lived experience of hepatitis C and its treatment among injecting drug users: qualitative synthesis. *Qual Health Res.* 2009 Sep;19(9):1321-34.
65. Butt G, Paterson BL, McGuinness LK. Living with the stigma of hepatitis C. *West J Nurs Res.* 2008 Mar;30(2):204-21; discussion 22-33.
66. Herek GM. AIDS and Stigma. *American Behavioral Scientist.* 1999;42(1106).

67. Frye V, Fortin P, MacKenzie S, Purcell D, Edwards LV, Mitchell SG, et al. Managing identity impacts associated with disclosure of HIV status: a qualitative investigation. *AIDS Care*. 2009 Aug;21(8):1071-8.
68. Link BG, Phelan JC. Stigma and its public health implications. *Lancet*. 2006 Feb 11;367(9509):528-9.
69. Herek GM, Glunt EK. An epidemic of stigma. Public reactions to AIDS. *Am Psychol*. 1988 Nov;43(11):886-91.
70. Lekas HM, Siegel K, Leider J. Felt and Enacted Stigma Among HIV/HCV-Coinfected Adults: The Impact of Stigma Layering. *Qual Health Res*. 2011 Apr 15.
71. Herek GM, Capitano JP. Symbolic prejudice or fear of infection? A functional analysis of AIDS-related stigma among heterosexual adults. *Basic and Applied Social Psychology*. 1998;20(3):230-41.
72. Mak WW, Cheung F, Woo J, Lee D, Li P, Chan KS, et al. A comparative study of the stigma associated with infectious diseases (SARS, AIDS, TB). *Hong Kong Med J*. 2009 Dec;15 Suppl 8:34-7.
73. Alonzo A, Reynolds N. Stigma, HIV and AIDS: an exploration and elaboration of a stigma strategy. *Social Science and Medicine* 1995;41:303-15.
74. Fitzgerald JL, McDonald K, Klugman M. Unspoken but everpresent. Hepatitis C in a regional setting. Melbourne: University of Melbourne; 2004.
75. Juniarti N, Evans D. A qualitative review: the stigma of tuberculosis. *J Clin Nurs*. 2011 Jul;20(13-14):1961-70.
76. Long NH, Johansson E, Diwan VK, Winkvist A. Fear and social isolation as consequences of tuberculosis in VietNam: a gender analysis. *Health Policy*. 2001 Oct;58(1):69-81.
77. Grange J, Story A, Zumla A. Tuberculosis in disadvantaged groups. *Curr Opin Pulm Med*. 2001 May;7(3):160-4.
78. Reidpath DD, Chan KY. A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*. 2005 May;17(4):425-32.
79. Diário da República., 259. 1976 [15 August 2011]; Available from: <http://dre.pt/pdf1sdip/1976/11/25900/25122516.pdf>
80. Poiares C. Descriminalização construtiva e intervenção juspsicológica no consumo das drogas ou recuperar o tempo perdido Toxicodependências. 2000;6(2):7-16.
81. Resolução do Conselho de Ministros, (1999).
82. Decreto-Lei n. 15/93, (1993).
83. Portaria n 94/96, (1996).
84. Diário da República. Lei nº 30/2000. 2000; Available from: <http://dre.pt/pdf1sdip/2000/11/276A00/68296833.pdf>.
85. Hughes C, Stevens A. What can we learn from the portuguese decriminalization of illicit drugs? *Brit J Criminol*. 2010;50:999-1022.
86. Poiares C. A descriminalização do consumo de drogas: abordagem juspsicológica. *Toxicodependências*. 2002;8(2):29-36.
87. Decreto-lei nº130-A, (2001).
88. Valente MM. Consumo de drogas: Reflexões sobre o quadro legal. Almedina S, editor. Coimbra2006.

