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From Stigmatisation to Criminalisation:
**An exploratory study of the views on the criminalisation of HIV sexual transmission in
England.**

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A thesis submitted in partial fulfilment of the requirements of the
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Abstract

This thesis investigated the intricacies of moral, conative, and cognitive contents, in the context of the criminalisation of HIV transmission and HIV stigma. Though HIV is a rather recent challenge with its outbreak placed during the late 70s and early 80s, HIV-related stigma, social seclusion, and legal repression are well-studied phenomena. Despite being an epiphenomenon, the criminalisation of HIV transmission appears to be disproportionately focused on; sometimes, it is also denounced as a form of stigma. To disentangle structural, institutional, social, and individual aspects of the criminalisation of HIV transmission, an interdisciplinary approach based on constructionist realism was chosen, drawn upon philosophical, psychological and socio-legal works, through descriptive reviews and critical syntheses.

The multifaceted phenomena of both stigma and criminalisation required a layered or intersectional approach leading to a mixed-method study. This study investigated the views of participants from both key-informants and the general public on the topic of the criminalisation of HIV transmission. This mixed-methods study was designed to assess the impact of stigma research on participants and to consider its potential deleterious impact. Results highlighted that stigmatising views were associated with pro-criminalisation attitudes. The qualitative inquiry showed discrepancies between the rationales and principles invoked by participants and their different moral stances. The responsive analysis indicated potential prosocial effects of the study on participants and showed an increase of perceived stigma subscale scores among the participants from the public. This was interpreted as a familiarisation effect of the study and a secondary positive outcome. A sub-sample of participants showed increased blaming subscale scores, highlighting the ethical challenges of stigma research. Results were discussed in terms of knowledge and disclosure, in light of the primacy of moral ontological and epistemological aspects. Recommendations regarding stigma research were suggested in terms of longitudinal design, assessment reactivity, and/or evaluation of impact.

All models are wrong, but some are useful.

George E. P. Box

People know what they do; frequently they know why they do what they do; but what they do not know is what what they do does.

Michel Foucault

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And those who will.

Glossary of Acronyms

ART / HAART	Anti-Retroviral Therapy / Highly Active Anti-Retroviral Therapy
COPFS	Crown Office and Procurator Fiscal Service (Scotland)
CPS	Crown Prosecution Services (England and Wales)
CT	Constitution Thesis
FG / FGs	Focus Group / Focus Groups
GBH	Grievous Bodily Harm
HIV	Human Immunodeficiency Virus
HPV	Human PapillomaVirus
IPA	Interpretative Phenomenological Analysis
KI / KIs	Key-Informant / Key Informants
MCCQ	Multiple Choice Questions
MSM	Men who have Sex with Men
MMU	Manchester Metropolitan University
n/a	Not applicable
nr	Not retrieved / not reported
PEP	Post Exposure Prophylaxis
PrEP	Pre-Exposure Prophylaxis
RT	Regulation Thesis
SC	Social Categorisation
SDT	Social Dominance Theory
SR	Social Representations
STIs	Sexually Transmissible Infections
TA	Thematic Analysis
TasP	Treatment as Prevention
WHO	World Health Organisation

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INTRODUCTION

The criminalisation of Human Immunodeficiency Virus (HIV) is a sensitive topic for people living with HIV, professionals working with people living with HIV, and civil societies. As each society finds a compromise between individual and collective rights, individual and public interest, the criminalisation of HIV transmission raises new ethical, social, interpersonal, moral, and health-related challenges.

Foreword

Before entering the core subject of this dissertation, the events surrounding this doctoral journey might be worth considering. Two main ones contributed to the thought process, the approach, and the structure of this dissertation. The first one is a clinical case I was asked to reflect upon in a clinical meeting hosted by former colleagues, the second one is the case of Daryll Rowe.

Four years ago, at the very beginning of this project, I was invited to take part in a clinical meeting discussing the personality of a person who had been convicted and incarcerated twice for HIV transmission in another country. The disarray and perplexity of the prison medical staff were palpable and the relevance of a prison sentence was questioned without any possible answers to be given which led to a deep feeling of powerlessness among them. I maintained regular contact with the psychiatrist treating this person.

A couple of years later, during the data collection phase of this project, newspapers started releasing information about Daryll Rowe's case. Some participants mentioned this case when it was not ruled yet. I decided to attend, at least partly, the trial, the following information is based on personal notes taken during the first week of Daryll Rowe's trial in Lewes Crown Court (case T20177014). Preliminary matters and the constitution of the jury occurred on Tuesday 3^d October; the inaugural plea was held on Thursday 5th October, in the afternoon. The initial charges against Daryll Rowe consisted of ten counts of Grievous Bodily Harm (GBH), section 18 of the Offences Against the Person Act (OAPA, 1861)¹, four counts for causing GBH

¹ See [chapter 1](#) for legislation in England and Wales.

with intent and six counts for attempting GBH with intent, later reclassified as to five counts for each.

Daryll Rowe is a twenty-eight-year-old man, who was diagnosed with HIV in 2015 in Scotland. According to the inaugural plea of the lead prosecutor of the Crown Prosecution Service (CPS), and later from the expert witness from the Scottish sexual health clinic, Daryll Rowe declined treatment and medication regarding HIV and herpes. He was informed about his legal liability in case of onward transmission; he was also strongly advised to disclose his serostatus to potential sexual partners (as developed in the health professionals' guidance²). He then left to settle in the Brighton area, an area in which he developed several short-term relationships giving rise to the proceedings. In February 2016, the sexual health clinic in Brighton alerted the police services after the diagnosis of HIV in several gay men who described a similar partner, which appeared to be a complex decision for the medical staff.

After several months in Brighton, and a first interrogation by the local police, Daryll Rowe left and under a different identity, he settled in the North East, being accommodated successively by two men. The ten complainants are Men who have Sex with Men (MSM) who had sexual intercourse with Daryll Rowe; eight are from the Brighton area, the last two from North East. Seven of them have been, since their encounter with the defendant, diagnosed with HIV. Six of them carry a strain of the virus closely related to the strain identified in Daryll Rowe's blood. Virological strains are not evidence, rather (non) corroborative elements³, hence, all potential transmissions were not qualified, in terms of charges, as causing GBH with intent.

Among the incriminating evidence provided by the CPS, two main elements have to be mentioned. The first one is Daryll Rowe's denial to some partners of his HIV status via text message conversations and his disclosure to one of them; the second relates to the allegations of tampering condoms when sexual partners insisted on using them. The former was presented as a rejection of any potential claim of clinical denial regarding his condition, the latter as a premeditated preparatory act pointing the intention. The lead prosecutor qualified the facts of the case and the defendant's alleged actions as a "*cynical and deliberate campaign to infect*", insisting on the lies, the deception, and the verbally abusive behaviours afterwards to the alleged victims.

² This will be developed in [section 1.1.1](#).

³ See [section 1.1.1](#) on virological evidence.

In her allocutions, the lead prosecutor emphatically and consistently committed to showing how the ten male complainants were responsible gay men, regularly screened, using condoms, one of them was *even* working for an HIV Charity. She also insisted on how Daryll Rowe was, by the choices he made (declining treatment, trying to cure himself with alternative medicine or treatment such as drinking urine), everything but a reasonable patient, everything but a responsible person living with HIV. The diligence of the lead prosecutor in her choice of words not to assimilate Daryll Rowe's actions or behaviour to a whole community was remarkable and, surely, came from a great, watchful, and caring consideration for gay men and the LGBTBT+ community and people living with HIV. There is no opinion to be developed regarding the case, the verdict, the experiences of the defendant, and foremost of the victims. Simply, and because stigma is one of the key concepts of this study, it was unaffectedly observed in this slow, disaffiliative process, differentiating oneself from the others, haltingly but inescapably rejected from any possible in-group, sadly *human, all too human*.

On Wednesday 15th November 2017, Daryll Rowe was found guilty of five counts of causing GBH with intent and five counts of attempting GBH with intent. After less than two days of deliberation, the jury followed the recommendations of the CPS. In April 2018, Daryll Rowe was sentenced to life with a minimum term of 12 years; in November 2018, the case was taken to the Court of Appeal in London, but it was ruled that the grounds presented on Rowe's behalf to appeal against his conviction and sentence were deemed "unarguable". It is the maximal sentence ever pronounced in the context of HIV transmission in England and Wales.

Global context

The worldwide HIV pandemic

Since the beginning of the HIV epidemic in the mid-1970s, more than 75 million people have acquired HIV. Almost half of those who had been infected with HIV have died because of HIV-related illnesses. In 1996, the advent of the antiretroviral therapy (ART) marked the end of HIV as a death sentence and ushered in a new era where HIV was conceptualised as a chronic condition (Matic et al., 2006; WHO, 2006). As to 2016, it was estimated that, worldwide, there were 36.7 million people living with HIV, 19 million people on antiretroviral therapy (ART), 1.8 million new HIV diagnoses, and 1 million AIDS-related deaths (UNAIDS, 2017).

Criminalisation of HIV worldwide: transmission, exposure, and non-disclosure

References to past socio-legal issues regarding HIV can be found as far back as the beginning of the pandemic (Kenney, 1992), the most notable comparison being made with the legal issues

presented by syphilis in the nineteenth century (Brandt, 1988). Before ART, the criminalisation of HIV transmission was an epiphenomenon. The first known prosecutions occurred in the late 1980s in Germany and the USA (UNAIDS, 2012).

In 2016, 72 countries had legal provisions to criminalise the successful transmission of HIV, the exposure to HIV, and/or the non-disclosure of one's status to a sexual partner (HIV Justice Network and Global Network of People Living with HIV, 2016). Legal provisions can be generic (existing laws that include HIV transmission, exposure or non-disclosure) or specific. Some recent specific laws (e.g. N'Djamena Model Law) extended prosecution criteria, likely to include vertical transmission (Kazatchkine, 2010; Eba, 2015). Over time, the number of legal provisions to criminalise HIV transmission increased (Schüklenk, 2008) and local other types of offences or regulations emerged. For instance, in New South Wales (Australia), the mandatory disclosure of one's status to sexual partners is regulated under The Public Health Act, 2010 section 79(3).

Pro and anti-criminalisation rationales

The global situation is one of changing priorities, oscillating between prevention and protection, public health and Human Rights concerns (Orr, 1989; Matthiesson, 2010; Dennin et al., 2011). Pro-criminalisation arguments consider legal enforcement as a structural intervention likely to reduce the number of transmissions (Hermann, 1990), and as an individual punishment for harming one another (van Wyk, 2000; Francis and Mialon, 2009; Mathen and Plaxton, 2011).

By contrast, the anti-criminalisation rationale has been based on the protection of human rights (Mann, 1992; Cameron, 1993). The anti-criminalisation agenda has also been supported by empirical studies showing the deleterious impact of criminalisation on public health goals and people's well-being (Horvath et al., 2010; O'Byrne et al., 2013a; Philips et al., 2013; Gruskin et al., 2014). Globally, it is argued that the population most vulnerable to acquiring HIV are likely to be already subject to legal and social oppression, dependent on certain status or behaviours. These populations are undocumented people (Deblonde et al., 2015), sex workers (Baral et al., 2015; Shannon et al., 2015; Reeves et al., 2017), substance users (Csete et al., 2016), ethnic minorities (Gwadz et al., 2015), sexual and gender minorities (Carroll, 2016; Rodriguez, 2016; Ahmed et al., 2011), and people in detention (Jürgens et al., 2011)..

Criminalisation of HIV transmission in the UK

According to epidemiological modelling, between 100,000 and 110,000 people live with HIV in the UK, 13% of them are undiagnosed (Kirwan et al., 2016). In the British adult population, the prevalence is under 1%. Since 2005, the number of new diagnoses slowly decreased (Skingsley et al., 2015a; Skingsley et al., 2015b), reaching 5,164 people newly diagnosed in 2016 (Public Health England, 2017).

Since 2001, there were thirty-two (32) convictions for STIs and HIV transmission in the UK; twenty-six (26) convictions for HIV transmission and three (3) convictions for STIs transmission under the Offences Against the Person Act (OAPA, 1861) in England and Wales; three (3) convictions under the Scots Criminal Law for transmission in Scotland. The prosecution and the conviction adhere to specific rules (see [Chapter 1](#)) and determined conditions (Law Commission, 2014). The criminalisation of HIV transmission has, nevertheless, another impact on society, which might entail public health policies, leading to potential deleterious social consideration or a negative public image of people living with HIV (WHO, 2015).

The focus of the present study

The aim of this study is not a legal analysis, already robustly documented elsewhere, both globally (Weait, 2011; Grace, 2013, 2015; Stanton and Quirk, 2016) and locally (Weait, 2007; Chalmers, 2008; Symington, 2009; Kazatchkine, 2010). It is rather to understand the tendency to criminalise the transmission of HIV despite the consistent anti-criminalisation efforts, both in the UK and internationally⁴. This study came from the acknowledgement of a social double bind⁵. On the one hand, people living with HIV are likely to be stigmatised by criminalisation, which has public health and social consequences. On the other hand, the criminalisation of HIV transmission reflects an official condemnation, reframing both Criminal Law, social and intimate relationships (Weait, 2007).

Three sets of overarching questions are at the centre of this project:

1. What are the pro-criminalisation and anti-criminalisation rationales; what kinds of spontaneous arguments arise in the discussions? Do informed and uninformed people present the same arguments and rationales?

⁴ The number of publications from international organisations (UNAIDS / OHCHR, 2006; Weait, 2011; UNAIDS, 2012; Bernard and Bennett-Carlson, 2012; WHO, 2006, 2015; WHO and UNAIDS, 2015), scholars (Burriss and Cameron, 2008; Cameron et al., 2008; Jürgens et al., 2009; Langley and Nardi, 2010; Kazatchkine et al., 2015; Mykhalovskiy, 2015) and health professionals (Boyd et al., 2016) is to be noted.

⁵ This will be furthered in [section 4.3.2](#).

2. What are the moral judgements and emotional components involved in the rationale and are they related to any form of stigma or preliminary prejudicial views?
3. How do participants experience taking part in stigma research? Does the participation change, modify or reinforce their views? Is stigma research deleterious?

The present study focuses on the in-depth exploration of people's pro, anti-criminalisation views, and their social and moral foundations. Key-Informants (KIs) were interviewed one-to-one while participants from the public took part in a focus group (FG). A common semi-structured interview was used to explore their views on the criminalisation of HIV sexual transmission. Key informants were health professionals, legal system professionals and people living with HIV. The exploration of the explicit (deliberate) and the implicit (automatic) contents, focused on the congruent and discordant elements, and an analysis of moral and emotional aspects. The criminalisation of HIV transmission was explored based on a theoretical pluralism approach and the conceptual triangle of stigma, legality and morality. A constructivist realism approach was chosen (see [section 4.4](#)), in order to, firstly, encompass the theoretical and methodological pluralism found in interdisciplinary studies and in HIV research; and secondly, to pertain to almost a decade of clinical practice as a psychologist. Thus, a combination of topic-related and disciplinary works converges to explain this social phenomenon, which explains the presence of four background chapters and two supplementary desk research respectively related to chapter 1 and 4.

[Chapter 1](#) provides the legal ground for the prosecution and conviction of HIV transmission in England and Wales. Criminal cases leading to conviction are listed and information regarding the defendants and the complainants were retrieved; the sociodemographic mismatch between people involved in criminal cases and people living with HIV is discussed in terms of social treatment of HIV and possible biases. The HIV transmission occurred in the context of sexual contact in all criminal cases, hence the focus of this study on the views on the criminalisation of HIV sexual transmission. This chapter also led to the hypothesis that in the absence of a specific offence, the use of an existing offence (in this case GBH) to prosecute and convict the transmission of HIV might partly rely on the social perception of HIV.

To identify the current knowledge and gaps on the topic of the views on the criminalisation of HIV transmission, a review of empirical studies on this theme was performed ([Chapter 2](#)). It underscored the scarcity of research on this topic and that the majority of the participants in the studies retrieved were MSM and people living with HIV, informing the methods of the

present study (i.e. it led to include participants from the public). In terms of findings, themes elicited, such as disclosure and responsibility, summarised the emotional, relational, and professional challenges, faced by the populations sampled. Identified information needs were legal guidance and support for people living with HIV and professionals, and legal and sexual health-related information for MSM.

The two following chapters are articulated as respectively a descriptive and a critical analyses of HIV-stigma and stigma research. [Chapter 3](#) contextualises stigma research and the contact hypothesis (Allport, 1954) that is used as a variable in this study under the item of level of familiarity. It also provides an overview of HIV-stigma studies and their findings and summarises the medical rationale to address HIV-stigma. This chapter highlighted methodological and ethical challenges addressed in the [methods chapter](#). The critical counterpart developed in [chapter 4](#) consists of two main arguments, the moral component of social processes (primacy of morality in social perception) and the moral premises in stigma and health research (stigma as the reparation of an epistemic injustice and health a moral standard) informing the epistemological stances and the methodological choices of this study. Finally, this chapter hints towards the conclusive hypothesis that the criminalisation of HIV transmission stems from HIV-stigma and is a form of [institutionalised stigma](#).

[Chapter 5](#) summarises the methodological theoretical background of the study and details the study's procedure and analysis; this includes the research questions, the participants (sampling and recruitment), the procedure and design to the study, the data analysis, the integrity and biases of the study. This chapter also provides reflective accounts on the choice of methods, conducting the research, with an emphasis on ethical concerns.

Chapter 6 presents the findings of the present study focusing on the three main research questions: participants' views on the criminalisation of the sexual transmission of HIV, HIV-stigma and the social representations of HIV, and the impact of the research on participants. The former two are based on the qualitative data and its analysis while the latter is detailed using the mixed method part of the study and displays statistical analysis. The final section of this summarises the limitations and biases of this study.

[Chapter 7](#) discusses the findings of this study in the light of previous similar studies ([chapter 2](#)) and the hypotheses formulated in [chapter 4](#). Hence, three axes are articulated with stigma: knowledge, disclosure, and morality. Knowledge and stigma are discussed in terms of public

knowledge of the law, sexual health and HIV; disclosure and stigma are discussed in relation to barriers to disclosure and cumulative stigma; finally, the primacy of morality is discussed both theoretically and practically with a focus on possible framing for stigma-reducing interventions.

The [conclusion](#) of this study provides a summary of the study and suggests prospective studies and further research. Furthering the structural hypotheses, it is finally hypothesised that the criminalisation of HIV transmission is a specific form of stigma, namely, institutionalised stigma.

The present study is the first to explore views from the public on the criminalisation of HIV transmission, aiming to address current gaps in the literature and to provide a better understanding on how the social perception of HIV relates to the possibility of legal proceedings. Furthermore, while pre and post-assessment are common good practice in the field of stigma-reducing interventions, the impact of research process remains an understudied area. The interdisciplinary backgrounds that framed this study led to a tailored method design, assessing the potential impact (beneficial, neutral or deleterious) of the study on participants.

Key concepts

Morality. Morality refers to the beliefs about what is right and wrong, just and unjust. Morality also refers to the different levels of expression of morals; individually, morality is the quality of being moral; behaving in accordance with moral standards (Collins English Dictionary, 2015). Within a social context, morality refers to the degree of conformity to conventional standards of moral conduct. It can relate to a behaviour, a person or a group of people. Morality can also refer to a system of moral principles (Whitely, 1959). Immorality refers to the transgression of morality while amorality to its absence (Fassin, 2012).

The Kantian tradition affirms the universality of moral principles (Kant, 1785) while moral relativism states that the right and wrong, just and unjust, can differ from one system or group to another (Harré and Krausz, 1996). Another approach consists in determining the degree of normativity provided by a moral doctrine, expressed in terms of maximalism or minimalism (Ogien, 2007).

Morality is both implicit (one acts in a certain way without the awareness or claim of a moral principle) and explicit (one gives a rationale to justify a statement or an action), individual or

collective, formal or informal (Edelstein and Nunner-Winkler, 2005). One possible formal and indirect expression of morality is the Law. Hence, morality and Law overlap (Kramer, 2004). Law is a type of collective and consensual attempt to enact, promote and maintain a common good, a common right and a common justice. Informally, morality structures group standards, norms and values, whether implicit or explicit.

Legality. Legality is both the quality of being legal or lawful and the adherence to legal principles (Collins Dictionary, 2015). Legality is the result of a socio-institutional process. The institutional process of legalising or criminalising depends upon both the views of the public and of legislators. Each legal system is the product of a cultural and historical edification (Baker, 2013); the British legal system showing institutional specificities (Raz, 2004). Legality draws the line between what is collectively reprehensible, and what is socially reprehensible. The legally reprehensible is conceptualised as a limit society creates to maintain social order.

Stigma. *Stigma* has its origin in Greek *stizein*, meaning to brand, mark or *tattoo*. It was used to refer to slaves and soldiers who had their master's or commandant's names or signs tattooed or branded, with a hot iron, as a proof of ownership. Romans kept the same use and practices until the word's suffixation to *stigmata*, describing the wounds of Christ (Hoad, 2003). *Stigma* then undertook an extensive use as the *mark of suffering*, before it took one of its current meanings, namely the *visible sign of a disease*. The last and most used definition refers to a *distinguishing mark of social disgrace* (Collins Dictionary, 2015) or "*a strong feeling of disapproval that most people in a society have about something, especially when this is unfair*" (Cambridge Dictionary, 2015). Following Goffman's seminal work (1963), stigma is defined as the social process excluding and/or devaluing a (group of) person(s) based on a visible (discredited sign, such as skin colour) or invisible (discreditable sign, such as political views) attribute.

Two other concepts are related to stigma. Discrimination has two main uses (Collins, 2015): the ability to see and perceive fine distinctions or differences, and the unfair treatment of a person or a group. Prejudice comes from Latin *prae* (before) *judicare* (judge) or *judicium* (trial, judgment). All uses of the word (Collins, 2015) are a declination of this core sense: from the preceding judgment or opinion; to the act or condition of having an opinion beforehand; the dislike of a specific (trait, characteristic) group; the injury or harm resulting from a prejudice. Prejudice is also a legal notion and can refer to certain types of legal procedure (i.e. without prejudice). Prejudice in this dissertation will follow Allport's seminal definition of a "*feeling,*

favourable or unfavourable, toward a person or thing, prior to, or not based on, actual experience” (Allport, 1954, p6).

Legality refers to a structural level of social organisation, usually standing for a consensual common good. The ‘common good’ component of social agencies defines consensual moral values (good, bad, just, unjust). Both social and moral agencies create norms and standards. In this sense, the criminalisation of HIV transmission can be considered promoted in the name of a common good, despite the risks of devaluation and shaming of people living with HIV. Concomitantly, it may strengthen stigmatising norms towards people living with HIV. HIV-related stigma is defined as devaluing, shaming and/or holding prejudicial considerations towards HIV and/or people living with HIV (Herek, 2003).