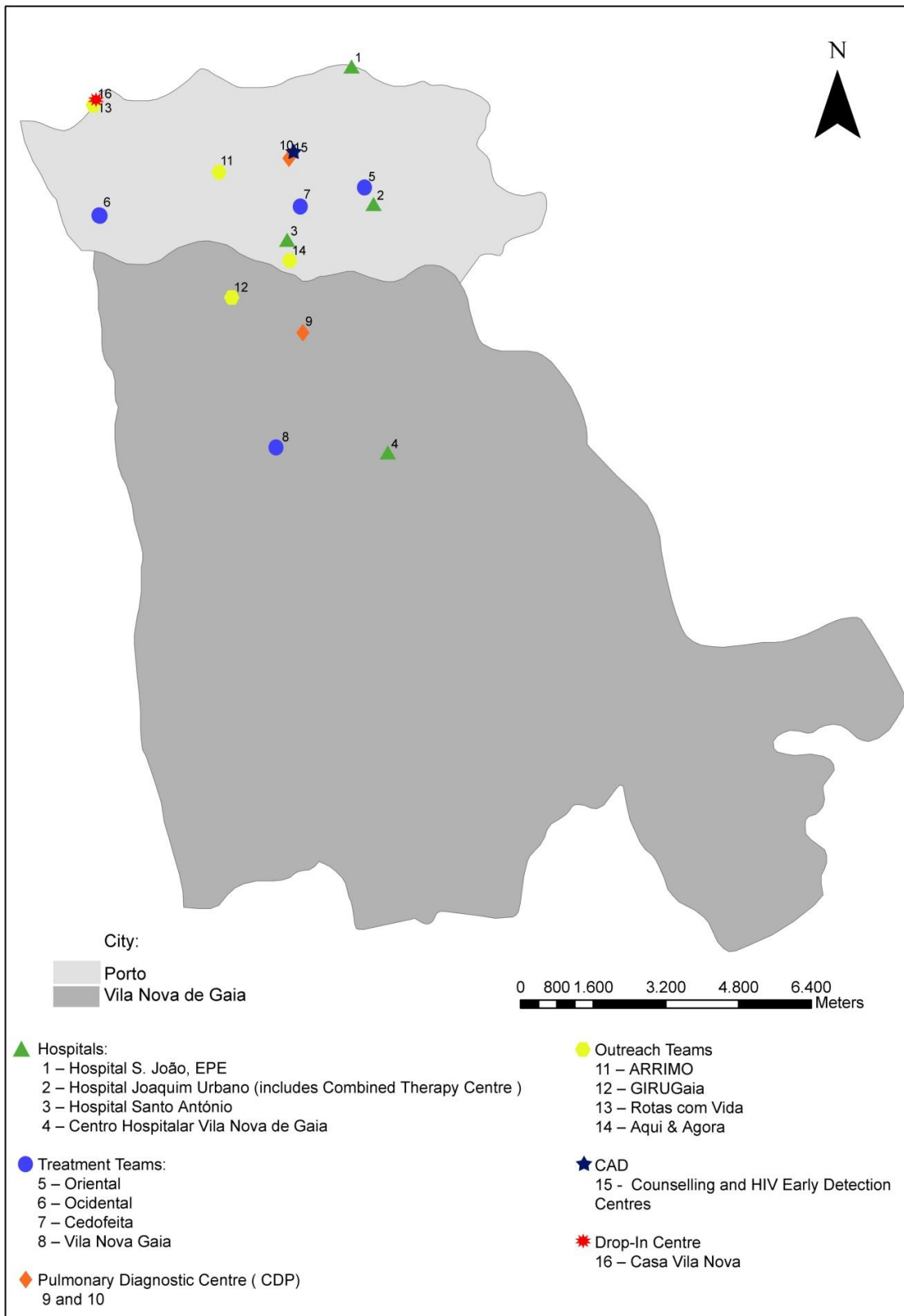
89. Institute for Drugs and Drug Addiction.; Available from: [www.idt.pt](http://www.idt.pt)
90. Diário de Notícias. Balanço - 10 anos após a descriminalização do consumo de droga. 2011; Available from: [http://www.dn.pt/inicio/portugal/interior.aspx?content\\_id=1837101](http://www.dn.pt/inicio/portugal/interior.aspx?content_id=1837101).
91. Grenfell P, Carvalho AC, Cosme D, Martins A, Barros H, Rhodes T. Scaling-up access to high-quality harm reduction, treatment and care for people who inject drugs in the European region, work package 3: A rapid assessment of the quality and accessibility of integrated TB, HIV and harm reduction services for people who inject drugs in Portugal [forthcoming]. Geneve: WHO- Europe; 2011.
92. Faculdade de Medicina da Universidade do Porto (FMUP). Program for Early Detection and Prevention of HIV/AIDS in Drug Users (Klotho) - Relatório de Monitorização (2007-2008)2009.
93. Program "Say no to a second-hand syringe" (1999-2009). National Coordination of HIV/AIDS Infection; National Association of Pharmacies; Ministry of Health.
94. National Coordination for HIV/AIDS Infection.; Available from: [www.sida.pt](http://www.sida.pt).
95. Associação Nacional de Farmácias. Programa de Troca de Seringas nas Farmácias (1993-2008).
96. Torre C, Lucas R, Barros H. Syringe exchange in community pharmacies--The Portuguese experience. Int J Drug Policy. 2010 Nov;21(6):514-7.
97. Associação Nacional de Farmácias. A intervenção das farmácias no tratamento das toxicodependências - relatório 2008. 2009; Available from: [http://www.anf.pt/media/metadona\\_16jul09.pdf](http://www.anf.pt/media/metadona_16jul09.pdf).
98. National Coordination for HIV/AIDS Infection. Available in: [www.sida.pt/](http://www.sida.pt/).
99. Sarmiento Castro R, et al.,. Tuberculosis in patients with AIDS. Complete treatment under direct observation. . Revista Portuguesa de Pulmonologia. 2001.
100. General Management of Prison Health Services.; Available from: [www.dgsp.mj.pt](http://www.dgsp.mj.pt).
101. Norte Vida - Associação para a promoção da Saúde.; Available from: [http://www.nortevida.org/v1/index.php?option=com\\_content&view=article&id=2&Itemid=5](http://www.nortevida.org/v1/index.php?option=com_content&view=article&id=2&Itemid=5).
102. Bastos SP. O Estado Novo e os seus vadios - Contribuição para o estudo das identidades marginais e da sua repressão. Lisboa: Dom Quixote; 1997.
103. Silva S. Classificar e silenciar: vigilância e controlo institucionais sobre a prostituição feminina em Portugal. . Análise Social. 2007;184:789-810.
104. Rhodes T, et al. Rapid assessment, injecting drug use, and public health. Lancet. 1999;354(9172):p.65-8.
105. Power R. Participant observation and its place in the study of illicit drug abuse. Br J Addict. 1989 Jan;84(1):43-52.
106. Holloway I. Qualitative research in health care.: Milton Keynes: Open University Press; 2005.
107. Glaser B, Strauss A. The discovery of grounded theory: strategies for qualitative research. New York: Aldine de Gruyter; 1967.
108. Clark T. `We're Over-Researched Here!'. Sociology. 2008 October 1, 2008;42(5):953-70.