CHAPTER 1 –CRIMINALIZATION OF HIV TRANSMISSION IN ENGLAND AND WALES: LEGAL PROVISIONS AND SOCIODEMOGRAPHIC CHARACTERISTICS OF THE PEOPLE INVOLVED IN THE CRIMINAL CASES

This brief introductory chapter presents the legal provisions used to prosecute and convict the transmission in on England and Wales jurisdictions. It is followed by the main section of this chapter that consists of two subsections: a summary of criminal cases and convictions for HIV transmission and a comparison between the sociodemographic characteristics of the people involved in the criminal cases and the people living with HIV. The sociodemographic mismatch is discussed in the light of international studies and critical analyses. The last section summarises the current debates.

A preliminary inquiry ([desk research 1](#)) was performed to understand the legal treatment of HIV and HIV-related legal decisions in the UK. This desk research investigated primary and secondary legislation and a set of 392 legal decisions. To summarise this review, the Law tends to be protective of people living with HIV and takes steps to ensure that the public is given the tools and means to be tested, screened and treated. The overview of judgements emphasised that legal practices are concerned with vulnerable people, and, in some instances, cumulative vulnerabilities of sub-populations such as migrants and asylum-seekers living with HIV, people living with HIV in precarious situations, and offenders living with HIV. Nevertheless, through the sex offences and the exposure cases, also transpires the idea that being exposed to and potentially acquiring HIV is a prejudice and a cause of distress. In regards to this legal history, the criminalisation of HIV transmission appears as an epiphenomenon. This chapter briefly summarises the legal ground for the criminalisation of HIV transmission and cases up to date.

1.1 HIV and Criminal Law in England and Wales

When the UK Public General Acts are usually applied across England, Northern Ireland, Scotland and Wales, each region is ruled by a local Criminal Law: the English Criminal Law for England and Wales, the Scots Criminal Law for Scotland, and the Northern Ireland Law for Northern Ireland. Criminal offences in England and Wales are common law offences (created by case law) and statutory offences (set down in statute, Acts of Parliament).

The Criminal Law in the three legal regions is based on two elements. The *actus reus*, the guilty act(s) or external element, which includes positive action or omission, and the *mens rea*, the guilty mind, which can be described as intentional, reckless, by belief or suspicion (Ormerod, 2013). In the context of HIV transmission, the guilty act can refer to one's action or omission leading to one another acquiring HIV; the guilty mind can refer to the state of mind and knowledge of the person who transmitted HIV.

Before any criminal case in the UK, Tierney (1991) considered several existing offences likely to be used to prosecute the transmission of HIV: manslaughter as common law offence and several statute law offences, bodily harm (section 18 and 20 of the OAPA) and the malicious administration of poison or noxious thing (section 23 of the OAPA, 1861). While such considerations were made at a time ART did not exist and in the absence of legal proceedings, it conveys a strong sense of harm (manslaughter, poisoning) in being transmitted or acquiring HIV⁶. To this day, prosecutions and convictions in England and Wales were concerned with the sexual transmission of HIV⁷ and were based on sections 18 or 20 of the OAPA.

1.1.1 Legal provisions in England and Wales

This section summarises the legislation in force and prosecution policies in England and Wales. None of the legislation in force specifically mentions the transmission of HIV as an offence *per se*, but generic offences can be used under certain circumstances. Prosecutions and convictions have been held in England and Wales under section 18 and 20 of the 1861 OAPA; these sections belong to the 'Acts causing or tending to cause Danger to Life or Bodily Harm.

OAPA, 1861

Section 18 - Shooting or attempting to shoot, or wounding with intent to do grievous bodily harm.

Whosoever shall unlawfully and maliciously by any means whatsoever wound or cause any grievous bodily harm to any person, with intent, to do some grievous bodily harm to any person, or with intent to resist or prevent the lawful apprehension or detainer of any person, shall be guilty of felony, and being convicted thereof shall be liable to be kept in penal servitude for life.

Section 20 inflicting bodily injury, with or without weapon.

Whosoever shall unlawfully and maliciously wound or inflict any grievous bodily harm upon any other person, either with or without any weapon or instrument, shall be guilty of a misdemeanour, and being convicted thereof shall be liable to be kept in penal servitude.

⁶ This point is highlighted as some participants used this comparison and compared HIV transmission to manslaughter ([section 6.1.1](#)); this will be discussed in terms of social perception and representations of HIV ([section 3.2](#)) and the public's HIV-knowledge in ([section 7.2](#)).

⁷ The tainted blood scandal did not lead to any criminal convictions in the UK, rather to a blood products and blood donation policy adjustment (Kelly, 1993; Angelotta et al., 2007; Kodate, 2012).

The legal guidance of the Crown Prosecution Service (CPS) for Intentional or Reckless Sexual Transmission of Infection (2011) specifies prosecution criteria under the 1861 Offences Against the Person Act (applicable in England, Wales, and Northern Ireland⁸⁹).

There are several elements required to prosecute someone for the sexual transmission of HIV in the UK. The first one is one's knowledge of their HIV-positive status¹⁰. The second is one's capacity to understand how HIV is transmitted and how to prevent onward transmission. The third is the action leading to the transmission from the person A to person B. The last one is the intentional or reckless behaviour leading to HIV transmission. Intention refers to the deliberate act and will to transmit HIV. Recklessness requires that the person could foresee a potential harm or deleterious effect on someone else, had a possible means to prevent that harm and did not act accordingly. Usually, the absence of protective measures refers to unprotected sex. The evidence or likelihood of the transmission from the defendant to the complainant raises the practical and procedural question of the admissibility of phylogenetic evidence. In 2006, charges against M. Collins were inconclusive due to the lack of phylogenetic evidence linking the type of HIV virus carried by the defendant to the one carried by the complainant. While the admissibility of phylogenetic evidence in cases where viruses are similar could not differentiate between cases of direct transmission and transmission through a common third party, phylogenetic evidence can exclude the possibility of transmission between two persons when the types of HIV-virus are not related (Bernard et al., 2007).

Current policies tend to consider that the disclosure of one's HIV positive status to sexual partner(s) in the absence of any other offence, excludes the criminal liability in the eventuality of an onward transmission. This stance emphasises the partner's consent to the possible outcome. Such a policy also encourages disclosure, which has proven to be a challenge for both people living with HIV¹¹ and people working with people living with HIV. The curative and preventative role of people working with people living with HIV (medical staff, community) bares with contradictions when the possibility of onward transmission is foreseeable.

⁸ Retrieved from www.legislation.gov.uk.

⁹ Legal provisions in Northern Ireland are similar to those in England and Wales, except the maximal applicable penalty, as specified by The Criminal Justice (No. 2) (Northern Ireland) Order 2004. To this day, there have been no convictions for the transmission of HIV in Northern Ireland. "OAPA, Section 19 - Inflicting bodily injury, with or without weapon (Northern Ireland) - *Whosoever shall unlawfully and maliciously wound or inflict any grievous bodily harm upon any other person, either with or without any weapon or instrument, shall be guilty of an offence and liable, on conviction on indictment, to imprisonment for a term not exceeding 7 years*".

¹⁰ See [section 1.3](#) for further discussion.

¹¹ This will be discussed in [section 7.3](#).

Further to legal guidance, health professionals had to reconsider both their duty of care and potential criminal liability regarding their knowledge of patients living with HIV likely to transmit the infection onward (Chalmers, 2013). International guidelines from the European Centre for Disease Prevention and Control (Andersen et al., 2013) and national guidelines (Dodds et al., 2005; Kausar and Bradbeer, 2006; Gibson and O'Donovan, 2009; British Psychological Society (BPS), 2009a; Phillips, Poulton et al., 2014) both insist on three main key-points. Firstly, the duty of confidentiality as a standard practice (Williams, 2011). Secondly, the duty of information and advice to the patient living with HIV (so that s/he is given the means to protect her/himself and others) and, among other things, encouraging disclosure to potential partners (Griffith, 2017). Finally, exceptions to confidentiality and the type of information to be given to third parties are listed. Such a procedure can occur in the context of a legal order (i.e. subpoena) or a spontaneous initiative to prevent an onward transmission (e.g. in the case of Daryll Rowe, the Sexual Health Clinic alerting authorities). In the community, charities working for and with people living with HIV have been providing information to the public and people living with HIV through short and accessible documents (Terrence Higgins Trust and National AIDS Trust, 2010; Terrence Higgins Trust, National AIDS Trust and HIV Scotland, 2013; Terrence Higgins Trust, 2016).

1.2 Criminal convictions for HIV transmission in England and Wales¹²

1.2.1 Overview of criminal convictions for STIs and HIV transmission in the UK

As to early November 2018, 32 criminal cases were ruled in the UK (Table 1). There were three convictions for STIs transmission in England. There were twenty-six (26) convictions in England and Wales, three (3) in Scotland and none in Northern Ireland for HIV transmission. All were cases of successful transmission; two cases reported convictions for both successful and unsuccessful transmission. In ten instances, there were more than one complainants¹³. In three instance, the defendant was found not guilty in regarding HIV transmission but was convicted for others (e.g. one acquittal for two complainants). Remaining counts related to instances where the complainants were not transmitted the virus, three counts for criminal recklessness in *HM Advocate v Devereaux (2010)* in Scotland and five counts for attempted transmission in *HM v Rowe (2017)* in England. Both defendants were also convicted for the transmission of HIV.

¹² Information about legal cases parties was retrieved from press releases¹², court reports or excerpts available online¹².

¹³ The number of complainants was retrieved in the context of a final verdict and a final sentence not in the context of the beginning of legal proceedings or prosecution. For instance, there were two complainants in the first trial of Mohammed Dica in 2003, before the final (fourth) trial and sentence in 2005.

Table 1 Summary of criminal convictions for STIs (in grey) and HIV transmission in the UK by jurisdiction

DATE, COURT and JURISDICTION			DEFENDANT				COMPLAINANT		PLEA/COUNTS					SENTENCE	
Number	City / Court	Date	Name of the defendant	Gender	Citizenship ethnicity	Age	N complainants	Gender	Plea	HIV	STI	Transmission	Unsuccessful transmission	Verdict	Prison (months)
England and Wales															
1	Liverpool, Eng.	Jan-04	Adaye	M	Asylum seeker from South Africa	40	1	F	Guilty	1		1		Guilty	48
2	Teesside, Eng.	Feb-05	Feston Konzani	M	Asylum seeker from Malawi	28	5	F	Guilty	5		5		Guilty 3, acquitted 2	120
3	London, Eng.	Mar-05	Mohammed Dica	M	British Black Minority Ethnic (BME)	38	2	F	Not guilty	2		2		Guilty 1, acquitted 1	54
4	Leicester, Eng.	Jul-05	Paulo Matias	M	Portuguese	38	1	F	Guilty	1		1		Guilty	36
5	Cardiff, Wa.	Jul-05	Unknown female	F	British	20	1	M	Guilty	1		1		Guilty	24
6	Northampton, Eng.	Jul-05	David Golding	M	White British	28	1	F	Guilty		1	1		Guilty	3
7	Exeter, Eng.	Dec-05	Derek Hornett	M	White British	44	1	F	Guilty	1		1		Guilty	39
8	Isleworth, Eng.	Apr-06	Mark James	M	White British	47	1	M	Guilty	1		1		Guilty	40
9	London, Eng.	Jun-06	Sarah Jane Porter	F	White British	43	1	M	Guilty	1		1		Guilty	32
10	Liverpool, Eng.	Nov-06	Clive Rowlands	M	White British	43	1	F	Guilty	1		1		Guilty	30
11	Bournemouth, Eng.	Jan-07	Unknown Zimbabwean male	M	Zimbabwean	35	1	F	Guilty	1		1		Guilty	42

DATE, COURTT and JURISDICTION			DEFENDANT				COMPLAINANT		PLEA/COUNTS					SENTENCE	
Number	City / Court	Date	Name of the defendant	Gender	Citizenship ethnicity	Age	N complainants	Gender	Plea	HIV	STI	Transmission	Unsuccessful transmission	Verdict	Prison (months)
England and Wales															
12	Gloucester, Eng.	Nov-08	Ercan Yasar	M	Turkish	29	1	F	Guilty		1	1		Guilty	24
13	Preston, Eng.	Nov-08	James Cawley	M	White British	41	1	F	Guilty	1		1		Guilty	12
14	England.	Jan-09	Peace Marangwanda	M	BME		2	F	Guilty		1	1		Guilty	12
15	Maidstone, Eng.	Aug-10	Nicholas Richards	M	BME	32	1	F	Guilty	1		1		Guilty	12
16	Wolverhampton, Eng.	Jul-11	Nkosinathi Mabanda	M	BME	44	1	F	Guilty	1		1		Guilty	48
17	Teesside, Eng.	Oct-11	Simon Mc Clure	M	White British	38	1	F	Guilty	1		1		Guilty	32
18	Newcastle, Eng.	Oct-12	Leslie Pringle	M	White British	48	1	F	Not guilty	1		1		Guilty	42
19	Plymouth, Eng.	Mar-13	Louis Harris	M	BME	30	1	F	Guilty	1		1		Guilty	30
20	Leicester, Eng.	Sep-13	Unknown Zimbabwean male	M	Zimbabwean male	32	1	F	Not guilty	1		1		Guilty	54
21	Carlisle, Eng.	Sep-14	Alan Mason	M	White British	45	1	F	Guilty	1		1		Guilty	32
22	Swansea, Wa.	Jun-15	Mweetwa Muleya	M	BME	28	2	F	Guilty	2		2		Guilty	84
23	Cardiff, Wa.	Aug-15	Unknown	M	White British	45	1	F	Guilty	1		1		Guilty	27
24	Swansea, Wa.	Jan-16	Simba Kuuya	M	BME	32	1	F	Guilty	1		1		Guilty	28
25	Bristol, Eng.	Dec-16	Simon James	M	White British	46	2	F	Guilty	2		2		Guilty	60

DATE, COURT and JURISDICTION			DEFENDANT				COMPLAINANT		PLEA/COUNTS					SENTENCE	
Number	City / Court	Date	Name of the defendant	Gender	Citizenship ethnicity	Age	N complainants	Gender	Plea	HIV	STI	Transmission	Unsuccessful transmission	Verdict	Prison (months)
England and Wales															
26	Nottingham, Eng.	Aug 2017	Antonio Reyes-Minana	M	British	25	2	M	Guilty	2		2		Guilty	72
27	Lewes, Eng.	Nov-17	Daryll Rowe	M	British	27	10	M	Not guilty	10		5	5	Guilty	144
28	Reading, Eng	Sept-18	Japhet Osei	M	BME British	23	2	F	Guilty	2		2		Guilty	60
29	Preston, Eng	Oct-18	Aaron Sutcliffe	M	British	29	2	F	Guilty	2		2		Guilty	81
Scotland ¹⁴															
1	Glasgow, Scot.	Feb-01	Stephen Kelly	M	White British	33	1	F	Guilty	1		1		Guilty	60
2	Glasgow, Scot.	Nov-06	Giovanni Mola	M	Italian	38	1	F	Guilty	1	1	2		Guilty	111
3	Dumbarton, Scot.	Feb-10	Richard Devereaux	M	White British	41	4	F	Guilty	4		1	3	Guilty	120

¹⁴ In Scotland, the Crown Office and Procurator Fiscal Service (COPFS) released the updated guidance on Intentional or Reckless Sexual Transmission of, or Exposure To Infection (COPFS, 2014). To this day, all the criminal convictions for HIV transmission have occurred in the context of sexual transmission during consensual sexual intercourse. HIV-related crimes are known as assault in the case of a successful intentional transmission, as culpable and reckless conduct in the case of non-intentional transmission and as reckless endangerment for exposure (COPFS, 2014). To this day, there have been four trials and three convictions in Scotland: Stephen Kelly in 2001, Giovanni Mola convicted for transmission of Hepatitis C and HIV in 2006, Richard Devereaux in 2010, and one *non-guilty due to insanity* verdict in 2005. The number of victims ranged from one to four; sentences ranged from five to ten years.

Complainants were mostly females (40/55). Age and ethnicity were poorly reported. Available information reported that three female complainants were minors at the time of the offence; an age range from 6 to 82 years old, most of them were White British. The majority of the complainants were living with HIV (45/55) and charges were related to the transmission of HIV. Three complainants were transmitted an STI and charges related to the transmission of an STI; the six remaining complainants were not living with HIV or an STI and charges were related to the exposure to HIV (*HM Advocate v Devereaux*) or the attempted transmission of HIV (*HM v Rowe*).

Defendants were mostly males (30/32), age ranged from 20 to 46 years old, with a mean age of 36. In press release, defendants coming from an ethnic minority (15/32) were often introduced according to their ethnic background, most usually Black-British. For the majority, the route of transmission of HIV was not reported, however, one (James Cawley) was said to have acquired HIV through a blood transfusion, and three defendants through drug-injection.

The three STIs cases were held in England in relation to the transmission of herpes, hepatitis B, and gonorrhoea. Gonorrhoea and hepatitis B are curable. The gonorrhoea case *R v Peace Marangwanda (2009)* is somehow atypical. Victims were two minors, and other charges for sexual offences did not lead to a successful trial; prosecution for the transmission of an STI was thought to be a protective measure and a way to control the defendant. Sentences ranged from three months (herpes case, *R v Golding (2006)*) to two years.

Information retrieved concerning conviction cases were compared to available socio-demographic information about the pandemic and new diagnoses from Public Health England's publications. Globally, the information characterising people involved in criminal cases (leading to a conviction) do not correspond to the population of people living with HIV or people newly diagnosed with HIV (see [Table 2](#)). Before discussing this demographic information in details, a similar description of the criminal cases in England and Wales is provided in the following section.

Table 2 Demographic data on people living with HIV, people newly diagnosed with HIV, defendants, and complainants in criminal cases in the UK

Socio-demographic characteristics of Sources	Year ^a	N	Total	Gender		Route of acquisition				AGE RANGE					ETHNICITY	
				Male	Female	Heterosexual sexual contact	Homosexual sexual contact	Drug injection	Other	<15	15-24	25-34	35-49	>50	White British.	Other
People living with HIV	2015	N	101,200	61,097	27,672	41,945	41,016	1,909	2,136	315	2427	13,032	43,035	29,960	52,753	48,447
		%	100%	69%	31%	47%	46%	2%	2%	0%	3%	15%	48%	34%	53	47%
People newly diagnosed with HIV.	2016	N	5,164	3,939	1,226	2,110	2,810	130	110	27	546	1,590	2,030	971	2,449 ^b	2,241 ^b
		%	100%	76%	24%	41%	54%	3%	2%	<1%	10%	31%	39	19%	52%	48%
	2015	N	6,095	4,551	1,537	2,360	3,320	210	190	38	755	2,094	2,353	1,046	2,703	3,269
		%	100%	75%	25%	39%	54%	3%	3%	1%	11%	33%	38%	17%	44%	54%
	2014	N	6,172	4,619	1,551	2,490	3,360	160	150	34	733	2,048	2,272	1,113	2,792	3,468
		%	100%	75%	25%	40%	54%	3%	2%	1%	11%	33%	38%	19%	45%	56%
	2006	N	7,439	4,499	2,940	4,340	2,670	210	220	117	704	2,921	3,030	667	2,587	3,165
		%	100%	60%	40%	58%	36%	3%	3%	2%	9%	39%	41%	9%	35%	43%
HIV Conviction Cases [2001;2018]	Defendants	N	29	27	2	nr ^c	nr	3	1	0	2	11	17	0	16	14
		%	100%	93%	7%	nr	nr	10%	3%	0%	6%	34%	53%	0%	52%	48%
	Complainants	N	50	15	35	33	13	0	0	0	5	3	1r	1	14	2
		%	100%	30%	70%	74%	26%	0%	0%	Incomplete data						

Note.

^a Data were retrieved from Public Health England <https://www.gov.uk/government/statistics/hiv-annual-data-tables>. Complements were retrieved: as to 2014 and 2006 from Skingsley et al. (2015); as to 2015 statistics from Kirwan et al (2016); as to 2016 figures from National HIV surveillance data tables.

^b Ethnicity was unknown or not reported in 9% of the sample; the percentage is based on the available data.

^c Not reported.

* Not reported

1.2.2 Characteristics of the 26 criminal convictions for HIV transmission in England and Wales

In the 26 criminal cases, twenty-two (22) were held in England - East Midlands (n = 3), London (n = 3), North East (n = 3), North West (n = 5), South East (n = 3), South West (n = 3), and West Midlands (n = 1) – and four (4) in Wales. This represented 26 defendants and 45 complainants. All convictions were related to HIV transmission during consensual sexual intercourse. In total, there were 35 counts related to the reckless transmission of HIV, and 10 counts related to the intentional and the attempted transmission of HIV.

Complainants were mostly females (30/45). Age and ethnicity were poorly reported. Available information reported that at least two female complainants were minors at the time of the offence; their age range from 17 to 82 years old, most of them were British and their ethnicity was rarely specified.

Defendants were mostly males (24/26), age ranged from 20 to 48 years old (at the time of the trial), with a mean age of 36. In press release, defendants coming from an ethnic minority (12/26) were often introduced according to their ethnic background, most usually Black-British or presented as non-British citizens. For the majority, the route of transmission of HIV was not systematically reported, however, one (James Cawley) was said to have acquired HIV through a blood transfusion, two were said to have acquired acquiring HIV through injected substances. Finally, the proportion of ethnic minorities among defendants is high (12/26). The number of victims (after verdict and acquittals) ranged from one to ten. Sentences ranged from one to twelve years, for a mean duration of four years. Longer sentences are associated with the highest number of victims.

Similarly, to the description of national In terms of gender, men are overrepresented as defendants and females as complainants. This may be linked to the over-representation of male-to-female transmission among the conviction cases (21/26) with only two female-to-male transmissions and three male-to-male.

1.2.3 Socio-demographic mismatch and socio-legal treatment of HIV

Demographics of people living with HIV and demographics of people involved in criminal cases for HIV transmission seem opposite. This highlights the potential gaps in the current understanding of the social treatment of HIV and raises many questions in relation to gender,

ethnicity, and sexual orientation. The scarcity of studies on this demographic mismatch led to consult international studies to inform this discussion.

Geographical specificities

While a similar mismatch was identified in the sociodemographic of the criminal cases for HIV transmission in the UK and in England and Wales, there are two main features to note. Firstly, the small number of convictions does not allow for a statistical modelling comparing the prevalence of HIV and the number of criminal cases per region, but descriptively, a region with a higher criminalisation rate does not stand out. Secondly, it is important to note that all the cases involving male complainants were held in England and Wales.

Gender

The gender mismatch is twofold as it relates to both the underrepresentation of male complainants and the overrepresentation of female complainants. Firstly, this may be explained in the light of gender biases in the judicial system and the known phenomenon of underreported male victims in the case of other offences against the person (Carmo et al., 2011; Dutton and Nicholls, 2005; Tsui et al., 2010).

To this, can be added a stigmatising view of the male victim, enacted in police forces and support services (Young et al., 2018; Javaid, 2015). Some authors further this argument to question the ideal victim and the ideal victim stereotypes, gender, and heteronormativity (Cohen, 2018; Javaid, 2017). While the underrepresentation of male victims is argued on the basis of low rates of disclosure and reporting of crime, and biases in the criminal justice system, the overrepresentation of females as complainants can be argued in direct relation to HIV perception.

Authors questioned a possible structural heteronormativity whereby heterosexual females may undergo a greater prejudice, or be the innocent victims of the epidemic (Schellenberg et al., 1995; Blumenreich and Siegel, 2006). The innocent/guilty dichotomy is often used to differentiate the context of acquisition¹⁵. Similar observations and findings in terms of overrepresentation of female complainants and male defendants are documented in other European countries (see Bolúmar-Montero et al., 2015 for Spain). In a recent French survey, approximately 10% of the 3022 respondents reported having been tempted to press charges

¹⁵ This will be furthered in section [3.2](#) and in the section introducing [behaviourally driven health conditions](#).

and 2.6% reported having been threatened with charges from a partner; MSM, substance users and people belonging to an ethnic minority were less likely to be tempted to press charges and more worried about legal proceedings while the people in the category “other men and women” were more prone to have considered pressing charges (Suzan-Monti et al., 2018). This study highlighted the vulnerability of minorities and their fear of criminalisation. While considering that the idea of pressing charges can also be part of processing the HIV diagnosis¹⁶ and does not lead to legal proceedings, this survey also shed light on the sense of prejudice that people who are not one of the key populations of the epidemic might experience. Authors suggested that the French context of HIV criminalisation was revolving around the protection of women (Ribeiro, 2016; Le Naour and Musso, 2009).

Ethnicity

The overrepresentation of defendants coming from ethnic minorities suggests the possible intersection of cumulative attributes (Crenshaw, 1989). At the intersection of crime, migration, ethnicity or citizenship background and HIV, legal decisions and media portrayals seemed to have led to the construction of a stereotype: The Black man living with HIV infecting the British woman (Persson and Newman, 2008). Similar findings in terms of racialisation of HIV criminalisation in the media were found in Canadian context (Mykhalovskiy et al., 2016; Roth and Sanders, 2018).

Sexual orientation

As hinted in the previous paragraphs, the underrepresentation of the MSM population and of male-to-male transmission can be questioned in terms of biases in the criminal justice system. Thus, each stage of the judicial process should be queried: disclosure, complaint, prosecution, and conviction. Furthermore, if the underreporting of crime male victims is known, the same phenomenon is being studied in oppressed or stigmatised, minorities. A recent study concluded that the impact of homophobia, experienced or anticipated stigma led to crime underreporting and decreased legal recourse (Miles-Johnson, 2013). Eventually, given the early mobilisation of the LGBT community in the fight against AIDS (Pollak, 1992), the perception of risk and HIV may differ from the non-LGBT community¹⁷ (Adefuye, 2009; MacKellar et al., 2007; Bardella, 2004).

¹⁶ This will be mentioned by KIs, see [section 6.2.2](#).

¹⁷ This is an aspect brought up by some KIs, and this will be exemplified in [section 6.1.3](#).

Two of the most recent convictions, *R v Reyes-Minana* in Aug. 2017 in Nottingham and *R v Lowe* in Nov 2017 in Lewes, are respectively the second and third ones for male-to-male sexual transmission of HIV. These trials and the media reporting of the cases are likely to affect the public perception of both the LGBT+ and people living with HIV communities.

1.3 Brief Overview of the Socio-legal Aspects in Current Debates

All convictions but one were handed under section 20 of the OAPA, 1861. The recent conviction of Daryll Rowe raises many questions and stands for an unprecedented decision. This case shows particular features: this is the first conviction for intentional transmission and attempted transmission of HIV in England and Wales; this is the third conviction of a gay man in England and Wales and in the UK; this case involved the highest number of complainants and counts (10) in England and Wales and in the UK. This case appears a legal exception, in the sense that this conviction sets extremely high standards and jurisprudential criteria to convict someone under section 18 of the OAPA for the transmission and attempted transmission of HIV (GBH with intent).

Contrastingly, it might also prevent any further prosecution under section 18, the likelihood of meeting similar cases seeming quite low. Socially, this case posits Daryll Rowe as an exception in the gay community, the community of people living with HIV, and among the cases leading to a conviction. Daryll Rowe's case, its media coverage, and the public's reactions¹⁸ illustrate how sensitive the debate is, and how sensitive remains the social context for minorities, in this case, the LGBT+¹⁹ and people living with HIV communities. This case also reframes the ongoing socio-legal debates on the criminalisation of HIV transmission.

Globally, two main arguments against criminalisation are found, principlist (Weait, 2013) and consequentialist (Lowbury and Kinghorn, 2006). The first is by principle against the criminalisation of STIs/HIV transmission, as this leads to the grouping of people as potential offenders. In this sense, the Law might appear more deleterious than protective. The latter emphasises the consequences of policies and their negative impact on public health goals and strategies. Both insist on the actions to be taken regarding the educational and health-related needs underlying the issue of transmission (e.g. prevention policies and strategies). While legal

¹⁸ This case was mentioned by participants on the basis of information released in the media.

¹⁹ Lesbian, Gay, Bisexual, Transgender/Transsexual. The term LGBTQQIA+ is also found (Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersex, Asexual, pansexual and allies - heterosexual people supporting the community)

guidance and cases leading to a conviction are defined, debates on the appropriateness of such a legal response to HIV transmission remain. Likewise, the criminalisation of HIV transmission and recent judgements reframes, or at least questions, legal and social concepts of knowledge, intention, recklessness, harm, prejudice, consent, and responsibility.

The issue of knowledge might not appear obvious, given the legal guidance and cases described. However, it can be related to the risk of transmission incurred by undiagnosed people living with HIV, more precisely to deliberate risks and deliberate avoidance or refusal of testing (Bennett et al., 2000). As outlined in the Law Commission report (2014) citing Spencer²⁰, “[a] person is aware of the risk of passing on a sexually transmissible disease not only where he knows he is infected, but also where, although not certain, he knows that he may be”, wilful blindness might prevail over knowledge of one’s HIV status (Stone, 2017). Another issue related to knowledge is the knowledge of one’s status from a third party and related duties. While professional bodies have established standards of practice²¹, the question remains unaddressed regarding the public. Eventually, questions must be raised regarding the potential deliberate behaviour one could engage in with the knowledge of the possible acquisition of STIs/HIV (Warburton, 2004), such as the issues raised by health professionals about ‘barebacking’ (Adam, 2005; Carballo-Diéguez and Bauermeister, 2004; Davies, 2015).

Legal definitions of reckless transmission are defined by the knowledge and capacity of the person to foresee a potential harm and not act in a preventative way. The issue of recklessness in the context of HIV transmission falls into two grey areas. The first one relates to the risk and the probability of a transmission to occur. Indeed, people living with HIV under medication often live with an undetectable viral load, making onward transmission impossible (Hughes, 2013; Rodger et al., 2014). The second relates to the actual use of preventive measures and the accidental failure of such measures.

This leads to the crucial question of both individual and collective responsibility (Marks et al., 1999; Chan and Reidpath, 2003). It also highlights a potential unequal or asymmetric responsibility as people living with HIV could be held more responsible for (not) transmitting HIV than people not living with HIV for (not) acquiring HIV (Harris and Holm, 1995; O’Leary and

²⁰ Spencer, J. R. (2004). Liability for Reckless Infection: Part 2. In *New Law Journal*.

²¹ However, in a foreign context, Chan (2013) insisted on the duty to breach confidentiality to inform and protect others.

Wolitski, 2009). Hence, the shared responsibility stance emphasises the responsibility to protect oneself and one another. It also grants equal responsibility for both partners in the context of a sexual transmission. However, such a stance remains controversial and is directly related to moral and ontological (Rangel and Adam, 2014) and framed by socio-normative (Kenyon et al., 2016) views on relationships. Hence, responsibility in the context of HIV sexual transmission relies upon individual and structural constructs that might lead one to object to the shared responsibility stance.

The legal definition of consent varies whether in the context of sexual offences or other offences (Simpson, 2016). Consent in sexual relationships is ambiguous and legal definitions hardly consider emotional and psychological aspects (Stannard, 2015). In the case of HIV transmission, most of the defendants deceived their sexual partners about their status. The Law clearly distinguished consenting to a sexual act from consenting to the risks related to a sexual act. However, further to Rowe's case, it has been argued that charges of rape would have been relevant, debating the criminalisation of HIV transmission and deception in the context of sexual offending (Welsh, 2017). Therefore, the non-disclosure or concealment of information (living with an HIV) likely to lead to the withdrawal of consent is a key feature. Informed consent (Cooper and Reed, 2007; Cherkassky, 2010) and disclosure are offered as the solution to deceitful transmission. Disclosure and subsequent informed consent, if wanted or expected, are not systematic. Main reasons or factors for non-disclosure include the fear of rejection, lack of social support, and stigma experiences²² (Derlega et al., 2004; Obermeyer et al., 2011; Kalichman et al., 2016).

1.4 Summary

While pro-criminalisation views are rarely publicly sustained, cases leading to a conviction provide a social and moral rationale within the legal framework. As a legal and social phenomenon, the criminalisation of HIV transmission remains a marginal phenomenon. From a structural (legal) point of view, it brings to the fore very diverse aspects of social life that might affect every one of us (e.g. the definition of consent). Furthermore, in the absence of a specific offence, two generic offenses were deemed relevant as to include the reckless or intentional transmission of HIV, thus relying on both people's use and interpretation of the Law, and people's possible sense of harm and prejudice in acquiring or being transmitted HIV.

²² This will be discussed in [section 7.3](#).

The lack of congruence between the sociodemographic of the pandemic and of the conviction cases is interpreted as a specific feature of the criminalisation of HIV in England and Wales.

[Section 1.2.3](#) highlighted the mismatch between the sociodemographic characteristics of the people involved in the criminal cases and the people living with HIV. The discussion highlighted the possible twofold role of stigma, impeding potential complainants to press charges or increasing a sense of prejudice leading to legal proceeding in others.

Several directions shall be taken from this introductory section. The first one is a retrospective study ([Chapter 2](#)) to inform the methodological choices. The second is an empirical inquiry ([Chapter 5](#) and [6](#)), investigating experiences and perception of HIV and moral opinions on the criminalisation of STIs/HIV transmission. The last one is a theoretical and interdisciplinary inquiry aiming at the disentanglement of the social fact focusing on stigma theories and HIV-stigma ([Chapter 3](#)) and epistemology ([Chapter 4](#)).

CHAPTER 2 – VIEWS ON THE CRIMINALISATION OF HIV TRANSMISSION: A REVIEW OF EMPIRICAL STUDIES IN THE UK

2.1 Background

Since the first conviction in the UK, a number of studies investigated peoples' opinions about the criminalisation of HIV and related themes (e.g. knowledge of criminal liability; disclosure of one's status to sexual partner(s), concerns among people living with HIV, the impact of changes in community settings and/or professional practices. This chapter comprises a systematic review of empirical studies exploring the views on the criminalisation of HIV in the UK. It aims to identify current trends in research and synthesise findings regarding the British population and context.

2.2 Method

Given the variability of studies to be included in terms of methodology, design and sample size, and to ensure the validity of the systematic review, two sets of guidelines were used: the PRISMA guidelines for systematic review and meta-analysis (Shamseer et al., 2015; Moher et al., 2015), and the meta-synthesis method for qualitative and health studies (Walsh and Downe, 2005; Paterson et al., 2001; Dixon-Woods et al., 2001).

2.2.1 Sources and search strategy

Publications were retrieved from the following electronic databases: PubMed, Scopus, Science Direct, and Ethos. Keywords used were a combination of "HIV", "STI" "STIs/HIV", "law", "crim*", "expos*", "transmi*" and "UK", "Brit*", "Engl*", "Northern Ir*", "Scot*", "Wales or Welsh". Keywords were searched for in the full text to be inclusive of as many articles as possible. Other sources (e.g. Google Scholar, community survey reports) provided possible sources of non-impacted and non-referenced publications, applying the same criteria. Eventually, the reference lists of included articles were checked for additional papers or sources otherwise not identified.

2.2.2 Eligibility criteria

Publications were included if their focus or their outcomes related to the criminalisation of HIV transmission. Studies were excluded when another topic was investigated (i.e. disclosure), unless the outcomes or findings provided empirical and comprehensive data regarding the

criminalisation of HIV transmission. Studies providing secondary outcomes, such as criminalisation as the main theme in a qualitative study, were deemed relevant, while only mentioning the criminalisation of HIV as a factor was deemed insufficient. All articles were empirical studies, whether qualitative, quantitative or mixed. Systematic reviews, position papers, editorials, legal analyses, commentaries or forensic sciences studies (e.g. phylogenetic studies of the virus as evidence) were excluded. Studies must have been held in the UK, and published before December 2017.

2.2.3 Data extraction

For each study, data was extracted and compiled in a database that included the following clustered information: description of the study (author, year of publication, reference, main topic as transmission, exposure or other, criminalisation as a primary or secondary theme); method and design (theoretical background framing the study, recruitment, sampling, primary and secondary objectives, methods, data analysis, and standardised scales used); sample (number of participants, sub sample, age, gender, ethnicity, professional background, location, and any other information available); limitations and biases (sampling bias, sample size, inter-reliability rating, coding and other); results (descriptive statistics, parametric and significant results, and/or key findings).

2.2.4 Limitations

The studies retrieved present several biases related to sampling (i.e. self-selection and recruitment biases) and the diverse methods used leading to a low comparability between studies. Likewise, studies exploring the same topics used different conceptualisations making comparisons between studies problematic. Qualitative studies (n = 9) were subject to the quality of the researcher and the skills of the interviewer; there are no means to assess or compare researchers' potential impact on the findings.

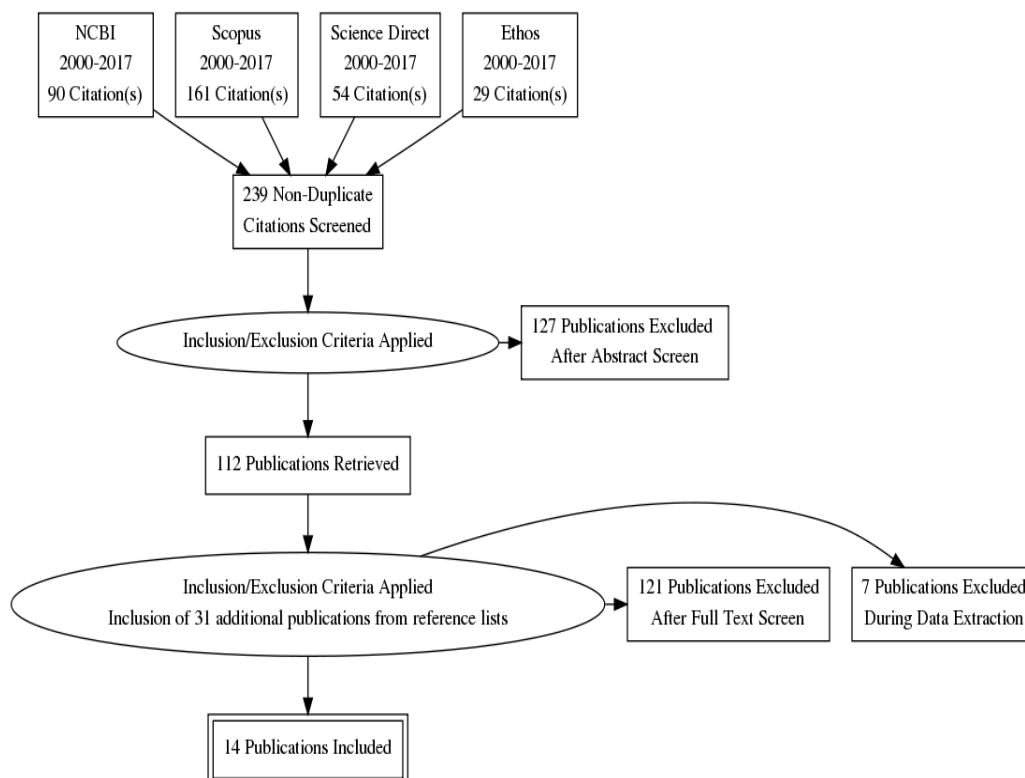
The small number of empirical studies and the high number of opinion, theoretical and review papers could be explained by the fact that criminalisation in the UK is an epiphenomenon. It can be hypothesised that the sensitivity of the topic might lead to research difficulties to obtain ethical approval, to recruit participants, and to lead the research, due to the use of information that may fall out of the research confidentiality agreement (Dickson-Swift et al., 2007; Tourangeau and Yan, 2007; Krumpal, 2013). Hence, the generalisability of the findings is low, but its informative input appeared necessary.

2.3 Results

2.3.1 Articles retrieved

An initial search, after eliminating duplicates, retrieved 239 articles. Abstracts were inspected and 127 ineligible ones were excluded for not meeting the inclusion criteria. The majority of these excluded publications were legal articles and position papers, or studies held in another country. In total, 112 full-text publications were read and 31 additional studies were identified from reference lists. Most of the empirical studies retrieved were North American and mentioned the UK context without a UK-based study. Furthermore, when UK-based, the majority of the publications retrieved cited criminalisation of HIV transmission but rarely provided a comprehensive investigation or detailed outcomes²³ (e.g. Pachankis et al., 2015a). This resulted in the inclusion of fourteen publications, twelve research papers or reports, and two doctoral dissertations (see [Figure 1](#)).

Figure 1 Review of empirical studies on the criminalisation of HIV transmission: search and inclusion summary



²³ “The Criminal Law, HIV and Human Rights Survey”, a five-country survey, was identified (http://www.aidsactioneurope.org/sites/default/files/2.Our_work/2a.Advocacy_work/CSF_meeting_reports/CSF_11_AnnexE.pdf or http://hiveurope.eu/Portals/0/Stockholm/for%20media/Ongoing_projects.pdf), but the final report and related data have not been retrieved.

2.3.2 Characteristics of the studies included

The general characteristics of studies are summarised in [Table 3](#). Given the small number of studies and the absence of standardised and comparable data, a meta-analysis was not possible. A critical narrative review is, therefore, provided.

Number of studies retrieved

Studies retrieved were published between 2005 and 2017. In total, fourteen (14) publications were included. Two of them were based on the same data and are, therefore, presented jointly. One doctoral dissertation (Rodohan, 2010), presented two studies.

Aims

Aims of the studies were heterogeneous. Mixed methods studies among people living with HIV and MSM identified opinions on criminalisation of HIV, while qualitative studies investigated the rationales underlying participants' explicit views or the impact of criminalisation on people's lived experiences. Studies among professionals investigated their views and the effect of criminalisation on their professional practice.

Theoretical background

Not all studies provided a theoretical framework. Backgrounds mentioned were critical theory, sociology of deviance, and needs assessments practices.

Sample, method, and design

Nine out of fourteen (64%) of the studies were qualitative studies, five used in-depth interviews, and four used focus groups. The method of analysis was Thematic Analysis (TA) for nine studies; one study used Interpretative Phenomenological Analysis (IPA). The five other studies were mixed method surveys that included Multiple Choice Questions (MCQ), open-ended questions and self-reported items. Five publications were published by the Sigma Research project. Surveys were administered using both paper and online questionnaire. Eight out of fourteen studies were focusing on England and Wales. Studies focusing on the whole UK were mostly surveys. Findings or results were not always displayed by jurisdiction.