109. Mitchell W, Irvine A. I'm Okay, You're Okay?: Reflections on the Well-Being and Ethical Requirements of Researchers and Research Participants in Conducting Qualitative Fieldwork Interviews. *International Journal of Qualitative Methods*. 2008.
110. Boss PG. The role of intuition in family research: Three issues of ethics. *Contemporary Family Therapy*. 1987;9(1):146-59.
111. Peel E, Parry O, Douglas M, Lawton J. "It's No Skin off My Nose": Why People Take Part in Qualitative Research. *Qualitative Health Research*. 2006 December 1, 2006;16(10):1335-49.
112. Karnieli-Miller O, Strier R, Pessach L. Power Relations in Qualitative Research. *Qualitative Health Research*. 2009 February 1, 2009;19(2):279-89.
113. Fry C, Dwyer R. For love or money? An exploratory study of why injecting drug users participate in research. *Addiction*. 2001 Sep;96(9):1319-25.
114. Hughes R. Recruiting injecting drug users. In: *Understanding and responding to drug use: the role of qualitative research*: EMCDDA; 2000.
115. Denzin NK, Lincoln YS. *The SAGE Handbook of Qualitative Research*: SAGE Publications; 2011.
116. Ciccarone DH, Kanouse DE, Collins RL, Miu A, Chen JL, Morton SC, et al. Sex without disclosure of positive HIV serostatus in a US probability sample of persons receiving medical care for HIV infection. *Am J Public Health*. 2003 Jun;93(6):949-54.
117. Klitzman R, Bayer R. *Moral secrets: Truth and lies in the age of AIDS*. Baltimore: University Press; 2003.
118. Sobo EJ. Human immunodeficiency virus seropositivity self-disclosure to sexual partners: a qualitative study. *Holist Nurs Pract*. 1995 Oct;10(1):18-28.
119. Wozniak L, Prakash M, Taylor M, Wild TC. Everybody's got it, but...: situational and strategic participation in normalized HCV discourse among injection drug users in Edmonton, Canada. *Int J Drug Policy*. 2007 Oct;18(5):388-96.
120. Butt G. Stigma in the context of hepatitis C: concept analysis. *J Adv Nurs*. 2008 Jun;62(6):712-24.
121. Faye B., Irurita VF. Balacing perspective: the response to feelings of being condemned with Hepatitis C virus. *Journal of Substance Use*. 2003;8(2).
122. Bourdieu P. *Razões Práticas - Sobre a teoria da acção* Celta 2001.
123. Goffman E. *A Apresentação do Eu na Vida de Todos os Dias*. Lisboa: Relógio d'Água 1993 (1959).
124. Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill *Sociology of Health & Illness*. 1983;5(2 ).
125. Simmonds L, Coomber R. Injecting drug users: a stigmatised and stigmatising population. *Int J Drug Policy*. 2009 Mar;20(2):121-30.
126. Pierret J. The illness experience: state of knowledge and perspectives for research *Sociology of Health & Illness*. 2003 25(3).
127. Hays RB, McKusick L, Pollack L, Hilliard R, Hoff C, Coates TJ. Disclosing HIV seropositivity to significant others. *AIDS*. 1993 Mar;7(3):425-31.
128. Bogart LM, Cowgill BO, Kennedy D, Ryan G, Murphy DA, Elijah J, et al. HIV-related stigma among people with HIV and their families: a qualitative analysis. *AIDS Behav*. 2008 Mar;12(2):244-54.