Table 3 General characteristics of studies

REF		Methods				N	SAMPLE (based on available data)	RESULTS / MAIN FINDINGS (Summary and/or Verbatim from the publication)
#	Authors, year, title	Criminalisation as a primary or secondary outcome/topic	Design and Method		Analysis			
1	UK Coalition of People Living with HIV and AIDS. (2005). <i>Criminalisation of HIV transmission: results of online and postal questionnaire survey.</i>	Primary Community survey	Mixed	Survey with MCQ	Descriptive distribution and interpretation	233	165 People living with HIV in the UK 68 Other in the UK	1/ People living with HIV tend to be less pro-criminalisation. 2/ 42% of the respondents consider intentional transmission should be criminalised 3/ 76% of the respondents consider convictions increase stigma
2	Dodds C., Keogh P. (2006). Criminal conviction for HIV transmission: people living with HIV respond.	Primary Community response to HIV criminalisation Primary	Qualitative	20 FG	Thematic analysis	125	People living with HIV in England and Wales	1/ <u>Dominant themes</u> : shared responsibility and increase stigma. 2/ <u>Secondary themes</u> : questionable veracity of evidence and reliability of witnesses, Behaviour change implication, and perception of racial bias in the judiciary system, negative press impact, and criminalisation as a way forward.
3	Weatherburn, P. et al. (2008) Multiple chances: findings from the United Kingdom Gay Men's Sex Survey 2006. / Dodds, C. (2008). Homosexually active men's views on criminal prosecution for HIV transmission are related to HIV prevention need.	Secondary focus (SIGMA Research) Yes/no question	Mixed	Survey with MCQ	Descriptive distribution and interpretation	8132	MSM in the UK 3369 MSM never tested for HIV 4218 MSM last tested negative 565 MSM living with HIV	1/ 21.3% knew that people with HIV had been imprisoned in the UK for passing their infection without intending to do so 2/ 74.3% of all men expected HIV positive disclosure from potential sex partners 3/ <u>Lack of knowledge</u> regarding criminalisation but also regarding HIV prevention transmission
4	Bourne, A., Dodds, C., Keogh, P., Weatherburn, P., Hammond, G. (2009). Relative Safety 2: Risk and unprotected al intercourse among gay men diagnosed with HIV.	Primary focus: SIGMA Research Report Perception of risk and responsibility	Qualitative	Interview	Thematic analysis	42	MSM living with HIV in England and Wales Age range [18 ;58] 33 White/White British, 9 Other	1/ <u>Risk calculation and risk management strategies</u> (sex with other people living with HIV, previous online contact as an evidence of disclosure). 2/ <u>Fear</u> of transmitting, fear/experiences of rejection when disclosure. Cautious behaviours, sex with other people living with HIV, online contact (evidence of disclosure) 3/ Small proportion of people afraid of/ <u>worried about super/co-infection</u>

								4/ <u>Harm to social and moral identity</u>
5	Dodds, C., Weatherburn, P., Bourne, A., Hammond, G., Weait, M., Hickson, F., ... & Jessup, K. (2009). <i>Sexually charged: the views of gay and bisexual men on criminal prosecution for sexual HIV transmission.</i>	Primary focus, secondary analysis: Views on criminalisation (sampled from Weatherburn et al., 2008) SIGMA Research Report	Mixed	Survey with open ended question	Thematic analysis	6757	MSM in the UK 565 MSM living with HIV 3962 MSM pro-criminalisation views 1121 MSM anti-criminalisation views 1674 MSM unsure about their views	1/ Pro-criminalisation views were more common among men who were younger, had never had an HIV test, had lower levels of education, lived outside of London, reported sex with both men and women in the previous year, were not in a relationship with a man, and had lower numbers of male sexual partners. 2/ Anti-criminalisation views were more common among men living with HIV, living in England, especially London, being older, having university-level education, and a high number of male sexual partners in the previous year 3/ No real factors associated with the unsure opinion
6	Weatherburn, P., Keogh, P., Reid, D., Dodds, C., Bourne, A., Owuor, J., ... & Jessup, K. (2009). <i>What do you need? 2007-08 findings from an online survey of people with diagnosed HIV.</i>	Secondary focus SIGMA Research Report Needs of people living with HIV	Mixed	Survey	Descriptive distribution and interpretation	1777	People living with HIV in the UK 1359 males / 351 females Age range [17 ;78] 1180 White/White British / 597 Other	1/ 32% have concerns about potential prosecution for onward transmission of HIV during sex. 2/ Some respondents said criminal prosecution for sexual HIV transmission and the threat of deportation hindered disclosure and distilled fear. 3/ Fear of friendships becoming relationships with potential for sex and onward HIV transmission. 4/ Sero-discordant relationships were especially fraught about sex, with a wide range of anxieties about HIV transmission reported
7	Dodds, C., Bourne, A., Weait, M. (2009) Responses to criminal prosecution for HIV transmission among gay men with HIV in England and Wales.	Primary focus Research paper: Impact on lived experiences of people living with HIV	Qualitative	Interview	Thematic analysis	42	MSM living with HIV in England and Wales	1/ <u>Knowledge</u> : 1/3 men in the sample articulated awareness of, and accurately expressed the matters, which the prosecution has to prove. Nonetheless, their understanding sometimes contained key flaws. 2/ <u>Altered behaviours and revised meanings</u> : Several men feared condemnation from their local gay community should it become known that they had engaged in unprotected sex as a diagnosed man, particularly if that sex resulted in transmission of HIV. These findings demonstrate

								some of the key challenges in seeking to influence human behaviour
8	Rodohan, E. (2010). <i>Criminalisation for sexual transmission of HIV. Emerging issues and the impact upon clinical psychology practice in UK.</i>	Primary focus Doctoral Dissertation	Quantitative	Survey	Parametric and cluster analysis	107	Professionals in the UK 22 males / 84 females Age range [26 ;77] 104 White/White British / 3 Other	1/ Fear of litigation and problem regarding confidentiality (subpoena for one participant) 2/ Professional liability, dilemma between duty of care and policing 3/ Tendency to inform patients, encourage and support disclosure and keep track of information given 4/ Legal guidance needed
9			Qualitative	3 FG	IPA	15	Professionals	
10	Bourne, A., Hickson, F., Keogh, P., Reid, D., & Weatherburn, P. (2012). Problems with sex among gay and bisexual men with diagnosed HIV in the United Kingdom.	Secondary focus Sexuality and sexual health of MSM living with HIV Research paper from SIGMA Research	Quantitative	Survey	Standardised items and factor analysis	1217	MSM living with HIV in the UK Age range [17 ;76] 1146 White British / 71 Other	1/ <u>Worries about prosecution/criminalisation</u> of HIV transmission 24.2% 2/ <u>Worries about passing HIV to partners</u> 37.3% 3/ <u>Fear of rejection</u> from potential partners 34.7% 4/ <u>Worries about disclosing</u> HIV to partners 31.8% 5/ Desire for <u>clearer guidance</u> for men, their sexual partners, and health professionals about how and why such prosecution operate. Most were critical of the use of the criminal law and the consequences for risk negotiation.
11	Wayal, S; (2013) Sexual networks, partnership patter and behaviour of HIV positive men who have sex with men: implication for HIV/STIs transmission and partner notification.	Secondary focus Doctoral Dissertation	Qualitative	Interview	Thematic analysis	24	MSM living with HIV in England	1/ This is the first study in the UK to show that the fear of being criminalised for HIV transmission can be a barrier to notifying partners of STI, especially casual partners in circumstances of non-disclosure of HIV status.
12	Phillips, M. D., Schembri, G. (2015). Narratives of HIV: measuring understanding of HIV and the law in HIV-positive patients.	Primary focus Research paper	Qualitative	Interview	Thematic analysis	33	People living with HIV in England and Wales 28 males / 5 females	1/ Knowledge of the Law without understanding its application (e.g. personal vs legal definition of intention) 2/ Moral obligation to prevent transmission onward 3/ Needs assessment for tailored needs function to the level of knowledge and the level of risks of transmission

							Age range [19;53] 22 White or White British / 11 Other	
13	Dodds, C., Weait, M., Bourne, A., Egede, S. (2015). Keeping confidence: HIV and the criminal law from HIV service providers' perspectives.	Primary focus Research paper	Qualitative	12 FG	Thematic analysis	75	Professionals in England and Wales 53 health professionals 33 community professionals (double affiliation)	1/ Basic knowledge but confusion about legal meaning 2/ Dilemma between duty of care and moral implications 3/ Fear of liability, increase track record when information and advice given by the professional 4/ Need for skill-building capacity, promotion of disclosure and self-acceptance
14	Jelliman, P., Porcellato, L. (2017). HIV is now a manageable long-term condition, but what makes it unique? A Qualitative Study Exploring Views About Distinguishing Features from Multi-Professional HIV Specialists in North West England.	Secondary focus Research paper Professionals' views on HIV specific features as a long term condition	Qualitative	3 FG	Thematic analysis	24	Professionals in North West England 5 males 19 females 11 health professionals 13 community professionals	1/ Participants agreed that the law was unhelpful, potentially traumatic for patients, and harmful to public health. 2/ Criminalisation contributes to the exceptionalism of HIV (stand-alone features)

Population

After verifying sources and duplicates, this systematic review compiled data from 10,597 participants. The socio-demographic information of participants was not systematically reported; therefore, it is described based on the available data ([section 1.2.2.2](#) and [Table 4](#)).

Participants were professionals in four studies, MSM in two studies, and people living with HIV in nine studies (MSM living with HIV in four studies, people living with HIV in three studies, people living with HIV and unspecified other in one study, people living with HIV and MSM in one study). Participants were mostly recruited through community settings. Professionals recruited as participants were local and/or contacted through professional networks.

Online surveys were advertised through the community, professional and personal (referral) channels. The majority of participants were MSM (n = 7567, 71%). People living with HIV represent 26% (n = 2731) of the sample. Professionals working with people living with HIV (n = 221, 2%) were from health or community sectors. The category 'other' (n = 68) described people living with HIV where not all socio-demographic information was reported (UK Coalition of People Living with HIV and AIDS, 2005).

In terms of gender, 91% of participants were male. Regarding sexual orientation, 71% identified as a sexual minority (MSM, lesbian, gay or bisexual). Compared to the British population living with HIV, MSM were overrepresented; women and heterosexual people were underrepresented. Compared to the conviction's sample, the only similarities were demographics of gender and the high proportion of male participants.

Table 4 Sociodemographic distribution of people living with HIV, new diagnoses, conviction cases and systematic review populations in the UK (including all jurisdictions)

Sociodemographic characteristics of		Total / Estimation people			Gender		Sexual orientation	Ethnicity	
		N %	Living with HIV	Not living with HIV	Male	Female	LGB and MSM	White British	Other
People living with HIV	2015	101,200	101,200	Not applicable	61,097	27,672	41,016	48,447	40,322
		%	100%		69%	31%	46%	55%	45.42%
People newly diagnosed with HIV	2016	5,164	5,164		3,939	1,226	2,810	2,449	2,241
		%	100%		76%	24%	54%	52%	48%
	2015	6,095	6,095		4,551	1,537	3,320	3,269	2,704
		%	100%		75%	25%	54%	54%	44%
	2014	6,172	6,172		4,619	1,551	3,360	3,468	2,704
		%	100%		75%	25%	54%	56%	43%
	2006	7,439	7,439		4,499	2,940	2,670	3,165	2,965
		%	100%		60%	40%	35%	43%	57%
HIV Convictions 2001-2018	Defendants	29	29	0	27	2	3	17	15
		%	90%	9%	93%	7%	10%	52%	48%
	Complainants	50	42	8	14	36	13	Incomplete data	
		%	83%	18%	28%	72%	26%		
	Total	79	72	8	41	38	16		
		%	86%	15%	53%	47%	20%		
Population from the systematic review		10,597	2,731	7,856	9,621	468	8,333	7,483	2,628
		%	26%	74%	91%	4%	79%	71%	25%

2.3.3 Findings

Despite the different aims and sample characteristics, four key themes were identified across studies: ‘knowledge of the Law’, ‘explicit opinions on criminalisation’, ‘explicit opinions on disclosure’, and ‘moral aspects’ (e.g. moral agency, moral dilemma). The synthesis of this review is presented for each population identified in the reviewed studies.

People living with HIV

The majority of people living with HIV were worried about transmitting the virus (UK Coalition of People Living with HIV and AIDS, 2005; Bourne et al., 2009; Weatherburn et al., 2009). Reasons for this preoccupation related to a genuine desire to prevent someone else experiencing what they experienced (Bourne et al., 2013; Phillips and Schembri, 2015). The criminalisation of HIV transmission was experienced as a stigmatising social feature (UK Coalition of People Living with HIV and AIDS, 2005) since an HIV-positive status could be associated with a presumption of potential harm or noxiousness (Bourne et al., 2013; Dodds, Bourne and Weait, 2009). While the majority of people living the HIV understood or even

agreed with the criminalisation of deliberate (intentional) transmission, the criminalisation of reckless transmission and exposure was feared due to the potential deleterious impact on the whole community (UK Coalition of People Living with HIV and AIDS, 2005).

The daily management of HIV as a long-term condition weighed towards the daily management of risks. People living with HIV used different strategies to either handle situations where there was a risk of transmission or prevent possible prosecutions (Bourne et al., 2009). For instance, the disclosure of one's serostatus online was used as previous evidence of disclosure in case of legal proceedings (as an information given beforehand to the partner). However, such a strategy was only relevant for people who had a clear and comprehensive understanding of the prosecution criteria. Importantly, most of the people living with HIV in this review did not have a full understanding of the legal aspects of transmission (Dodds, Bourne and Weait, 2009; Phillips and Schembri, 2015). While concepts such as intention, harm, and recklessness were rather clear from a legal point of view, people living with HIV tended to define this concept from an individual or psychological point of view. The focus on disclosure seem to relate to the information given to a potential consenting partner.

Stances on disclosure and individual responsibility showed the dual burden criminalisation leads to. The disclosure was a feared moment (e.g. fear of rejection and anticipated stigma) and the fear of criminalisation was pointed as a barrier to the disclosure of HIV status to potential sexual partners (Weatherburn et al., 2009; Wayal, 2013). By contrast, disclosure was sometimes the responsibility of the person living with HIV (the onus of not transmitting HIV to a partner) rather than for the partner to take action to protect themselves (Weatherburn et al., 2008; Dodds, 2008). The shared responsibility was discussed or mentioned by participants across studies (Dodds and Keogh, 2006; Weatherburn et al., 2008; Dodds et al., 2009). Such a stance illustrates a social shift in how sexual and intimate relationships were constructed, in the sense that the assumption that the other person is not HIV-positive is too uncertain and might not be valid anymore. Finally, four studies reported views that criminalisation increases stigma and harms social identity (UK Coalition of People Living with HIV and AIDS, 2005; Dodds and Keogh, 2006; Bourne et al., 2009; Dodds, Bourne and Weait, 2009).

Men who have Sex with Men (MSM)

As a population, MSM differed greatly in terms of knowledge, views and moral stances (Weatherburn et al., 2008; Dodds et al., 2009). It seems that older people who were young

men at the start of the pandemic and suffered the decimation of the gay community tended to hold less pro-criminalisation views (Dodds et al., 2009). Older MSM largely focussed on HIV as a long-term but manageable condition. Older MSM tended to have greater concerns about disclosure and related the fear of disclosure to the concealment of one's status and/or one's sexual orientation (e.g. non gay-identified MSM). In contrast, younger MSM, who did not experience the early years of the pandemic held greater pro-criminalisation views and were more likely to hold stigmatising views towards people living with HIV. HIV stigma within the gay community manifested as a secondary feature. Moreover, this subgroup tended to expect disclosure from their potential partners (Weatherburn et al., 2008). Both older and young MSM demonstrated a poor knowledge of the Law and a poor understanding of preventive measures (e.g. PrEP).

Professionals working with people living with HIV

The four studies among community and health staff highlighted the lack of legal guidance and discussion about the criminalisation of HIV transmission (Rodohan, 2009; Dodds et al., 2015; Jelliman and Porcellato, 2017). Professionals experienced difficulty as a result of regulations relating to internal policies, an emphasis on informing the patients, and insisting the patient disclosed to potential partners. Experienced professionals were less worried about their professional liability and litigation than younger ones. Their knowledge of the Law was mostly understood in the context of their legal duties and how this reshaped their role and relationships with patients. Encouraging or discouraging a patient to pursue legal action was a sensitive topic and tended to be perceived as a personal or moral stance rather than a professional one.

2.4 Discussion

2.4.1 Number of studies and population

While many studies, among the 112 retrieved, mentioned the deleterious impact of criminalisation on public health (Lowbury and Kinghorn, 2006), preventive strategies (Young et al., 2015) and the well-being of people living with HIV (Burns, 2009), it was rarely based on empirical data. As detailed above, the population sampled among the studies retrieved was not fully representative of people living long-term with HIV, people recently diagnosed with HIV or those who have undergone a legal proceeding related to their HIV status. The scarcity of research in this area may also be related to the high sensitivity of the topic and the difficulty of investigating it, whether personal or socio-political (Paiva et al., 2015).

The majority of similar studies (empirical research or systematic reviews) are from North America and are not focused on HIV transmission; rather they investigated the lived experiences and/or the impact of transmission, exposure and non-disclosure legal provisions. Leaving aside the structural health dissimilarities (Brown, 2003), this literature is discussed below in the light of impact studies, as this may inform the research into stigma and HIV in a British context.

2.4.2 Impact studies in North America

Compared to the UK and its jurisdictions, the USA and Canada have more wide-ranging legal provisions (criminalisation of transmission, exposure, and non-disclosure), hence, more convictions. Empirical studies are more numerous (O'Byrne et al., 2013), and the systematic reviews retrieved were focusing on exposure Law in the USA (Harsono et al., 2017) and in Canada (O'Byrne et al., 2013). The following section summarises the findings of North American similar studies before presenting the findings of impact studies.

Empirical studies in North-America

The majority of studies focused on people living with HIV, people at risk of acquiring HIV (e.g. MSM), and professionals. Studies among people living with HIV explored very specific dimensions such as the perceived responsibility in preventing transmission (Wolitski et al., 2003), moral agency and conflicting subjectivities among 'barebackers' (Brisson, 2017; Frasca et al., 2013; Barry et al.; 2008).

The same discrepancies in opinions between HIV-negative MSM and MSM living with HIV were found in the criminalisation of non-disclosure of one's HIV-status (Horvath et al., 2010). MSM not living with HIV tended to consider that unprotected sex without disclosure should be illegal. While British studies included health and community professionals, American studies also included criminal justice professionals. These same features are found in American and Canadian health and community professionals but with the difference that professionals' in Canada have their notes subpoenaed more often (Sanders, 2015). Globally, professionals are facing an obvious dilemma between the duty of care and policing (Swendeman et al., 2009; for American context see French, 2015). Key concepts or specific dimensions are explored, such as a professional interpretation of significant risk (Mykhalovskiy, 2011).

Impact studies of the criminalisation of HIV transmission, exposure, and non-disclosure

Further to the rise of legal provisions for HIV exposure in North America, researchers and public health leaders called for the evaluation of such policies on public health goals (Lazzarini

et al., 2013). Following the pro-criminalisation rationale that criminalisation would be a preventative strategy, recent studies tried to assess the impact of criminalisation laws on the global development and burden of the epidemic.

People living with HIV who resided in a state with legal provisions for HIV non-disclosure were more adherent to ART than those living in an area where transmission and/or exposure is criminalised. Among 1873 participants, predictors of better adherence were an older age, a White or Hispanic ethnic background, and a perceived social capital (Phillips et al., 2013). Another study evaluated the impact of non-disclosure laws on sexual risk-taking behaviour (Burriss et al., 2007) and concluded that the impact of criminalisation was unclear. More recently, using statistical modelling (generalised estimating equations), the possible relationship between the presence of criminal exposure law at the state level²⁴ and the epidemiological data regarding diagnosis rate had been assessed; results indicated that legal enforcement did not have a preventive effect (Sweeney et al., 2017) and could even have a deleterious impact on prevention and screening efforts (O'Byrne et al., 2013b).

North-American studies were identified as building a scientific corpus to orientate policies towards prevention and treatment rather than criminalisation. This approach may yield improved health outcomes as movements towards criminalisation have yet to stem the pandemic, and might even contribute to its spread. For instance, non-disclosure laws are likely to prevent patients from disclosing important information to their medical staff, making the latter unable to prevent secondary transmission (Patterson et al., 2015).

In terms of public health goals, criminalisation was sometimes credited as a fear induction strategy. The fear appeal (or fear-induction) is a traditional behaviour change technique (Michie et al., 2013). Though proven efficient in some contexts (Tannenbaum et al., 2015; Ruiters et al., 2014; Smerecnik and Ruiters, 2010), it shows low efficacy and sometimes deleterious long-term effects in the specific context of HIV (Earl and Albarracin, 2007). The view that fear induction can be harmful has gained support from medical professionals and researchers (Muthusamy et al., 2009). Current preventive approaches are rather based on a positive approach to health and sexuality and people's autonomy (Bayer and Fairchild, 2016).

²⁴ There are three legal levels in the USA: city, state and federal Laws. Thirty states have legal provisions for HIV exposure.

Criminalisation and stigma

Studies reporting stigma as a major concern were mostly based on people living with HIV. Furthermore, while the majority of the studies emphasise that criminalisation feeds HIV-stigma, whether invoked (argument) or reported (lived experiences), no studies provided comparable empirical measures. It is interesting to note that items exploring views of HIV criminalisation have been integrated into the Canadian Stigma Scale (Beaulieu et al., 2014). These items account for the reciprocal relationship between the level of HIV stigma and views on criminalisation of HIV transmission. While this construct appears to be a valid theoretical and logical statement, it may require further investigation and a context-sensitive approach.

2.5 Conclusion

Globally, the population sampled was sympathetic to the criminalisation of intentional transmission but remain undecided on other circumstances. The legal knowledge of the participants was poor and relied on popular concepts of intention differ, highlighting the need of a public education in relation to the law²⁵.

UK-based studies highlighted contingent themes, such as disclosure and responsibility, summarising the emotional, relational and professional challenges, faced by the population sampled. This can be understood in the context of a significant lack of knowledge regarding HIV and criminal Law, emphasising the overall educational needs (legal guidance and sexual health). Despite the structural and legal differences, examining other national contexts drew attention to the consensual evidence-based rationale against criminalisation, its deleterious impact on public health objective, people's well-being, and equal opportunities. The conflicting norms between public health priorities and criminalisation of HIV transmission have also been denounced as an *anomic affective climate* (French, 2015) impeding prevention. [Anomie](#) will be introduced in the next chapter while conflicting norms will be discussed in terms of [prescriptive behaviours](#) in chapter 4.

Regarding the population sampled, the majority of the participants were MSM, one of the most vulnerable groups regarding HIV acquisition; other vulnerable groups (e.g. people who inject drugs, sex workers) and professionals were not proportionately represented; people living with HIV were mostly MSM and represented one-fourth of the general sample. The

²⁵ This will be discussed in [section 7.2](#).

population sampled gathered key populations but did not investigate the views of lay people, legal or criminal justice professionals. This will be addressed in the present study.

Finally, the link between stigma and criminalisation has been reported as a core finding in studies among people living with HIV. Nevertheless, the nature and content of this relationship rely on the testimonial value of opinion and personal experiences. The present study will aim at furthering the potential relationship between stigma and criminalisation. The following chapter introduces [stigma theories and HIV-stigma \(Chapter 3\)](#), as a prerequisite to the [epistemological and methodological inquiry \(Chapter 4\)](#) that informed the [methods \(Chapter 5\)](#) used in this study.

CHAPTER 3 – FROM STIGMA TO HIV-STIGMA AND HOW IT IS CHALLENGED

While current anti-criminalisation rationales claim that the criminalisation of HIV transmission increases stigma, it is hypothesised in this study that criminalisation stems from HIV-stigma. This hypothesis is mostly developed in [chapter 4](#) but this chapter, despite its descriptive tone, provides all the background information framing the epistemological and methodological stances adopted. The first section explores the double context (social and scientific) in which stigma studies emerged. The second provides an overview of stigma research and explores the relevance of current HIV-stigma theories. Hence, excerpts from the qualitative part of this study (interviews and focus groups) are provided to illustrate how stigma is experienced, perceived and/or constructed. The third develops the medical rationale to tackle HIV-stigma.

3.1 Emergence of stigma studies

This section introduces the context leading to the emergence of stigma research and the contact hypothesis (Allport, 1954) as it informed both the methods (the level of familiarity as an item in phase 1) and the epistemological inquiry in the following chapter.

3.1.1 American Context and the Birth of Stigma Studies

The American segregated context before 1954 gives depth and credit to seminal studies on ethnic minorities. Whilst a post-segregation context seems to explain and expand the scope of stigma research, despite the abolition of slavery in 1865, authorised or legal forms of exploitations were perpetuated²⁶. This doctrine is known under the idiom “*separate but equal*”, and lasted until 1954.

In 1896, the law case *Plessy v Ferguson* confirmed the up to then latent doctrine of “*separate but equal*” (Groves, 1951). In 1890, Louisiana State passed the Separate Car Act (Rountree, 2004) that required separate railway cars and accommodations for Black and White people.

²⁶ The reformation following the civil war, led to Reconstruction Amendments and a will to guarantee rights and equality to all citizens. The 13th amendment of the constitution - examined on January 31 and ratified on December 6, 1865 – declares “*neither slavery nor involuntary servitude, except as a punishment for crime whereof the party shall have been duly convicted, shall exist within the United States, or any place subject to their jurisdiction*” (Constitution of the United States of America, 1865/2016). However, slavery although abolished, found new social expressions (Daniel, 1979). Through labour organisation, e.g. peonage and sharecropping (Daniel, 1973; Nieman, 1994), a form of lifetime exploitation with an implicit transmissibility to descendants was maintained.

Homer Plessy, an *octoroon* free man (reportedly of seven-eighths European descent and one-eighth African descent), bought a first-class train ticket but was refused the 'white' wagon. Homer Plessy appealed to the law for equal treatment. However, the Supreme Court followed the jurisprudence stating that separation was not anti-constitutional²⁷. From 1896, the doctrine (Roche, 1951) seemed officially promoted, considering the separation of public space between White and Black people (defined by one ancestor) as not entailing the 13th Amendment. The legal turn came in 1954 when the Supreme Court stated that separate public schools were unconstitutional (*Brown v. Board of Education of Topeka*). While this example is linked with ethnic or racial discrimination, it illustrates how [social categorisation](#) and discrimination is socially embedded.

Since 1954, a de-segregation process has slowly operated, leading to a form of anomie: the discriminated minority having institutional means and recourses²⁸. Goffman and Allport empirically studied racial and religious prejudice and stigma in post-1954 America. Racial and social preference studies started in the USA after the legal abolishment of racial segregation (Gopnik and Meltzoff, 1977; Kohlberg, 1969; Brand et al., 1974) investigating ethnic and religious interactional patterns and preferences²⁹. Primarily investigating school environment, studies focused on how segregation was recreated in groups of children (i.e. not playing together) and tried to formalise interventions to promote equality. Historically, equality promotion and affirmative action, acted in 1965, are the policies drawn upon this field of research (Anderson, 2004). Concomitantly, stigma research focused on other minorities or stigmatised groups, such as disabled persons (Hunt, 1966) or people living with a mental health difficulty (Lemert, 1948).

The social world and the social structures are obviously interdependent. Nevertheless, it seems that, in the absence of a structural equality, stigma studies or stigma-related preoccupations would be outshined by the necessity of a legally granted equality and the fight for civil rights. Stigma arose and remains investigated in a socially discrepant context, characterised by a structural, legal or theoretical equality and a social disapproval. The fight for civil rights is a

²⁷ Further to *Plessy v Ferguson*, national Black civil rights movements encompassed local communities and aimed at forming a national alliance. The national movement became organised and structured after World War I (for comprehensive details, see Maslow and Robinson, 1953).

²⁸ However, the recent rise of the Black Lives Matter movement highlights the persistence of inequality. Following Merton's anomic states, the lack or non-responsive of institutional means should, therefore, lead to ritualism or rebellion.

²⁹ This field of research is still prolific, focusing on the conceptual acquisition of the notion of race/ethnicity (Cockerham, 2011), racial favouritism (Rutland et al., 2015; Aboud, 2003) and bias (Lai et al., 2014).

fight against structural discrimination that occurs in a context of structural inequality. Stigma studies emerged concomitantly with the acquisition of a structural equality, in the 1950s, in the USA. It also has to be noted that [Goffman](#) and [Allport](#)'s studies were investigating the social perpetuation of diverse types of prejudice against visible minorities, namely against Black people (up to then discriminated against) but also Jewish people and how some members of these communities were ostracised. The two following section summarise the theories informing respectively theoretical Goffmann and Allport's seminal works.

3.1.2 Theoretical roots of stigma studies

From sociology of deviance to stigma

Early sociological studies focused on the understanding of and methods to investigate social contexts or phenomena (Small, 1895; Spencer, 1898), whether generic (labour, education...) or specific (i.e. suicide). While Durkheim (1922) and Merton (1938) proposed a theoretical and normative understanding of social rejection and seclusion, others theorists such as Lemert, informed Goffman's seminal work.

Durkheim studied social processes and theorised the emergence of social norms and deviance. Defining deviance as a statistical notion *derived from the norm* (Durkheim, 1894), he studied how norms, explicit (i.e. Law) or implicit (i.e. conventions), produce social order and promote certain moral values. Three concepts remain at the heart of stigma studies. The functionalist approach, according to which society is a homeostatic system and conflicts are part of the equilibrium, reinforcing beliefs, values and behaviours. The collective representation³⁰ defined as an implicit shared notion contributing to social life and social order as the specific value socially constructed and attributed (neither true nor believed per se) to the thing (i.e. animal, symbol) by a given group (Durkheim, 1910). The anomie, defined as the discrepancies between personal or small groups standards (i.e. norms, values) and wider social standards (i.e. embodied in legal provisions or policies, etc.).

Merton (1938, 1964, 1967) extended the concept of anomie, a social state of normlessness, to the discrepancies, in terms of norms and values, between minor and major groups at a given time in a given space (a minor group can be a major one in a different context). Merton described five types of groups' adjustment to anomic state³¹. Each anomic state is a potential

³⁰ A precursor to social representation theory (Moscovici, 1961), see [section 3.2.3](#).

³¹ Five types are conformity, innovation, ritualism, retreatism and rebellion. They are defined according to two criteria: the presence of a common cultural goal and the institutional recourse. E.g. when both groups

context of stigma for the minor group. Following anomie and deviance (Durkheim, 1894; Mead, 1934; Tannenbaum, 1938), studies focused on the interactions between minor and major groups and their effects (see [section 3.2.2](#)), leading to the conceptualisation of Labelling Theory.

Lemert (1951) differentiated primary deviance (i.e. deviant or transgressive behaviour and its consequences) from secondary deviance (i.e. society or group's condemnation of behaviours and expected roles from the condemner and the condemned). Primary deviance has an official status: it is illegal. Secondary deviance is related to the transgression of social and moral norms. The fatherhood of Labelling Theory is often given to Becker (1963). The external ascription as deviant and the related set of roles and expectations shape social life and people's behaviours. The two main fields of research, which emerged from this perspective, are crime and stigma studies, focusing on respectively primary and secondary deviance.

Goffman's interest focused on the effects of Labelling Theory on individuals in daily life. A label is an attribution (i.e. sex, gender, skin colour, political view); it can be actual (accurate feature) and/or virtual (potential feature, likely to be erroneous). The individual corollary of Labelling Theory is social identity, defined as a dynamic negotiation between attributions and social status, by oneself (internal ascription) or others (external ascription). A label in itself has no valence. Nevertheless, external attributes related to the label can be positive, neutral or negative. Stigma concerns negative attitudes related to the negative attributes of a label. In this sense stigma is always a virtual external attribution leading to exclusion, seclusion or avoidance.

Stigma and spoiled identity (Goffmann, 1963)

Goffman (1963) provided the first typology of stigma according to two main aspects:

- (a) The nature of its object: *deformities* (i.e. amputee, podocniosis), blemish of individual *character* (weakness, lack of honesty), and *tribal stigma* (i.e. religion, social class)
- (b) The degree of perceivability: when stigma is due to visible or obvious differences (such as skin colour or physical deformities) the person is the carrier of a *discredited* mark; when

have a common goal, anomie is resolved through a conformity or an innovation process. Conformity occurs when the minor group has institutional means to protect its difference, whereas innovation is related to the absence of institutional means, the common cultural goal protecting the minor group from persecution (Merton, 1964, 1967).

stigma relates to a less visible attribute (e.g. political persuasion) it is referred to as *discreditable*.

Goffman also explored the interactions between social identity and personal identity (i.e. uniqueness, sense of self) through people's experiences of stigma and their consequences. The partial or total internalisation of a *shameful differentness*³² (Lemert, 1951) is a degree of acceptance among the stigmatised. Goffman did not provide strategies to alter or reduce stigma but observed spontaneous management strategies (e.g. positive counter-identification, information, and advocacy). These strategies are similar to the groups' adjustment strategies to anomic state identified by Merton (1938); for instance, advocacy is an example of conformity process, while information is an innovation process.

Based on labelling theory and theories of deviance, early sociological works on stigma focused on two aspects: social organisation and group dynamics. The next section explores social psychology related works, based upon prejudice theories.

From obedience and attribution theory to prejudice

Concomitantly, premises of prejudice studies are found in obedience and submission to authority studies as they identified the individual determinants of potentially stigmatising or prejudicial process. These individual determinants can be personal (i.e. personality), relational (i.e. the individual's relationship to the group, obedience) or interactional (i.e. a combination of both).

The authoritarian personality is a state of mind, or stable personality traits, characterised by the belief in absolute obedience or the submission to one's own authority, and the oppression of one's subordinates following this belief (Adorno et al., 1950; Epstein, 1965). Subsequent studies (Kerlinger and Rokeach, 1966) focused on dogmatism and cognitive rigidity as dominant factors in the authoritarian personality (Rokeach et al., 1955, Rokeach, 1956). Criticisms from the psychological field denounced a political bias and an underlying form of dogmatism and/or moralism (Parrot and Brown, 1972). Nevertheless, recent works in political psychology (Altemeyer, 2006) and political philosophy (Norris, 2005) renewed this theory. More interestingly, authoritarianism is sometimes used as a personality dimension in

³² Also referred to as internalised or self-stigma.

personality disorders research (Blair, 2011) and as a variable in prejudice modelling (Bäckström and Björklund, 2007).

Drawn upon a Gestalt approach, Lewin aimed at identifying patterns' rules or determinants; and was one of the first relational theorist in psychology (Lewin, 1943) and studied leadership modes (Lewin et al., 1939). Leadership modes have a complementary field of research in submission to authority³³. This led to a series of studies on submission to authority within different contexts (e.g. professionals abusing clients, cults)³⁴. Findings from a recent study investigating personality traits related to obedience (Begue et al., 2014) suggest that people who are concerned with being liked or approved might be more responsive to authority (obedient) and more likely to perform actions they would not otherwise. This enlightens the dispositional traits, explaining how stigma can be perpetuated by otherwise non-stigmatising people.

The nature of prejudice (Allport, 1954)

Allport defined prejudice as the combination of an attitude of favour or disfavour, and an overgeneralisation leading to erroneous beliefs (Allport, 1954). As a process implying thoughts, beliefs, emotions and context, prejudice is the individual ground of stigma as a social process (Phelan et al., 2008), based on Social Categorisation (SC) and Attribution Theory³⁵. SC is the attribution, by individuals to others, of characteristics leading them to belong to the in-group (same characteristics) or the out-group (different characteristics)³⁶. SC is cognitive (perception, thought) and emotional but not systematically rational (can be erroneous). SC leads to clusters (perceptive entities) enabling quick identification of objects (even though erroneous) and guiding daily behaviours (i.e. avoidance of out-groups). Clusters are schemes that tend to be

³³ One of the best-known social psychology experiment is Milgram's (1963) simulated electric shocks. The original paper defined obedience as "the dispositional cement that binds men to systems of authority" (Milgram, 1963).

³⁴ Nevertheless, studies on obedience have been widely criticised methodologically (Garfinkel, 1967), regarding transferability of findings to non-experimental contexts (Orne and Holland, 1968), and finally regarding the submission to the researcher's authority as participants' trust in the institution might lead to an exacerbation of conformity or submissivity, therefore, biasing the results (Reicher et al., 2012).

³⁵ Heider defined (1959) the fundamental attribution error as the consistent underestimation of situational pressure and overestimation of dispositional traits (personality) regarding the explanation of a given behaviour, hence highlighting the tendency to personalise (and not contextualise) the explanation of behaviours. In the context of stigma, this relates to the cognitive biases reinforcing the depreciation of the stigmatised ones.

³⁶ The in-group refers to any group of affiliations (memberships) and operate at different levels of socialisation (e.g. family, school, and parish). In-group membership provides individuals with references such norms, values and status, whether ascribed or achieved. The out-group refers to the social group a person does not want any affiliation with. Allport (1954) reported that 79% of the interviewees were unable to name or identify an out-group.

confirmatory. Clusters' functioning can explain the discrepancies between categories and evidence, the resistance to evidence and the persistence of misattributions.

Allport identified five types of negative outcomes of SC: verbal rejection, avoidance, discrimination, physical attack and extermination (Allport, 1954). Therefore, SC is the individual process leading to prejudice, resulting from a cognitive and conative process involving a sense of self in relation to belonging group(s). Ultimately, according to Allport, individuals' relations with in-groups and out-groups are not opposite. It implies that there can be preferences without stigmatisation. Lastly, prejudicial attitudes or positive actions are consequences of beliefs (conscious or not); beliefs are constructs built up within in-groups' standards and are used as a schemas to read the social world.

Allport (1954) suggested the exposure and interaction with out-group members are likely to address the negative outcomes of SC and modify social clusters. If the prejudicial belief is related to fear, the exposure to and experience of a non-threatening person from the out-group might lead to reframing erroneous beliefs. This is called *the Contact Hypothesis* (Allport, 1954, p261) or later the intergroup contact theory (Pettigrew, 1998). Contact reduces prejudice when the following six conditions are present: mutual interdependence, common goal, equal status of group members, informal interpersonal contact, multiple contacts with several members of the out-group and social norms promoting equality. This corresponds to Merton's (1938) conformity and innovation strategies. Recent studies confirmed that prejudice is associated with less contact with the out-group (Binder et al., 2009). Conversely, contact with the out-group is an efficient strategy to reduce prejudice (Pettigrew and Tropp, 2006; Pettigrew et al., 2011), especially when sustained by a figure of authority from the in-group (Gomez and Huici, 2008).

The studies reviewed so far covered cover the wide spectrum of stigma enactment, from the implicit categorisation and attribution to the rationalised discriminatory practices. The disciplinary identity of current stigma, prejudice and discrimination research is today less obvious than it used to be. The global understanding of stigma led to the interdisciplinary study of each label or condition to take preventive actions or design stigma-reducing interventions (see [section 3.3.3](#)) (Stuber et al., 2008; Chaudoir et al., 2013). The next section introduces current models of stigma and prejudice in the context of sexual health and HIV.

3.2 An overview of stigma theories and HIV-stigma studies

This section synthesises stigma models and HIV-stigma research, focusing on individual determinants ([sections 3.2.1](#)), community or group determinants ([section 3.2.2](#)), and mixed models ([section 3.2.3](#)). This section aims at showing the diversity of HIV-stigma research and is a premise to question the medicalisation of stigma research (section 3.4) that will be questioned from an epistemological point of view in the first part of [chapter 4](#).

3.2.1 Individual perspective on prejudice: investigating the implicit

Further to Allport's works, personal determinants and individual processes involved in prejudicial cognition and stigmatising attitudes have been investigated. Two main fields of research have been developed in relation to HIV: Attribution Theory and the attitudinal field.

Further to Heider's attribution theory and the fundamental attribution error (Heider, 1958, 1959), a series of social psychology experiments were performed to identify the effects of context on the types of misattribution (Jones and Harris, 1967; Ross et al., 1977). Synthesising two decades of research (Berkowitz, 1965; 1977), Pettigrew (1979) formulated a generic group-dependent attributional scheme at the intersection of cognitive and social processes.

The *ultimate attribution error* defines inter-group misattributions following two main tendencies. When in-group members perceive an action performed by an out-group member as negative, they tend to attribute it to a personal disposition (i.e. personality), while the same act with the same negative connotation performed by an in-group member tends to be explained by the context. Conversely, when a positive action is performed by a member of the outgroup, in-group members tend to justify the positive actions following four types of justifications (Wiener, 1972): the exception case (e.g. "but s/he's not like them); the luck argument (i.e. exception case attributed to situational factor); the high motivation/effort argument (i.e. will against natural tendency); context manipulation (e.g. "that's what they want us to think but...).

This logical analysis of erroneous cognition can explain how context and attribution mitigate the effect of the contact hypothesis (Allport, 1953) but also how people can resist to facts, this will be discussed in [section 7.4.2](#). If behaviours can be openly discriminatory (i.e. hate crime) attitudes are latent appraisals (Maio and Olson, 2000). In the context of stigma, attitudes refer to silent stigma, such as avoidance strategies of the stigmatised group or prejudicial thoughts;

this is also referred to as blatant and subtle prejudice (Pettigrew and Meertens, 1995). Implicit attitudes and explicit behaviours have a mutual influence (Whitfield and Jordan, 2009)³⁷.

The use of implicit attitudinal measures towards HIV has increased in health research (Krieger et al., 2010), mostly to assess potential stigmatising attitudes in healthcare (i.e. Wagner et al., 2014). Implicit measures are used to screen vulnerable populations (Kincaid et al., 2012; Czopp et al., 2004) and tailor interventions addressing implicit cognitions associated with specific health-related behaviour (Stacy et al., 2000) or treatment (Golub et al., 2017). This also gives an empirical grounding to stigma-reducing strategies³⁸ (such as perspective taking (Todd et al., 2011) or mimicry (Inzlicht et al., 2012) and cognitive and/or neuropsychological studies (Derks et al., 2008; Senholzi and Kubota, 2016).

3.2.2 Group dynamics and social determinants of stigma

While social psychology furthers individual determinants of stigma, sociological approaches focus on the inter-group relationships and social organisation theories, developed below.

Link et al. (1987; 1989) emphasised the role of perceived stigma (individuals' awareness of the discrimination and devaluation directed towards those with conditions that are viewed unfavourably). When acquiring a stigmatised condition, perceived stigma becomes self-relevant. The fear of rejection leads to secrecy and social contact avoidance³⁹. While Link's model focuses on mental illnesses and the labelling effect of a diagnosis (Beavan et al., 2011; Ellison et al., 2015; Yamaguchi et al., 2017), the Brazilian policy regarding leprosy also illustrates how naming can impact social perception and behaviours⁴⁰. Such an approach

³⁷ Methodological challenges remain in the understanding of the relationship and context of influences (Maass et al., 2000). The Implicit Association Task is a widely used implicit task (Greenwald et al., 1998; Greenwald et al., 2003) measuring the strength of linguistic associativity (Fazio and Olson, 2003; Carney et al., 2010). Generally, when self-report (self-awareness) and implicit biases are in agreement, the behaviour is more easily predicted as congruent (Greenwald et al., 2009).

³⁸ This will be developed in section [2.3.3](#) and discussed in section [7.4.1-2](#).

³⁹ A meta-analysis (Livingston and Boyd, 2010) found a reliable association between perceived stigma and a low social support/integration.

⁴⁰ In Brazil, in the 1970's, to address stigma and exclusion of lepers and cure them, A. Rotberg, a leprologist, initiated a campaign renaming leprosy as Hansen's disease (or Hanseniasis). After three decades of Education and Health policies, the effects of such a policy on social representation (Oliveira et al., 2003), on patients (White, 2005) and the pandemic itself were studied. Epidemiological data and campaign materials for leprosy and Hansen's disease were compared. The analysis concluded that renaming leprosy led to new discursive practices (assimilating biomedical vocabulary) through which new social meaning (disease, curable) and practices have been promoted (Santos et al., 2012). The dissociation of leprosy from Hansen's disease led to the paradoxical situation of two words and their related attitudes for the same reality: Hansen's disease is a curable condition while leprosy is still stigmatised and socially recognised through the advanced symptoms of the disease. Regarding leprosy, the medical community led the renaming process to educate and cure the population.

frames the possibility of new labels as means for people's empowerment. The behaviour, or the main symptom, is emphasised rather than the qualification of the being.

In the case of HIV, the renaming process came from both the community (Dilmitis et al., 2012) and the medical community. It tries to address misconceptions such as the distinction between the virus (HIV) and the clinical syndrome (AIDS), or street names such as the gay plague (Rollins, 2002), as much as the risky rhetoric of preventative programmes and public health (Scott, 2003). People living with HIV and activists fight the reduction of a person to a medical label, which explains why this dissertation does not use any acronyms and follows previous recommendations (Dilmitis et al., 2012).

Further to Goffman's two-dimensional model (nature and perceivability), Jones (1984) suggested six dimensions potentially leading to stigma. Each dimension refers to the social categorisation and the type of misattribution related to a condition:

1. *Peril* or dangerousness: often related to unpredictable behaviours and activated through the identification of (potentially erroneous) social cues related to mental illnesses (e.g. awkwardness, lack of social skills, appearance), inducing fear and discomfort (Corrigan, 2004, 2007; Link et al., 1987).
2. *Origin*: as possibly the individual's responsibility in its acquisition (biological, genetic, behaviourally or unknown) have a different impact: innate or induced conditions (e.g. Down syndrome, PTSD) are pitied while behaviour-dependent disorders (e.g. substance abuse) are more stigmatised (Corrigan et al., 2000; 2001). In the context of HIV, this will be furthered in the section on [social representations](#) and discussed in [section 6.2](#).
3. *Concealability*: visible symptoms or attributes are more likely to be stigmatised.
4. *Course*: evolution of the condition
5. *Stability*: treatment efficacy, and curability. Stability also refers to the predictability of the person's behaviour living with a certain stigmatised condition.
6. *Disruptiveness*: the impact of the condition in daily life (e.g. ability to hold down a successful professional activity).

These dimensions interact. For instance, conditions perceived as stable and curable are perceived as less disruptive; visible conditions or symptoms lead to an increased perception of dangerousness. Aesthetic aspects might have different social interpretations, whether explicitly bodily (amputee) or behaviour-related. The final three dimensions, course, stability, and disruptiveness, present similarities. Course and stability refer to the likelihood for a person

to recover and benefit from treatment (Corrigan, 1998; Jones et al., 1984) while disruptiveness refers to the impact on relationships or social insertion. When disorders are considered less disruptive, in which case they may be perceived as more stable, they might also be less stigmatised (Corrigan, et al., 2001).

HIV in the early years of the pandemic was not 'concealable' whether the person was under medication (i.e. side effects such as body fat distribution) or not (i.e. weight loss, skin marks, flu like symptoms). Pharmacological improvements in the treatment of HIV led to changes in the possible social recognition of people living with HIV, at least in countries where treatment is available and accessible (Chaudoir et al., 2013). This model explains inter-individual variability, as each diagnosed person is not stigmatised to the same extent (Crocker, 1999). While HIV is frequently associated with a social vulnerability (e.g. an increased risk of poverty, lower socioeconomic status and lower levels of education, see Whittle et al., 2017), this also highlights the presence of potential protective factors (Mustanski et al., 2011; Poon et al., 2012; Johnston et al., 2017).

Living with HIV is now a long-term condition (Deeks et al., 2013). Jones' (1984) model integrates the impact of the social perception of HIV regarding the origin and controllability dimensions, namely, sexual promiscuity and the lack of controllability regarding sexual behaviours (Joffe, 1995; 1998). This is exemplified by the following quote from a focus group participant (FG2P1) who described his youth experience, linking HIV-stigma with homophobia and explaining the different types of rejection:

You know when HIV came up and people, mostly gay men were seen as evil sick propagators of all kinds of depravities, illnesses etc. (...). I was a kid in the early 80s, that is when I actually came out as a gay man, and I remember it was a horrible time, because we were all petrified of how to get it because nobody knew how the infection was transmitted. (...) Apart from the fear of becoming infected, you were looked upon as if you were a criminal, as if you were a monster in society. The whole epidemic was among gay men, foremost, or people who were drug-addicted. Suddenly all these minorities were being stigmatised, very much under the cover, people being sacked, people not being employed, people were not allowed to socialise, to work with others, people were kicked out of their home. There was the stigma; people were ashamed of saying they had a member of the family who suffered from HIV.
FG2P1, 10-24

Social Dominance Theory⁴¹ (SDT) models social hierarchy and intergroup relationships (Sidanius et Pratto, 1999). Social hierarchy in human groups is described as universal (Lanski,

⁴¹ SDT is drawn upon multiple references such as Marxist, feminist, critical, evolutionary theories, and integrate social psychology and sociology elements. SDT highlights the multi-layered structure of social organisation, and consequently interactional and multiple aspects of power relationships.