129. Herek G, Capitanio J. AIDS stigma and sexual prejudice. *American Behavioral Scientist* 1999;42(7).
130. Paterson BL, Backmund M, Hirsch G, Yim C. The depiction of stigmatization in research about hepatitis C. *Int J Drug Policy*. 2007 Oct;18(5):364-73.
131. Temple-Smith M, Gifford S, Stoov Eacute M. The lived experience of men and women with hepatitis C: implications for support needs and health information. *Aust Health Rev*. 2004;27(2):46-56.
132. Hopwood M, Treloar C. The experience of interferon-based treatments for hepatitis C infection. *Qual Health Res*. 2005 May;15(5):635-46.
133. Surlis S, Hyde A. HIV-positive patients' experiences of stigma during hospitalization. *J Assoc Nurses AIDS Care*. 2001 Nov-Dec;12(6):68-77.
134. Thomas S. The importance of Social Imagery in Interpreting Societally Devalued People to te Public. *The International Social Role Valorization Journal* 1994;1
135. WHO. Track 2: Health literacy and health behaviour 1998; Available from: <http://www.who.int/healthpromotion/conferences/7gchp/track2/en/>.
136. Lekas HM, Siegel K, Schrimshaw EW. Continuities and discontinuities in the experiences of felt and enacted stigma among women with HIV/AIDS. *Qualitative Health Research* 2006;16:1165-90.
137. Gilbert L, Walker L. 'My biggest fear was that people would reject me once they knew my status...': stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health Soc Care Community*. 2010 Mar;18(2):139-46.
138. EMCDDA. 2010 National Report (2009 data) to the EMCDDA: New development, Trends and in-depth information on selected issues. 2010.

# 7. Appendix

**Appendix no.1 - Geographic distribution of HIV, TB, HCV and harm reduction services in Porto and Vila Nova de Gaia**



## **Appendix no.2 – Informed consent sheet**

# DECLARAÇÃO DE CONSENTIMENTO

*Considerando a "Declaração de Helsínquia" da Associação Médica Mundial  
(Helsínquia 1964; Tóquio 1975; Veneza 1983; Hong Kong 1989; Somerset West 1996 e Edimburgo 2000)*

## **Designação do Estudo: Estudo sobre a experiência no acesso ao tratamento de VIH e Tuberculose em utilizadores de drogas injectáveis em Portugal.**

**Eu**, abaixo-assinado, (nome completo do participante) \_\_\_\_\_  
\_\_\_\_\_, compreendi a explicação que me foi fornecida, por escrito e verbalmente, da investigação que se tenciona realizar, para qual é pedida a minha participação. Foi-me dada oportunidade de fazer as perguntas que julguei necessárias, e para todas obtive resposta satisfatória.

Tomei conhecimento de que, de acordo com as recomendações da Declaração de Helsínquia, a informação que me foi prestada versou os objectivos, os métodos, os benefícios previstos, os riscos potenciais e o eventual desconforto. Além disso, foi-me afirmado que tenho o direito de decidir livremente aceitar ou recusar a todo o tempo a minha participação no estudo. Sei que se recusar não haverá qualquer prejuízo na assistência que me é prestada.