1984). SDT states that the maintenance of stigma is due to multiple levels of embedding (i.e. institutional, individual, see Sidanius and Pratto, 1993). SDT led to the social dominance orientation scale (Pratto et al., 2006) assessing the explicit desire of an individual for a group dominance. SDT has been applied in sexual health context to understand the interaction and norms of subgroups, complex cumulative stigma and social identities (Rosenthal and Levy, 2010). For instance, Knight et al. (2016) studied HIV Pre-Exposure Prophylaxis (PrEP) perception among people at risk of HIV and reported that, for some participants, PrEP was associated with conflicting norms, which informed policy-makers, feasibility and implementation plans.

3.2.3 HIV-Stigma: Mixed Models and Other Theories

Stress theories

Stress theory defines stress as an external event (acute) or a situation (chronic) that leads to specific coping strategies. Stress models study the long-term effects of both stress coping strategies, psychological and somatic effects of stress minimisation or denial. Early works (Quick et al., 1987) showed increased stress was associated with changes in health-related behaviours (e.g. increased intake of tobacco, alcohol and drug use). Other negative social, physical (Thoits, 2010) and psychological outcomes (Lantz et al., 2005), e.g. sleep disturbances, sexual dysfunction, depression, and suicide (Feskanich et al., 2002), were reported.

Further to Stress Theory, authors specified psychological stigma-stress (Compas et al., 2001), differentiating voluntary from involuntary stress responses⁴². Coping strategies only refer to the former, as to the way an individual tends to react when faced with adverse events and/or a hostile environment (Kozhevnikov et al 2014). Engagement and disengagement with the stressful event refer to traditional approaches or avoidance strategies. Following this model, stigma is an individual response to a set of internal and external factors. Responses to identity threats have been described as a complex set of strategies (Berjot and Gillet, 2011): protective or enhancement motives lead to different strategies to preserve either the personal identity, social identity or both.

Minorities are more likely to undergo social stress exacerbating general stress and mental health consequences. Between SDT, stress and social stress theories, Meyer (1995, 2003) formalised the Minority Stress Theory, which focusses on health issues related to social

⁴² Involuntary and voluntary stress responses are not mutually exclusive; rather they affect each other.

oppression⁴³. The early days of the HIV epidemics decimated the gay community in the USA and Europe, at a time homosexuality was still criminalised and psychiatrised (taken out of the DSM in 1987 and out of the ICD in 1991 (see Minard, 2009). In reaction to this decimation, the community led the fight for medical treatment and against stigma, reframing community health and the contribution of community to the health pathway.

Therefore, some authors argue that living with HIV or being at risk of acquiring HIV is a sexual minority health issue (Cargill and Stone, 2005; Baral et al., 2013). This view was developed by the KI3 with a further analysis in terms of pink-washing and its consequences:

KI3: I think until the mainstream of gay society accepts that HIV is their issue, hum, I do not think that is going to change. I think historically, that is an issue. There was a period of time when we wanted to make it not be about gay men. I mean to the point of which there was more focus deliberately placed on heterosexual transmission figures, of which it was well known that a lot of those transmission were happening in sub-Saharan Africa. But, that was not mentioned. It was almost a political pink-wash more than a whitewash, trying to say this is not a gay disease, hum, which I think, from a public health perspective was a mistake. Because, it enabled a feeling of HIV to not be a gay thing and it removed ownership of the disease and of the virus. I think gay men as a whole, need to, and particularly in this country, need to understand that it is predominantly in the UK, a gay disease. And the demographics I mean that in terms of the transmission demographics, not that it is exclusively a, you know, a disease that affects gay men. And I think that is subtly lost, but also kind of denied.

Minority stress and other stressful life events are cumulative (Szymanski and Gupta, 2009; Calzavera et al., 2012; Wagner et al., 2017). Often framed under intersectionality theory (Crenshaw, 1991; Fukuyama and Ferguson, 2000), studies focused on subgroups presenting specific vulnerabilities or labels (Boone et al., 2016) such as childhood sexual abuse among bisexual men (Kisler, 2013); MSM practicing unprotected anal intercourse, whether living with HIV (Welles, 2009) or not (Jeffries et al., 2012; Mimiaga, 2009). In this sense, HIV stigma is intrinsically multidimensional (Carrasco et al., 2017), and intertwined with other types of stigma, labels or variables such as age, gender (Sangaramoorthy et al., 2017), sexual orientation and ethnicity (Arnold et al., 2014). These findings suggest that high minority stress may be associated with risk-taking behaviours (Hamilton and Mahalik, 2009; Hatzenbuehler et al., 2009) that increase the likelihood of HIV transmission or acquisition.

Inter-group theories focus on the experience of minorities, their relationships to other groups and associated consequences. The next section is devoted to other approaches, aiming at understanding the underpinnings of intergroup relationships.

⁴³ From a global perspective, and sexual health context, minority stress also refers to diverse “minor” identities, related to gender (Logie et al., 2012), sexual or LGBT+ (Frost et al., 2015), ethnic minorities (Denton, 2012), and the intersection of several ‘minor’ identities (Balsam et al., 2011).

Social representation theory (Moscovici, 1961, 1976, 1979): diversity and context-sensitivity
Drawing upon Durkheim's concept (1910), SR theory offered a layered communication theory and an epistemological grounding (Moscovici, 1998a, 1998b) affiliated with socio-constructivism (Vygotsky, 1985)⁴⁴. Social Representations (SR) are dynamic and modifiable collective representations that are inherent to communication, interactions, and language practices and modifiable through communication and language behaviours (Moscovici, 1961). SR Theory assumes that language, representations, thoughts and emotions operate at both implicit and explicit levels. At the core of SR Theories (Moscovici, 1976), stereotypes are thoughts, values, or images implicitly shared by members of a community. Whether positive (socially valued), neutral or negative, implicit (automatic) or explicit (deliberate) stereotypes are clues guiding social perception and attitudes (Devine, 1989). SR theories also led to the Stereotype Threat Theory that posits that stigmatised group members are likely to underperform due to an internalised negative stereotype (Steele and Aronson, 1995). The stereotype threat is linked to self-stigma (Pennington et al., 2016).

In the early years of the epidemic, HIV was mostly associated with homosexuality, which was and continues to be stigmatised (Joffe, 1995; Arnold et al., 2014). SR associated with HIV stigma relates to the negative perception of its routes of transmission: unsafe sex and blame regarding the lack of precautions used in sexual behaviour (Goodwin et al., 2004; Joffe, 1996, 1999; Markova et al., 1995), and drug use practices (Goodwin et al., 2003; Herek, 1999; Herek et al., 2003). The last decade saw an increase in SR and thematic exploration studies to identify the main barriers to specific behaviours (e.g. condom use, testing) and/or in key populations (e.g. MSM - see for instance Griffin, 2011, sex workers, and professionals⁴⁵). Two studies are summarised below to illustrate the cultural embodiment of SR in general population.

A comparative study explored the narratives of 500 young people from six African countries⁴⁶ (Winskell et al., 2011). Results suggested that narratives from high-prevalence areas in Nigeria showed a predominant moral characteristic, namely an *"unforgiving moral agenda, dominated*

⁴⁴ Provided with a context-sensitive framework and a method - mapping a set of conceptual (psycholinguistic) and logical relationships around an object (here HIV) operating explicitly (language) and implicitly (framing, attitude) - SR theories are a traditional socio-constructivist approach, less known and used in Anglo-Saxon world, the latter being the cradle of stigma studies.

⁴⁵ In Brazil, Oliveira (2013) studied SR among health professionals over a decade. The evolution of HIV/AIDS SR shows persistent themes (e.g. fear, death, prevention sex, disease) and peripheral elements (e.g. shame, drugs, promiscuity). However, among health professionals, new SR arose. Dichotomies such as innocence/guilt, right/wrong pervade, while the concepts of equality of care and long-term conditions emerge. The author explained this evolution with both pharmacological improvement and social changes.

⁴⁶ Burkina-Faso, Kenya, Namibia, South East Nigeria, Swaziland and Senegal.

by conservative Christian dogma on sexuality, and tend to focus on the misdeeds of characters, primarily female, that lead to their infection". By contrast, narratives from high-prevalence areas in Swaziland were more positive and tended to focus on resilience. Contrary to the results of quantitative studies that found negative attitudes (Genberg et al. 2009) and stigma (Du et al., 2017) were less likely in a high prevalence country, this study highlighted the importance of the cultural framing and local emerging themes (e.g. immorality, religion, empowerment).

SR do not lead to stigma, though stigma is the enactment of a negative SR. Studies exploring SR of HIV show structural similarities and content specificities. The common points refer to structural elements (i.e. outsider as a threat, moral and emotional polarisation⁴⁷) and content-related elements depend upon cultural specificities, informing the methods of this study.

Ecological models

Other theories do not initially focus on stigma but provide a more generic account of social influences. If multi-motive and transactional models focus on the reactions and coping strategies of a stigmatised person or group, it seems relevant to extend and apply this to the person or group who is the agent or said stigmatising agent. While the stigmatised person or group is directly threatened, the stigmatising agent(s) may (erroneously) perceive the out-group member(s) as a threat. The nature or quality of the threat (real vs imaginary) then becomes the distinctive criteria between the two people or groups.

The Framework Integrating Normative Influences on Stigma (Martin et al., 2008) model is an attempt to synthesise and organise stigma research findings according to normative (prescribing) factors. Following a traditional ecological approach, the FINIS framework identifies three levels: the micro-level: social and illness characteristics, socio-psychological and cognitive insights, and the macro-level: media images and influences, national context, and the meso-level: social media and treatment systems. For instance, celebrity disclosures of living with HIV, such as the "Charlie Sheen effect⁴⁸", affected spontaneous requests about HIV, testing and information about symptoms (Brown and Basil, 1995; Ayers et al., 2016). This

⁴⁷ Differentiating stereotypes, blame and stigma, Riley and Bah-Odoom (2010) found that stereotyping and blame were protective factors from sexual risk-taking behaviours, while stigma was associated with reduced safety in intended sexual behaviours. By way of explanation, stereotyping and blaming might lead individuals to have a stronger sense of their perceived vulnerability and engage in protected sex, while stigma might reflect ignorance and out-group attribution leading an individual to consider oneself not at risk.

⁴⁸ <http://www.bbc.co.uk/news/health-35629036> and <http://www.cbc.ca/news/health/sheen-hiv-1.3458219>.

meso-level element might affect a population's SR and attitudes towards people living with HIV (Kennedy et al., 2004).

The Multi-Motive model (Smart-Richman and Leary, 2009) defines different contexts and mechanisms leading to three types of social reaction: prosocial strategy (maintaining a positive in-group identity), avoidance and antisocial strategy (maintain negative out-group identity). Stigma, as an antisocial process, could then be explained by an initial *event of perceived rejection*. The perceived rejection is a key-point in this model as it includes the perception and potential biases of the stigmatiser. This implies that the initial subjective experience of rejection generates a mirror response. With cautious considerations, it may also lead to the initial experience of perceived rejection *a priori*, in what could be explained by self-stigma, misinterpretation or cognitive distortion.

These last models introduced give a typology of groups and individuals' strategies, compatible with most of the theories aforementioned. The upcoming section summarises the last subset of stigma literature, putting forward these strategies as evolutionary products, on both stigmatising and stigmatised sides.

Evolutionary theories of stigma

Evolutionary theories⁴⁹ integrate social processes from a nature/culture interactionist approach, such as the developmental perspective (Lickliter, 2008) or the dynamical evolutionary approach (Kenrick et al., 2003, 2002). The main assumption is that existing traits or behaviours are due to selection process and adaptation to environment; the main corollary is that behaviours, sociality and biology modify each other. Hence, stigma is seen as the result of social learning and socialisation (Belsky et al., 1991) related to mating or a preservative strategy. Visible signs of disease or deformities are avoided; individuals are excluded to protect the group and promote the natural selection of specific traits (Kurzban and Leary, 2001). Regarding HIV, the visible signs associated with living with HIV (i.e. skin problems, body fat distribution) tend to disappear with the availability of treatment, though disparities between low, middle and high-income countries remain. Stigma as a natural process with an evolutionary function is a reaction to an ego or group threat; therefore, identifying the type of

⁴⁹ The Theory of Evolution by Natural Selection (Darwin, 1859) has been imported to social sciences under the term of social Darwinism (Tarde, 1884; Gautier 1880). Erroneously associated with bio-determinism and eugenics (Hodgson, 2004), it contributed to attachment (Bowlby, 1969) and imprinting theories (Lorenz, 1935), the phylogenetic perspective in psychology (i.e. Piaget, 1972), socio-biology (Wilson, 1975) and biocultural approaches (Neuberg et al., 2000).

threat (mating, social rivalry, threat of a disease) is a prerequisite to building an effective intervention (Schaller and Neuberg, 2012).

3.3 Addressing HIV Stigma: Public Health Rationale⁵⁰

3.3.1 Expressions of stigma

Stigma is enacted through actions or the absence of actions that openly discriminate (i.e. verbal abuse), referred to as discriminatory or dignity attacks (Friedman et al., 2016). The second form of enacted stigma, silent and distinct from discrimination, consists of avoidance strategies of the potential target, and subsequent reactions when avoidance strategies fail (e.g. non-verbal attitude, relational ambivalence).

Stigma experiences range from effective stigma (victim of enacted stigma) to perceived stigma (acknowledgement of an external stigmatising norm), to internalised stigma. Also referred to as internalised shamefulness (Goffman, 1963; Lemert 1951), self-hate (Allport, 1954; Lewin, 1941) and self-stigma (Corrigan et al., 2009), internalised stigma is the acknowledgement and validation of stigma about oneself. Associated with perceived stigma (Pascoe and Smart Richman, 2009; Pryor et al., 2004), anticipated stigma (Quinn and Chaudoir, 2009) refers to the degree to which people expect to be stigmatised because of a specific trait. Relatives, partners (Pryor et al., 2012; Östman and Kjellin, 2002), professionals and caregivers (Ogunmefun et al., 2011; Murray et al., 2016) in contact with stigmatised people might experience stigma by association, also called secondary or courtesy stigma (Angermeyer et al., 2003)⁵¹. Each type of stigma affects people's health and well-being, as well as sexual and public health priorities.

3.3.2 HIV-stigma as a psychosocial impediment to sexual and public health

Recent theories on health and sexuality tend to adopt an ecological point of view and to integrate psychosocial components. Translational epidemiology (Ward et al., 2014), the Syndemic Model of Health (Singer and Clair, 2003), and the Sexological System Theory (Jones et al., 2011) define at least three levels of determinants of health, and as such three levels of interventions (Robinson et al., 2002):

- a) The structural level or the social environment defining local contexts (i.e. Law, policies, access to healthcare),

⁵⁰ Section 3.4 is the revised and updated version of a paper previously published: Chollier, M., Tomkinson, C., Philibert, P. (2016). STIs/HIV Stigma and health: A short review. In *Sexologies*, 25(4), pp. e71-e75.

⁵¹ Examples of each type of stigma are provided in [section 6.2.1](#).

- b) The behavioural level (a behaviour or an absence of behaviour having an impact on health or sexuality, can include relational aspects and any behavioural determinant),
- c) The biological level (pharmacological treatment).

Since ART, living with HIV became a long-term condition. Some authors argue that biomedical focus led to the neglect of psychosocial aspects; stigma consequences (i.e. low self-esteem, depression, anxiety) explaining partly non-adherence to treatment (Lowther et al., 2014). HIV-stigma, defined as devaluing, shaming and prejudicial thoughts and actions towards HIV and/or people living with HIV (Herek, 2003), occurs at both structural and behavioural levels and impedes the ability to medically address the pandemic: to screen, treat and follow-up people (Hodgson, 2014).

Cumulative stigma and access to health care

HIV-stigma reflects and catalyses other stigmas such as social class, gender inequalities (Parker and Aggleton, 2003) sexual orientation (Ayala and Diaz, 2001; Garcia et al., 2015), ethnicity (Novick, 1997; Joffe, 1998) or migratory status (Agu et al., 2016). While health care access highly depends upon health care facilities, it can be influenced by local structural factors (WHO, 2013). For instance, recent studies reported an association between the criminalisation of homosexuality ('legal stigma' or primary deviance) and poor service and access to HIV care (Arreola et al., 2015; Santos et al., 2016).

Screening impediment

Stigma interferes with HIV prevention and screening, contributing to late presentation and diagnosis (Stall et al., 1996; Arnold et al., 2014 Arora and Wilkinson, 2017; Gwadz et al., 2018). Studies have found that feelings of shame and perceived social stigma impede HIV screening (Fortenberry et al., 2002; Ho et al., 2017). Furthermore, stigma, as an intersectional or multifaceted phenomenon, can lead to gendered patterns; anticipated stigma has been associated with less frequent testing among males while community stigma seems dominant among females (Treves-Kagan et al., 2017).

Routine testing and adherence

Stigma and fear of stigma are important factors in avoiding testing (Ho et al., 2017), non-disclosure of one's positive status and failure to seek assistance (Smith et al., 2008). It is particularly the case in vulnerable populations such as women living with HIV in Sub-Saharan Africa. Women raise social concerns about being seen at clinics, social condemnation and

potential discrimination (Montgomery et al., 2016). Personal concerns about attending a clinic manifested as the reminder of one's condition (Kilewo et al., 2001; Ngarina et al., 2013). The negative psychosocial factors are associated with non-adherence (Rice et al., 2017). HIV stigma compromises psychological well-being and sociality leading to internalised stigma and concealment for both adults (Katz et al., 2013) and adolescents (Martinez, 2012; Ankrah et al., 2016) living with HIV. Routine testing and adherence for people living with HIV decrease when they experience stigma in health care (Sweeney and Venable, 2016; Hall et al., 2016; Heestermans et al., 2016).

HIV-Stigma, health and healthcare

HIV-related stigma alters the general health outcomes in people living with HIV (Logie and Gadalla, 2009; Rueda et al., 2016). Furthermore, stigma in health care permeates all services (i.e. primary care). For instance, women living with HIV pursuing pregnancy report a strong feeling of being judged (Wagner et al., 2010). Despite neutrality and aspirations of non-judgment, students (Philip et al., 2014) or professionals' stigmatising views can be pervasive (Eaton et al., 2015; Stutterheim et al., 2014). Perception of patients oscillates from the innocent patient (i.e. born with) to the guilty patient (Schellenberg et al., 1995; Infante et al., 2006, Formozo and Oliveira, 2010). Nyblade (2009) reports three types of prejudicial beliefs (conscious or otherwise) among professionals: the fear of acquiring HIV associated with a strong lack of knowledge, the lack of awareness of stigma, its process and consequences, and the attribution of transmission through immoral behaviours. In developing countries, trust and satisfaction with HIV care providers were associated with fewer depressive symptoms and higher adherence (Langebeek et al., 2014).

Social, relational and psychological vulnerability

In unsupportive social contexts (e.g. loneliness, isolation), people living with HIV show poorer mental health (Logie & Gadalla, 2009) and more psychiatric symptoms (Tavakkoli et al., 2014). HIV stigma is associated with increased anxiety (Brandt et al., 2016) and depression (Olley et al., 2017). People living with HIV are also at a higher risk of suicidal ideation and suicide attempts (Rukundo et al., 2016), especially at key-moments such as diagnosis (Li, Tucker et al., 2016) or in the context of cumulative stigma (Ferlatte et al., 2017).

Internalised stigma alters one's self-perception (Fife and Wright, 2000), can lead to mental health issues (Fekete et al., 2017), and might lead to accepting situations otherwise unbearable; for instance, a higher prevalence of intimate partner violence was found among

women living with HIV (Dhairyawar et al., 2013; Colombini et al., 2016), exacerbated during pregnancy (Matseke et al., 2016).

3.3.3 HIV stigma-reducing interventions

HIV stigma models are framed within existing models or based on the experiences of people living with HIV (Earnshaw et al., 2013). This leads to concrete models on a given area and/or population, and to identify local trends or patterns (Holzemer et al., 2007) to tailor stigma-reducing interventions. Aimed at reducing stigmatising attitudes and supporting stigmatised people, interventions draw upon the Contact Hypothesis, confirmed by meta-analyses (Pettigrew and Tropp, 2006; Pettigrew and Tropp, 2008; Smith et al., 2009). Despite the methodological difficulties and lack of comparability of interventions that assess efficacy (Stangl et al., 2013), stigma-reducing interventions are becoming common practice (e.g. diversity training).

Interventions tend to target key populations, such as people living with HIV, experiencing stigma and/or self-stigma (Barroso et al., 2014); community members who may be able to reduce social prejudice (Kerr et al., 2015; French et al., 2014) and professionals such as care providers and teachers (Li et al., 2015; Makk et al., 2015).

Intervention strategies can aim at the acquisition of knowledge, an attitudinal and a behavioural change (Thorncroft, 2007); four main types are found (Brown et al., 2003):

- 1) Information/enlightenment strategy: the didactic approach consists of providing people with information about inequalities, their consequences and promoting equality by showing its benefits. Information strategies show limited efficacy (Pendry et al., 2007). They mostly fail to address the emotional component⁵² (shame, fear, anger) making the cognitive input (facts or rationales) ineffective in addressing erroneous cognitions (Dovidio et al., 2004). Finally, they are likely to reinforce negative attitudes towards out-group members (Doosje et al., 2002).

⁵² The main emotions related to the out-group exposure are fear, disgust (Tybur et al., 2009; Smith et al., 2007), pity and anger (Abrams and Houston, 2006). Except fear, emotions involved in stigma are moral emotions. Moral or secondary (Leyens et al., 2000) emotions are emotions rooted and depending on social contexts and consist of i) other-condemning emotions (i.e. contempt, anger, disgust) and ii) emotions in relation with the self (i.e. shame, embarrassment, and guilt - Haidt, 2003; Rozin et al., 1999). The in-group relationship to the outgroup in prejudicial/stigmatising context leads to inhumanisation (Paladino et al., 2002; Leyens et al., 2001) as the former tends to attributes less moral or self-conscious emotions to the latter (animalisation).

- 2) Skill building: training students, professionals or communities to make them recognise their own automatic biases. Main techniques used are the empathetic/perspective-taking interventions and structured role-plays (Abrams, 2010). However, their effectiveness depends upon participants' reflexivity and willingness to engage (Rickles et al., 2016). Certain conditions have the counter-effect of reinforcing negative emotions for participants (Pendry et al., 2007).
- 3) Skills-building, counselling and/or therapeutic (individual and/or collective) approaches for people living with HIV (van der Heijden et al., 2017) addressing either internalised stigma-dimensions (i.e. shame, self-esteem) or promoting global well-being (Sengupta et al., 2011).
- 4) Contact/interaction with people living with HIV: this consists usually of testimonials, or a planned interaction with the public, based on the Contact Hypothesis. Recently, it has been renewed and professionalised, people living with HIV leading workshops and training for health professionals (Jaworsky et al., 2016; Batey et al., 2016).