Foi-me dado todo o tempo de que necessitei para reflectir sobre esta proposta de participação.

Nestas circunstâncias, decido livremente aceitar participar neste projecto de investigação, tal como me foi apresentado pelo investigador(a).

Data: \_\_\_\_ / \_\_\_\_\_ / 20\_\_\_\_

**Assinatura do(a) participante:** \_\_\_\_\_

**O(A) Investigador(a) responsável:**

Nome: \_\_\_\_\_

Assinatura: \_\_\_\_\_

## **Appendix no.3 – Information sheet**

## **Folha de informação ao participante**

Caro participante,  
Está a ser desenvolvido um estudo sobre o modo como pessoas com história presente ou passada de consumo de drogas injectáveis vêem o acesso aos serviços de saúde, especialmente no que diz respeito ao tratamento do VIH e da tuberculose. Gostaríamos de contar com a sua participação.

A sua identidade será sempre protegida e nada que mencionar será ligado a si.

Antes de decidir se quer participar é importante que compreenda o motivo pelo qual o estudo está a ser efectuado e o que envolve.

Por favor leia atentamente este folheto informativo e coloque todas as perguntas que achar necessário.

**Obrigado pelo tempo concedido à leitura desta informação!**

## **Por que queremos falar consigo?**

A finalidade do estudo é entender como os utilizadores de drogas injectáveis têm acesso ao tratamento do VIH e da TB.

Serão abordadas pessoas que tenham história passada ou recente de utilização de drogas injectáveis, portadoras ou não do VIH e quer tenham feito, ou não, tratamento antiretroviral ou tratamento para a tuberculose.

A informação recolhida será usada na tentativa de assegurar melhores serviços para utilizadores de drogas injectáveis, em especial no que diz respeito ao acesso ao tratamento do VIH e da TB.

## **Quem é responsável pelo estudo?**

O estudo é financiado pela Organização Mundial de Saúde para a Europa e está a ser executado por investigadores na Universidade de Porto. O estudo é desenvolvido em colaboração com a London School of Hygiene and Tropical Medicine (Universidade de Londres), Reino Unido.

## **O que é que este estudo envolve?**

Gostaríamos de entrevistá-lo. A entrevista terá duração máxima de duas horas. Durante a entrevista será inquirido sobre experiência pessoal e opinião sobre o uso de drogas injectáveis, e tratamento de HIV, TB e dependência de drogas. Como inquirido pode levantar qualquer questão que pense ser importante e que não tenha sido abordada por nós.

Como participante não terá que falar sobre assuntos que prefira não discutir.

A entrevista será gravada para nos certificarmos que nenhuma informação é esquecida. A gravação será mantida num local seguro a que somente os investigadores do estudo têm acesso.

Mesmo após decidir participar poderá desistir da entrevista a qualquer altura e sem dar uma razão.

## **A pesquisa é confidencial?**

**Sim.**

Toda a informação que partilhar connosco será vista somente pelos membros da equipa de investigação. A informação será armazenada de forma segura. Isto significa que sempre que se utilizar alguma informação mencionada na entrevista nunca será usado o seu verdadeiro nome.

A única situação em que a confidencialidade poderá ser quebrada será caso revele informações que ponham em causa a sua segurança ou a de uma criança.

### **Quais serão os benefícios da minha participação?**

Será participante de um estudo que procura melhorar os serviços que os utilizadores de drogas injectáveis recebem, especialmente no que diz respeito ao tratamento de VIH e TB.

No final da entrevista ser-lhe-á oferecido um sumo e um snack.

### **Sou obrigado a participar?**

**Não.**

Caso decida não participar esta decisão não terá qualquer influência em nenhum dos serviços que usufrui.

### **Como será usada a investigação?**

Os resultados deste estudo serão divulgados a várias pessoas, incluindo aquelas que fornecem apoio no tratamento de VIH e TB e serviços para utilizadores de drogas injectáveis.

**Obrigado por ter lido este folheto!**

**A sua participação será muito valiosa.**

**As entrevistas apenas prosseguirão depois de colocadas todas as questões pelo participante e após assinatura do consentimento informado.**

**Ser-lhe-á dado este folheto informativo e uma cópia do consentimento informado.**

**Estudo sobre a experiência no acesso ao tratamento de VIH e Tuberculose em utilizadores de drogas injectáveis em Portugal**