Stigma affects both public health priorities (screening, adherence) and the well-being of people living with HIV. The difficulty in building tailored intervention targeting cultural and/or local attitudes and practices remains an impediment to public health improvement. If psychosocial stigma-reducing interventions are now common practice, further investigation is needed to anticipate and prevent internalised stigma among people living with HIV. Finally, it is important to note that the public health rationale to address stigma is mainly understood as a consequentialist argument (the deleterious impact of stigma on health) based on the promotion of health as a standard of living.

3.4 Summary

The inhibition of legally or socially reprehensible words, actions or omissions is part of social life and contributes both to social peace (inhibition of action) and to the persistence of prejudicial attitudes. This grey area of prejudice and stigma in social life remains at the core of the stigma process, namely silent prejudice (Smart and Wegner, 2000; Miles et al., 2011). In addition, HIV stigma is related to the HIV's routes of transmission: injection of drugs and sexual activity. Concomitantly, without any HIV awareness, substance misuse via injection and sexuality are subject to different public, political and moral judgements, hence, to stigma.

This chapter explored the heterogeneity of stigma theories, showing the theoretical and disciplinary pluralism in stigma research. This leads to three main key points in the context of

this study. Firstly, despite focusing on the same thing, these theories name and use different concepts that proceed from different appraisals of the world, whether disciplinary or ontological. This suggests that stigma theories are frames used by researchers to read the social world, thus, in the context of this study, an epistemological inquiry appears necessary (Adam, 2011).

Stigma theories identified common and consensual features of stigma process and provide complementing accounts to explain then address stigma. Therefore, it is thought that none of them are false but all of them are partial. Hence, a transtheoretical account of stigma and more generally of social perception could be suggested (see [Chapter 4](#)). Thirdly, this partiality can be linked with the complexity of the phenomenon and the theoretical pluralism informing these theories, an epistemological inquiry is developed in the next chapter ([4](#)). This chapter also highlighted methodological and ethical challenges that may arise regarding the influence of the researcher, the methods and theories at work in the research process. This chapter led to the use of a tailored design and precautionary measures that will be detailed in [Chapter 5](#).

CHAPTER 4 – FROM EPISTEMOLOGY TO METHODOLOGY: PREFACE TO THE METHOD CHAPTER

Reclusion, seclusion and extermination have always occurred between human groups, thus, the emergence of stigma studies hints towards a new apprehension of sociality. Inherent to social life and consensually related to the perception of a threat, stigma theories provide diverse explanations and solutions to the social phenomenon of stigma. If stigma as a socially constructed phenomenon has been explored (Stanger and Crandall, 2000), another aspect of social constructionism is developed in this chapter (Berger and Luckman, 1966; Giovanelli, 2017), focusing on the social determinants of stigma studies, then investigating the effects of the production of knowledge⁵³.

Stigma studies, models and stigma-reducing interventions are heterogeneous. This heterogeneity reflects the theoretical pluralism found in social sciences and questions the validity of both theoretical underpinnings and the knowledge produced. This theoretical pluralism affects ontological, epistemological and methodological aspects of stigma studies. This chapter explores the understanding of the epistemic consequences of adopting certain theories or premises. This chapter is informed by the social sciences critique of Foucault (1969, 1965) and LA tour (2000), insisting on the essential characteristics of social sciences and medicine.

This chapter consists of four sections. The first investigates the ontological pluralism in stigma studies leading to the hypothesis of the primacy of morality in social perception. The second explores the epistemological pluralism in stigma studies as a special case of social sciences, consequently hypothesising that stigma studies are, from a historical and conceptual point of view, the reparation of an epistemic injustice (Fricke, 2007). The third furthers the inquiry initiated in [desk research 2](#) on the medicalisation of stigma studies and emphasises the moral

⁵³ The traditional social epistemology premise, according to which knowledge is primarily social, is adopted (Fuller, 1992, 2002; Foley, 2002). It develops a notion of knowledge and/or truth as a socially acceptable consensus at a given time, in a given context. Consequently, the epistemological validity of theories or accounts is not of interest, rather there are scrutinised according to their premises, actual uses and functions. Based on a socio-constructionist stance on knowledge, the use and social meaning of beliefs (or knowledge) are explored; the establishment of stigma studies and the consequences of this establishment are investigated.

component of health and medicine. These three sections and hypotheses inform the stances adopted and their related methodological challenges detailed in the last part of this chapter.

Preliminary remark: towards a typology of stigma theories?

Noticing the diversity of stigma theories and their related methods of investigation (Marshall et al., 2017), developing a typology of these models appears tempting. Unanimously, stigma is a reaction to threat. Stigma theories dissect the stigma phenomenon to identify its determinants, developing rationales regarding the nature (real or imaginary) and the level of embedding (e.g. structural, relational, cognitive or evolutionary) of the threat.

Nevertheless, the perception of a threat is often explained through a combination of other concepts (e.g. social categorisation, identity threat, or social identity). Furthermore, according to the level of embedding, different functions of stigma are spotlighted (e.g. identity preservation, natural selection). This diversity can be explained by the wide range of theoretical backgrounds, disciplinary and epistemological stances (see [Table 5](#)) in stigma theories. This diversity reflects the pluralism and potential inconsistency found in the social sciences, this is furthered in [section 4.2](#).

Table 5 Summary of stigma theories

Main sets of stigma theories	Main disciplinary background	Focus on	Stigma as
Attribution theories	Social psychology, cognitive psychology, neurosciences	Individual process	Cognitive and conative process
Labelling theories	Sociology	Collective process	Identity preservation process
Intergroup theories	Sociology	Collective process	Group identity preservation process
Social Representation theory	Socio-constructivism, psychoanalysis, social psychology	Interaction individual and collective processes	Contingent element of individuals and groups' interactions
Ecological models	Systemics, ecosociology	Individual and collective processes	Structural and interactional process
Evolutionary theories	Biopsychosociology	Individual and collective processes	Preservation strategy

Encompassing pluralism, stigma theories can be unified under the umbrella term of a biopsychosocial approach (Frankel et al., 2003). Despite controversies and being considered as a *conceptual status quo* (Ghaemi, 2009), the biopsychosocial approach is widely applied in health research (Alonso, 2004), stigma studies (Blascovich and Tomaka, 1996; Blascovich et al., 2001) and HIV research (Lawrence, 2011). The epistemological weakness of the

biopsychosocial approach appears balanced by its operational and practical impact⁵⁴. Indeed, the identification of levelled determinants (causes, reasons, and factors) allows the targeting of specific areas of interest to address stigma, whether in a primary, secondary prevention or treatment approach (Macdonald et al., 2017; Mak et al., 2017).

Kusow (2004) argues that conceptualisations of a single social normative order are out of date and globalisation allows a diversity of subcultures and a plurality of orders. The fall of a unique social order questions both the multifacets of stigma, levels of embedding, and the will or action to address stigma. Is it a moral posture in itself (the ideal of equality) or a utilitarian one (means to address a wider issue)? In the context of HIV, addressing stigma is built-up on two main rationales: Human Rights⁵⁵ and health⁵⁶.

4.1 From Ontological Pluralism to Inconsistency: the Nature of Stigma and the Primacy of Morality

Stigma theories operate as a set of frames defining what a human being is (e.g. definition, properties), hereafter called ontology. The nature or the essence of what is a human being, and the related properties or characteristics, is a traditional controversy and an ongoing philosophical debate, often dismissed in social sciences. This theoretical pluralism and subsequent ontological pluralism are reflected in stigma studies. This is furthered below, illustrating the points with the topics of emotion and morality.

4.1.1 Moral Emotions: the simultaneity of perception and interpretation

Emotion theories in stigma studies

Cognition (i.e. worldviews, beliefs) and emotions are at the core of the stigma process, as shaming is embedded in a set of values supposedly transgressed by the shamed one. If emotions have been studied in stigma studies, it remains complicated (Yang et al., 2007) to investigate comprehensively morality in stigma studies as it might lead to direct discrimination or participants to withdraw if they feel attacked.

Early on, experimental studies affirmed that social attitudes were emotionally supported, defining prejudice as an “emotional attitude” (Cooper and Singer, 1956). Further to this,

⁵⁴ See section on [4.2.3](#) on interdisciplinarity and goal-oriented interdisciplinarity.

⁵⁵ As a complement to works previously cited on Human Rights and HIV, see Corrêa et al., 2008; Barr et al., 2011; Gerntholtz et al., 2011 Standing et al., 2011; Harries et al., 2016.

⁵⁶ Developed in sections [3.3](#) and [4.3](#).

studies tried to disentangle the emotion-prejudice relationships (Weitz, 1972), emotions being invoked as consequences (rationalising stereotypes) or as causes. Mackie and Smith (2002) focused on the emotional experience considering emotions in context and part of a set of relations that involve cognition, sociality (Abrams, 2010) and conation as information likely to guide and organise cognitive content (Schwarz, 1990).

On the opposite side of the spectrum, the emotion-based model of stigma susceptibility (Peters et al., 2004) has drawn upon the cognitive appraisal of emotion. This model considers that the emotional appraisal is determined by both the affective experience and the person's worldviews. Thus, a negative emotion leads to the perception of a threat or risk, and then stigma. If these two models seem contradictory, they both differentiate the emotional experience from the cognitive content and meaning attributed to the experience. These approaches stress the individual proclivities to stigma, through an interpretation or attribution process of the emotional experience likely to lead to systematic responses.

Theories of emotions are not always explicit in stigma studies; theories of emotion and theories of stigma are currently different fields that might not be brought together.

Evolutionary theories are closer to reflex theories and physicalist theories of emotions (Lindquist et al., 2012, 2013), while other theories do not provide a unanimous account of emotions.

Moral accounts and stigma

Moral reasoning refers to one's deliberate argumentation about moral concerns, while moral judgements are less structured and more automatic, and therefore, might not correspond to one's moral reasoning (Musschenga, 2008). This automaticity is at the core of the cognitive process of social categorisation. Essentially, one's rationale can be in contradiction with one's action. Moral psychology aims at identifying the determinants of moral judgement and behaviour. If the internalisation of rules has been studied almost for a century (Piaget, 1932) and investigated at early stages of development (Kohlberg, 1981, 1984), current studies are pluralistic and integrate explicitly moral philosophy and ethics. Schematically, three main types of theories emerge.

The first one is social intuitionism (Haidt, 2001, 2007, 2008) stating that moral evaluations come from intuitions and emotions are more related to perception than reasoning. The second (Hauser, 2006) follows Chomsky's rationalism and moral grammar, according to which morality

is a structural and cultural determinant that trigger emotions. The last one is a traditional utilitarian and consequentialist perspective (Green et al., 2001) stating that moral evaluations can be both emotional and rational, but should be concerned with the common good.

Throughout these systems, the genesis of moral judgements may vary, prioritising the intention, the action or the consequences (Borg et al., 2006). Consequently, if stigma is a negative moral judgement on one another, it is a priori impossible to determine the type and content of the latter, different moral judgment being likely to reach the same conclusion. Moreover, the way a moral dilemma is framed is very likely to impact on the final decision⁵⁷.

Moral theories aim at identifying the origin of morality and related thoughts and behaviours. Moral emotions (e.g. shame, guilt) are at the intersection of emotions and moral accounts; they are also at the core of prejudice and stigma process.

4.1.2 Stigma as Seeing-as and the Primacy of Morality

One of the main methodological challenges in psychology is that the investigation is likely to rely mostly on language and self-reported data. Hence, the need to disentangle what belongs to the experience (in this case social perception and stigma) and what belongs to the narration and sharing of the experience. Based on a constructivist and relational account of perception⁵⁸ mostly informed by Vygotsky's (1934, 1978) social constructivism and Wittgenstein's (1980) Remarks on the philosophy of psychology.

The first one is the nature of the (social) perceptual experience as a process involving simultaneously emotional, cognitive, and moral components. This implies an implicit, latent and unconscious content in the experience that language might not render. From this, is derived the second premise that any proposition referring to a perceptual experience is a partial interpretation (seeing-as and aspect-blindness) framed by one's sense-making process, language and social structures. The third consists in the illusion of a similar experience through language games, called here the illusion of interiority (this argument will find its epistemological counterpart, the illusion of external objectivity or exteriority, in section [4.2.1](#)).

⁵⁷ In a series of isomorphic (moral) problems, Tversky and Kahneman (1981) analysed participants' choice. The same dilemma was expressed in term of gain or loss. Authors showed that the same participants made different choices in gain vs loss conditions, when dilemmas are related to human lives, death or money. This study was criticised (Sunstein, 2005). Nevertheless, it states how wording influences decisions.

⁵⁸ Relational accounts of perception and perceptual experience are numerous and can be found in various fields in social sciences, such as psychoanalysis (Lacan, 1959), psychotherapy (Day and Krebs, 2010), cybernetics (François, 1999) or ecological theories (Gibson, 1977).

Stigma as seeing-as

Stigma as seeing-as has been briefly evoked in social and philosophical inquiries (Margalit, 1996; Butt, 2008; Cioffi, 2010). Granted the unreachability of the perceptual experience, its embodiment (emotional and bodily), and the conceptual content of the interpretation of a perceptual experience; SC ([section 3.1.2.4](#)) and social perception have to be reconsidered.

Indeed, SC can be read as an interpretation of the perceptual experience. This interpretation (i.e. categorising) is ruled by the aspect-blindness and aspect responsivity (i.e. by a conceptual content far short of language). The determinants of the conceptual content (categories) can be learnt, external or internal; they can be implicit or explicit, leading to different levels of awareness from the perceiver (Brueggemann et al., 2001). Therefore, stigma could be a form of seeing-as, a perceptual experience of one another with a negative social valence.

As any perceptual experience, the perception of one another is foremost a bodily experience that includes emotions, feelings and bodily sensations (an impression). This points to the appropriateness of the embodied cognition hypothesis (Gallagher and Varga, 2014) but has further implications. Once admitted the existence of moral emotions, they have to be considered as a primary experience and a form of conceptual content upstream from any deliberate judgement formation and any linguistic expression. This has serious implications in the philosophical approach of social challenges, especially regarding stigma, as it sustains the primacy of morality on ontology and epistemology (discussed in [section 7.4](#)).

While the precedence of morality over ontology and epistemology is a normative account in a continental tradition, it can include and gather varied philosophical works, whether theoretical works sustaining the same stance (Pascal, 1670; Putnam, 1978; Levinas, 1985; Horowitz, 2008) empirical works on morality (Haidt, *op. cit.*) or studies on social perception that posit the intrinsic moral component, such as evaluative judgements (Hutchinson, 2008).

This section highlighted how emotion and moral accounts differ in stigma-related studies, however, a generic account of social perception was formulated. In the present study, it is assumed that this ontological pluralism (what is an emotion, what is a moral judgement, how does it define human beings) reflects an epistemological pluralism.

4.2 From Epistemological Pluralism to Inconsistency: Stigma studies as the Reparation of an Epistemic Injustice

Epistemology is the study of knowledge, and its sub-fields are concerned with the nature, the validity and the condition of knowledge (Steup et al., 2014).

4.2.1 Stigma studies and social sciences

Synthesising the previous section and [Chapter 3](#), the diversity of theoretical backgrounds found in stigma research can be summarised as such:

- Evolutionary theories provide a monist (non-dualist and physicalist) ontological account that considers emotions and morality as biologically based and preservation-oriented.
- Other fields of research are heterogeneous and do not provide with an ontological account (Harmon-Jones and Winkielman, 2007):
 - Implicit theories are embedded in socio-constructivism, bio-psychosocial theories, materialistic theories;
 - SR theories can be founded in socio-constructivism, psychoanalysis, phenomenology and empiricism;
 - Intergroup theories can be based on socio-constructionism, ecological theories and materialism;
 - Ecological theories can refer to socio-constructivism, bio-psychosocial theories and systemic approaches.

Stigma studies reflect the epistemological diversity found in social sciences. Consequently, the same two-fold phenomena, as observed in social sciences, is observable in stigma research:

- A form of scientification (Porter, 1995) that provides a strong epistemological background but (as explained above) no, or diverse, ontological accounts, characterised by:
 - The quantitative empiricist turn: the production of standardised tools⁵⁹ (scales, questionnaires) have been increasing for a decade, allowing for comparative grounds and quantitative studies. Stigma has become an objectivable phenomenon.
 - The undecidability between a biological substrate (biopsychosocial approach) and a biological cause (physicalism): that leads to neurosciences studies of prejudice (Derks et al., 2008), the neurological substrate of cognitive content (Spiers et al., 2017) or interpersonal processes (Decety et al., 2010).

⁵⁹ See [desk research 2](#).

- A resistance to this quantitative empiricism in reference to the lived experiences, taking phenomenological accounts as the main reference.

The tension between these two tendencies is intrinsically related to the fundamental epistemological inconsistency or diversity of social sciences. Indeed, the inconsistency of social sciences is rooted in the fact that:

- The external objectivity is unreachable as the researcher's worldviews are always involved; this leads to the illusion of an external objectivity, confounded with validity (Koro-Ljunberg, 2010; Latour, 1999). The split or the contradiction between the ontology and the epistemology has direct consequences on the methodology and the knowledge produced (Hollway, 2008).
- The knowledge produced in social sciences is already out of date and is likely to be irrelevant as the research process modified the object studied, and often do not provide any account regarding the changes.

The aporia of social sciences

While Shkliarevsky (2007) provides a paradoxical reading of social sciences, it is here preferred the unsolvable paradoxical approach, or aporia (Koro-Ljunberg, 2010), as it justifies the field of social sciences by their indeterminacy (Bohman, 1991, 1999).

There is no critique or attack of social sciences, the inherent aporia of this area is simply pointed out. Five ways to (attempt to) resolve the aporia are suggested:

- The assumption of epistemological and ontological uncertainty: leading to fallibilism or scepticism;
- The rejection (deliberate) or denial (contingent) of any epistemology and the development of an ontology. However, such an approach would be irrelevant in the field of social sciences as it would lead to the development of a new ontology or metaphysics, and, therefore, grounded in philosophy more than in social sciences;
- The rejection or denial of an ontology and the adhesion to an epistemology: leading to mistaking the epistemology for an ontology (e.g. empiricism, positivism);
- The rejection or denial of both epistemology and ontology (e.g. atheoretical claim) that leads to a form of intuitionism, or to a common sense approach;
- The adhesion to an ontology and its related epistemology, leading to a consistent approach. The consistency of the ontological and epistemological accounts refers to the diversity of traditional philosophical systems or methods. In the context of stigma studies,

it ranges from a form of casuistry focusing on the lived experiences (e.g. phenomenology) to physicalism.

Inconsistency and pluralism in social sciences, and thereupon in stigma studies, can be counterbalanced by the disciplinary identity. Disciplinary identity provides (imperfect) identified objects, levels of analysis, and allows for the elaboration of many coherent theories. Stigma studies were investigated as a case study of social sciences, bearing with the same contradictions, reactivity to the social world and aspiration to scientificity. However, as an interdisciplinary field of research, it cannot rely on the disciplinary rigour and therefore, is a special case in social sciences.

4.2.2 Interdisciplinarity and the precedence of the object

Generic intake of interdisciplinarity

Interdisciplinarity⁶⁰ was defined early on as studies drawn upon at least two disciplines leading to the integration of disciplinary insights (Newell and Green, 1982). Based on a recent systematic analysis, Aboelela et al. (2007) defined interdisciplinarity as

“Any study or group of studies undertaken by scholars from two or more distinct scientific disciplines. The research is based upon a conceptual model that links or integrates theoretical frameworks from those disciplines, uses study design and methodology that is not limited to any one field, and requires the use of perspectives and skills of the involved disciplines throughout multiple phases of the research process”.

This inclusive and extensive definition elicits the varied forms of interdisciplinarity, either related to the background of researchers, the theories or the methods, sketching a potential inconsistency of the interdisciplinary approach.

Interdisciplinarity is the result of an ongoing process, the reshaping of modern disciplines, due to their lack of explanatory power or practical solutions (Graff, 2015). In the case of hard sciences' interdisciplinarity, the externality of the object allows for complementary approaches. As shown in the previous section, this cannot be the case in social sciences interdisciplinary works, even when coupled with hard sciences. Indeed, interdisciplinary research shows a lack of reproducibility (Wagner et al., 2011) that can be explained by the researcher's intake or personal variables (Nair et al., 2008), the evolution or modification of the object, the context-dependent variables, or the theoretical pluralism (see [Chapter 3](#)).

⁶⁰ Interdisciplinarity is an umbrella term that includes adisciplinarity, multidisciplinarity, cross-disciplinarity and transdisciplinarity.

Interdisciplinarity is possible if and only if the object studied is considered as the emergent property of an external and objectivable phenomenon that allows different conceptual intakes (Cromby, 2015). In this sense, interdisciplinarity, despite requiring disciplinary boundaries, gives primacy to the object studied (emergent property). Following the typology suggested by Huutoniemi et al. (2010), interdisciplinarity is defined in terms of empirical, theoretical and methodological premises, but also in terms of goals. Goals can be epistemologically or instrumentally-oriented or both (see also Hansson, 1999). In the case of stigma studies, and particularly regarding medical conditions, the goal is explicitly stated.

Stigma studies are framed from various fields (i.e. psychology, sociology, neurosciences) and applied on various emergent properties (i.e. concealable and non-concealable medical conditions, faiths, skin colours). Some related fields, such as medicine and neurosciences show an increase of interdisciplinary projects (Choi and Pak, 2008; Porter and Rafols, 2009); in fact, interdisciplinarity in medicine is seen as efficient to improve the quality of care (Tremblay et al., 2011). As shown in the case of HIV research, interdisciplinarity appears subject-dependent, (Adams and Light, 2014) and problem solving oriented (Meirelles, 2005; Light 2016).

It is maintained here that interdisciplinarity in social sciences is an impossible task, at the epistemological level; it is, however, possible in terms of practical purposes (Dini et al., 2011). At the intersection of medicine, social sciences and lived experiences, it is now hypothesised that stigma research is instrumentally-oriented (reducing stigma) and has a specific function *per se*, namely the reparation of an epistemic injustice.

4.2.3 Hypothesis: Stigma Studies as the Reparation of an Epistemic Injustice

Context: hidden morality, social sciences and secondary secularisation⁶¹

Secularisation is the historical process in which religious institutional power is replaced by civil society (Bruce, 2010). In Western European societies, secularisation led to the dismissal of an institutionalised and religious morality (Brown, 2009). This collective vacancy left an open ground for both a diversity of faith and moral values. At the institutional level, the vacancy has been principally replaced by science and evidence-based policies. Secondary secularisation has been described as a socio-institutional process, based on the split between the moral justification for an action and its effect(s)⁶². The effect becomes the objective outcome; the

⁶¹ Section 4.2.4 provides revised sections of a book chapter (Chollier and Tassinari, 2017).

⁶² In that sense, it is an institutionalised expression of the fact/value split (Putnam, 2002).

legitimation of the action (to address the negative outcome or promote the positive one) occurs thanks to scientific standards or evidence-based validation.

Interestingly, secondary secularisation, through the scientification of moral initiatives and/or the dissociation of the reasons for an action from its purpose or effects seems to enact, at least partially, a Universalist project (Patnam, 2000). If not addressed here (for further readings see Sandel, 1982, Rawls, 1999a, 1999b), it is worth mentioning the paradox it points out. If historically rooted in religions, morality and moral values are now more diverse in our globalised world, these values take shape in not only religion and faiths but also in different forms of spirituality (see for instance Krasny, 2010) or quests for personal transcendence (Lévinas, 1998; Kaufmann, 2008). Facing this heterogeneity of beliefs and claims, the quest for universal values and codes of conduct enacts a Western objectivist attempt to unify or bond all these beliefs and values.

Following Ogien's (2007) distinction between maximalist and minimalist ethics, the actual context regarding the socio-legal treatment of HIV is a declination of maximalism. The maximalist ethics framework consists of a proscribing legal system (what not to do) and prescriptive moral and deontic systems (what to do), articulated by forms of scientific reason and apparatus. Secondary secularisation, as a socio-institutional process, highlights the intrinsic moral foundation of action⁶³.

It is not said here that addressing stigma is not evidence-based, it is affirmed that even so, it cannot be exempted from a moral assumption. This implies that addressing stigma is not only justified based on the moral assumption but legitimated by a scientific corpus. The current trend of evidence-based morality (Goldenberg, 2005) can be found in other theories such as effective altruism (Singer, 2015; MacAskill, 2015), providing a consequentialist (Ord, 2008, 2009) and/or utilitarian rationales (Jamison et al., 2013).

Hypothesis: Stigma Studies as the Reparation of an Epistemic Injustice

Epistemic injustice (Fricke, 2007) refers to the diverse biases related to knowledge access (one can be prevented from accessing knowledge) and knowledgeable status (one can be considered knowledgeable; one is wronged as a knower). Epistemic injustice is a contemporary theory that furthers and contextualises new issues related to the concept of *ethos* (Roberts,

⁶³ The Kantian assumption is adhered to, while the Kantian ethical system is not (Kant, 1785).

1954/Aristotle), the character and characteristics of a speaker (e.g. reputation, authority, legitimacy). Hence, it is a complex, multi-levelled problem of recognition (McConkey, 2004).

Epistemic injustice has been characterised in different contexts or regarding different silenced (Dotson, 2011) and epistemically oppressed people (Fricke, 1999; Dotson, 2014). The reasons for not crediting one's words (second epistemic injustice) has been contextualised: indigenous people and ethnic minorities (Tosie, 2012) but also patients in a healthcare context (Wardrope, 2015; Carel and Kidd, 2014). As suggested by Anderson (2012), through its institutionalisation, stigma studies could contribute toward a greater degree of epistemic justice and a reduced anomie.

It is here hypothesised that stigma studies, as a form of institutionalisation, are serving a social and moral purpose. In contexts of structural equality, stigma studies are one of the possible institutionalised means to resorb an anomic state, favouring the conformity and/or innovation processes (such an interpretation could lead to the retroactive confirmation of an institutionalised stigma, this will be discussed later). It can also be read as an institutionalised speech (*logos*), giving credit to the experiences (*pathos*) of the silenced ones (discredited *ethos*). In this sense, a reciprocal utilitarian relationship appears between society and social sciences, enacting and promoting a moral project. Two main challenges are to be faced following this hypothesis.

Challenge 1: testimonial value and truth value

At the individual level, must be raised the issue of the value attributed to the experience of stigma. If stigma is an external emergent property, is one linguistic expression of a stigma experience sufficient to be defined as an objective phenomenon? If one's experience is definitely carrying with it a testimonial (phenomenological) value (Audi, 1997), can it be contradicted by another element? Stigma studies, by investigating what is otherwise dehumanised, may fall into the trap of over-victimisation (Bartlett, 2007).

Challenge 2: the underlying moral project(s) of stigma studies

Given the goal of stigma research and its practical output (stigma-reducing intervention), two main moral projects can be hypothesised in the context of HIV-stigma research.

Utilitarianism and contingent selective egalitarianism: Utilitarianism (Mill, 1901), schematically, justifies the means to the end. Further to this chapter, one of the moral purposes highlighted

and aimed at its health (see [section 4.2](#)). The means used to achieve it can then be diverse, ranging from structural interventions, stigma research and stigma-reducing interventions (see [section 3.4](#)) to invoking human rights (Meier et al., 2015). In this perspective, stigma studies are an instrument to establish a new order or restore a previous one, but such an order is not based upon equality, as equality is drawn upon a different rationale.

Universalism and inherent radical egalitarianism: since the early days of the HIV pandemic (McGourty, 1989; Closten and Isaacman, 1992; Mann, 1992) Human Rights have been invoked by researchers as a leverage to promote the access to health care and treatment, and to address stigma (Khosla, 2015; Kohi et al., 2006). Traced back to Aristotle in 350 BC (Irwin, 1999), also present in Kant's writings (1784), Universalist morality is now a possible rationale for health, confirming retroactively the (not exclusive) moral source of medicine and social science (Canguilhem, 1958).

4.3 From Sinful Diseases to the Medicalisation of Stigma: Health and Morality

From secondary deviance (i.e. stigma) to primary deviance (i.e. criminalisation), the key point of moral transgression is being analysed through the lens of the medicalisation of stigma studies (Kvaale et al., 2013) and health as a new form of morality (Kennedy, 1981) and questions moral standards in relation to health as a ground for criminalisation.

4.3.1 The sinful rhetoric

The punishing rhetoric of diseases has been found under the theme of possession (Wessermann and Graziano, 2010), curse (Rensen et al., 2011) or sin (Thomas, 1997; Williams et al., 2017). The social history of leprosy⁶⁴ exemplifies the social conjunction between sin, sex and diseases⁶⁵. Indeed, the disease is perceived as the punitive consequence for sexual

⁶⁴ In Western societies, based on biblical references to the disease (for philological analysis, see Grzybowski and Nita, 2016), leprosy was considered as a punishment for committed sins (Davies and Davies, 1989) or sins of ancestors. Leprosaria were both shelters and places of isolation for lepers who were banned from other social groups. Nevertheless, this exclusion had a counterpart (Browne, 1962), given what lepers endured on earth, they had already won their place in heaven⁶⁴ (Miller and Nesbitt, 2014). After the disappearance of leprosy, leprosaria slowly became asylums, carrying with a similar form of exclusion (Foucault, 1961). Today leprosy is curable but niches and mutations of the bacteria make it remain a public health issue (Noriega et al., 2016). In high-prevalence countries (e.g. India, Brazil), leprosy is still stigmatised (UN, 2008; WHO, 2012; Sermittirong and Van Brakel, 2014). Recent studies on SR of leprosy found that it was still associated with fortune and fate, sexual promiscuity, incestuous relationships or racial heritage⁶⁴; self-stigma have also been found among patients (Romero-Slazar et al., 1995; Rafferty, 2005).

⁶⁵ However, the sinful component is embedded in a dialectical movement and can be a ground for acceptance and support (Harris, 2010; Hoy, 2015; Cuceu and Pontikes, 2016).

practices considered as transgressive (see Herek, 2004). Similar perceptions and attributions can be found in regarding syphilis (Palmer, 2000), AIDS (Sainsbury, 1992) or HIV (Allen, 2000).

For decades, the sinful rhetoric has been studied in social perception (Gedzi, 2013), moral psychology and judgement formation fields (Reinig, 1990; Weiner, 1993). In most of the Western secular countries, the concept of sin is not systematically used in reference to religious beliefs; a pervasive use can be noticed nowadays. Lust or sexual depravation is found as a common social representation of the origin of infectious diseases, such as STIs, leprosy or HIV (Stevelink et al., 2011). Gluttony and related negative stereotypes are associated with overweight and/or obesity (Pattison et al., 2016). Narcolepsy is associated with sloth or laziness stereotypical traits (Stores, 2007). Pathological gamblers are perceived as greedy and angry personalities (Hing and Russell, 2017). More generally people living with mental health conditions are perceived as unpredictable, impulsive and aggressive (Crisp et al., 2000).

In reference to Goffman's initial description of stigma, all the traits attributed above relate to a lack of controllability and a weakness of personality. This then shows the tautological loop stigma induces (confirmation bias): a moral judgement on the person, based on a behaviour perceived as bad, justifying then the negative stereotype, confirming the moral judgement. The persistence of the sinful rhetoric questions the social representations and pervasive effects of language. More importantly, it highlights the ambivalence towards minor groups in social life, occurring in the global context of medicalisation.

Historically and disciplinarily, the distinction between discrimination, stigma and prejudice is clear. Discrimination relates to the structural level, stigma to the social level and prejudice to the individual level and respective fields in social sciences, namely, politics and policies, sociology and psychology. The [desk research 2](#) performed led to the observation that stigma focuses on medical conditions while discrimination emphasises social labels or categories and prejudice the cognitive process. The following section furthers the idea of the medicalisation of stigma and stigma studies.

4.3.2 Medicalisation and stigma

This process of medicalisation can be defined as a five steps process (Conrad, 1992, 2007): i) the definition of a problem in medical terms. ii) the description of the problem in a medical jargon, iii) the adoption of a medical theory or field to understand the problem, iv) the

possibility of a medical intervention to “treat” the problem, v) the launch of a specific method provided by specific professionals to “treat”.

In a Foucauldian perspective⁶⁶, medicalisation refers to the disciplinary power (conceptually normative and prescriptive) of knowledge influencing, not only how one perceives oneself, but also how one experiences oneself. Concerns regarding medicalisation have been raised in the context of mental health (Foucault, 1961), transgressive behaviours (Conrad and Schneider, 2010), sexuality (Hart and Wellings, 2002; Cacchiana and Tiefer, 2012; Giami, 2008, 2009), infertility (Forsythe, 2009), death (Clark, 2002) or intersectional topics, e.g. sexual deviance (Tiefer, 2014).

In the context of HIV, medicalisation is associated with social control, as the main explicit objective is to curb the epidemic (Giami, 2009). In Western countries, the impact of the community (LGBT+ and people living with HIV) modified the doctor-patient relationships and reframed community health and medical interventions (Smith and Whiteside, 2010; Trapence et al., 2012). KI4 shared his early experience working in the 1980s and his analysis of the HIV-care model spoliation by the medical community:

KI4: You start off with, in the 70’s and 80’s, the rise of gay pride of challenging the perception of society on what it means to be LGBT, and people discovering pride and begin to stand up for themselves, and suddenly comes along this infection that decimated the gay community. (...) And one can see it in terms of how the pattern of health care developed, and it was not until HIV was established in the heterosexual population that it was recognised to be a public health issue for the heterosexual population, that the government of the day began to say “we should do something”. And it is the same in America. It was LGBT people who were developing systems of care, who were developing systems of support for people living with HIV and AIDS. That was then embraced on mass by the medical population, and suddenly become medicalised and treatment such as AZT became online, and somehow, HIV and AIDS were reclaimed by the medical profession as something that was in their hands. Whereas all the models of care interventions were being developed by those within community, who were embracing those who in the community would become ill and die. And all those models have been adapted and that history has been written out.

⁶⁶ Here, medicalisation from a Foucauldian perspective is conceptual and institutional. Foucault’s works are detached from the medical practice and interpersonal relationships that he was familiar with, through his years of collaboration with Georges Canguilhem. Informed by the analytical continentalism and the epistemology of Jules Vuillemin (1954, 1984, and 1986), and Canguilhem’s (1943, 1958) medical epistemology of, his works provided a conceptual, historical, structural and epistemological analysis (archaeological project). Generic and disciplinary works (Foucault, 1965, 1969) found illustrative case studies focusing on specific objects or contexts (Foucault, 1961, 1978). Contrary to previous readings (e.g. Lupton, 1997), no ambiguity in Foucault’s works is perceived. The late turn towards the technologies of the self is seen as adding the concept of *tekne* to the previous triad of *doxa*, *dogma* and *episteme* (common sense, dogma and norms, knowledge/scientific knowledge). Medicalisation is, therefore, appraised as a latent process that does not explicitly prescribe or proscribe any attitude or behaviour and does not refer to individual intention (e.g. Busfield, 2017).

Furthermore, HIV is one of the fields of preventive medicine that alternates from behavioural (Toskin et al., 2015) to biomedical intervention (Giami and Perrey, 2012) to tackle both the HIV pandemic and HIV-stigma.

As detailed by Foucault (1963, 1965), medicine and social sciences operate (not exclusively) based on a social request (*doxa*), producing a corpus of knowledge (*episteme*), this knowledge is then reincorporated or assimilated in society under a normative *dogma*. Following this, the medical explanation of diseases should be able to establish new dogma, potentially less stigmatising. However, as observed in empirical studies, the medical rationale is as likely to feed as address stigma (Phelan, 2005; Kvaale et al., 2013). The medicalisation of HIV led to a form of normalisation (e.g. chronic condition, see for instance Thompson and Abel, 2016), however, it remains counterbalanced by a form of social exceptionalism (Flowers, 2010), leading to a social double bind.

Health-related behaviours vs stigma: a social double bind?

A double bind is the repeated contradictory injunctions occurring within a relationship (Bateson et al., 1956). Initially conceived through parent-child interaction, then extended to communication in relationships, the double bind echoed many paradoxical situations and contexts (Hesse, 2004; Tracy, 2004; Lau et al., 2009).

In the context of HIV, conflicting norms and values can be observed. Prevention campaigns insist on screening and getting tested, but used to be framed under the risky rhetoric (Nicoll et al., 2001) while community campaigns are focusing on tackling stigma (NAT, 2016).

Concomitantly with the launch of ART, Western media portrayals of HIV shifted from blame and fear to health and social justice (Labra, 2015) but the advent of criminal convictions reframed the blame discourse, switching from the gay community to heterosexual men from ethnic minorities⁶⁷ (see Persson and Newman, 2008). If mass media campaigns are proven efficient by increasing condom use (LaCroix et al., 2014) it settled a new behavioural norm (prescribed behaviour), leading to potential transgression (not performing the prescribed behaviour) that can lead (in the case of reckless or intentional transmission and exposure) to legal liability and criminal sentencing. The HIV social double bind can be centred on one core point, responsibility.

⁶⁷ Indeed, people living with HIV experience cumulative stigma, or attribute the stigma endured to other characteristics (i.e. ethnicity, sexual orientation, see Chinouya et al., 2017). In this sense, it could be argued that HIV stigma does not exist per se, but condenses several features (intersectionality of stigma).

Is being healthy being responsible?

A lung cancer stigma systematic review (Chambers, 2012) points out the social double bind of on the one hand selling tobacco products and on the other hand the promotion of smoking prevention or cessation campaigns. Lung cancer patients who are smokers and non-smokers are respectively perceived as the guilty and innocent patients, leading professionals to different attitudes (fatality vs person's responsibility); similar critical approaches have been developed regarding obesity (Goldberg, 2014). This leads to a crucial point regarding how societies tend to consider individuals and diseases. As pointed out at the early stage of biomedical preventive medicine⁶⁸ (Skrabanek, 1986; Marantz, 1990), the temptation to blame the patient is increased if the condition is preventable. It is even more probable when the individual's behaviour is directly related to the acquisition of a condition (e.g. smoking for cancer, having sexual activity without a condom for HIV).

This has been conceptualised in the context of stigma under the label Behaviourally Driven Health Conditions (Corrigan, 2010). This concept draws attention to i) the intrinsic negative moral value attributed to people living with a condition that has a behavioural component, ii) the tendency to make one accountable for his/her health. Non-communicable diseases prevention is framed as to prevent the acquisition of a condition, enacting the idea that one is responsible for one's health. In the case of infectious and communicable diseases, prevention is framed under the prevention of transmission and acquisition. This leads to a double level of responsibility, as any person transmitting an infection has previously acquired it.

The medicalisation of deviance

As evoked previously, the main fields of research emerging from deviance studies are crime (primary deviance) and stigma (secondary deviance) studies. Medicalisation of secondary deviance can take varied shapes. Evidence-based interventions aim at correcting unhealthy or deviant behaviours; similarly, unjustified or deleterious behaviours perpetuating secondary deviance (i.e. stigma) can be addressed. The focus of the present study leads to transpose this process in the context of primary deviance.

⁶⁸ Preventive medicine aims at the maintenance of health population and the prevention of communicable and non-communicable diseases (Clarke, 1974); it relates to hygiene and public health fields (Brotherston, 1953).

The medicalisation of primary deviance has been mostly studied under the scope of psychiatrisation (Penrose, 1939; Foucault, 1963; Monahan, 1973; Link et al., 1992; Caponi, 2015). Since the late 19th century⁶⁹ (Foucault et al., 1978), psychiatric, forensic experts (Expert-Witness, CPS 2015) have played a major role in criminal justice, in terms of procedures⁷⁰ (e.g. fitness to plead and/or stand a trial) and in terms of verdict or sentence (e.g. non-guilty due to insanity, see for instance Chiswick, 1978). In the context of the present study, medicalisation of secondary deviance and psychiatrisation of primary deviance relate respectively to considering people transmitting HIV onward as potential victims (of stigma) or as potential sufferers of mental health difficulty. Finally, a traditional and inherent question of psychiatry is reached here on the essence and appraisal of primary deviance, known as “*mad or bad*” (Prior, 2004; Maibom, 2008; Vossler et al., 2017). The *mad or bad* debate summarises how criminals are perceived and if the explanation given to their actions are linked with madness (leading to consider that human nature is good and criminal acts are consequences of a condition) or with badness (i.e. dual view of human nature). Again, the moral premises of the debate underline the moral component that underlies medical and psychiatric interventions.

Therefrom, it is hypothesised that the empirical part of this study is likely to render the following dimensions in terms of social perception of the person transmitting HIV onwards:

- the victim, the innocent one living with HIV, who might not have known or have accidentally passed HIV on;
- The one living with HIV who might be blameable regarding the acquisition of HIV (see SR and stigma related to the routes of acquisition, e.g. promiscuity or depravation) but not regarding the transmission;
- The ‘mad’ one, the one suffering from mental health issues who do not really know what he is doing, who would then experience a double stigma (HIV and mental health)
- The sane and ‘bad’ one, the amoral one, whom social perception is more likely to relate to the stigmatisation of offenders and the figure of the monster⁷¹ (Hoppe, 2014).

⁶⁹ Schematically, in the European tradition, the establishment and institutionalisation of psychiatry contributed to the advent of forensic psychology and psychiatry, while in the Anglo-American tradition, this led to criminology (see Petrunik and Deutschmann, 2008).

⁷⁰ Criminal Procedures Rules, part 33, Expert Evidence.

⁷¹ Stigmatisation of offenders is too much of a digression to be expanded. Yet, briefly, it might be worth mentioning that this is one of the stigmas the general public is the less empathetic and responsive to, mostly when crimes committed are (im)morally connoted (Hirschfield and Piquero, 2010; Moore et al., 2016; Chollier and Tassinari, 2017).

Addressing stigma as a means to achieve health

A healthy population remains a socio-political aim in most societies (Scambler, 2006). Stigma as a psychosocial impediment to health became a negative factor to address. Three broad domains of stigma consequences on health and well-being are identified:

- *The Impediment to health care access and seeking help*: stigma impacts on screening habits, seeking help, and depreciative self-perception in conditions such as tuberculosis (Li et al., 2013) overweight/obesity (Sikorski et al., 2011), mental illnesses (Parcesepe et al., 2013) but also issues such as domestic violence (Abramsky, 2011).
- The negative social perception is found in most of the chronic conditions (e.g. back pain, Holloway et al., 2007). Stigma experiences, in social life and in healthcare, increase drop-off rates, decrease attendance (routine testing) and *adherence* (compliance).
- Stigma experiences (being stigmatised) and internalised stigma can lead people to treatment discontinuation, *psychological vulnerability*, distress; mental health issues (i.e. anxiety, depression) and induce comorbidities. Stigma promotes higher depression, more social anxiety, more secrecy and social avoidance strategies, along with lower quality of life, self-efficacy, lower self-esteem, lower social functioning, less support and less mastery in most chronic conditions, especially mental disorders (Sirey et al., 2001; Earnshaw et al., 2012; Gerlinger et al., 2013). In extreme cases, stigma can lead to self-injury (mostly among adolescents, Berger al, 2017) and suicide (attempts and ‘successes’, see for instance Rozatkar, 2014).

This rationale can be developed in any stigma study focusing on a medical condition or a disorder. It is interesting to note that controllability in health-related stigma reflects social representations and stereotypes in relation to different spheres. Mental disorders are related to general unpredictable behaviours (Jodelet, 1989), eating disorders to the lack of control in feeding behaviours or its opposite (anorexia as a total control of the body), STIs, HIV, and infectious diseases in general, to the lack of controllability regarding sexual behaviours, (Joffe, 1995, 1998). Consequently, it could be argued that medicine and stigma studies produce a set of knowledge likely to counter the social representations and moral judgements. More importantly, these studies provide not only scientific knowledge but also i) an evidence-based rationale against some moral standards⁷² and ii) implicitly assert addressing stigma as a means to an end (health).

⁷² The term *moral standard* has been chosen by default. For instance, the stigmatisation of sex offenders can seem socially acceptable; however, it is argued that it impedes rehabilitation and desistance (Schivone and Jeglic, 2009).

4.4 Position Adopted in this Study and Methodological Precautions

As to philosophical truth, it is clear that, if my prudence is justified, the pluralities of philosophies makes the concept of philosophical truth inadequate and inappropriate, at least if the word *truth* is used in its ordinary way. (Vuillemin, 1986, p ix)

From the moral foundation of action to the moral source of medical and social sciences interventions, the moral aspects of clinical practice and research might appear less objective. However, medical morality (Pellegrino, 1979; Baker et al., 1993; Baker, 2007) and sex-related medical morality (Mort, 2000) have been robustly documented from a socio-historical perspective. It is not affirmed here that these aspects entail or diminish the practice, the research, or their impact; it is pointed how moral aspects tend to be dissimulated or packaged, when not under the bioethics umbrella. This leads, in research and practice, to the necessity of reflexivity and regulation, to raise awareness of what one is enacting without noticing (Finlay, 2002). This led to a methodological choice that include self-monitoring strategies and reflexivity to elicit the morality of the doctoral researcher.

Further to the epistemological argument developed in [section 4.3.2.1](#) based on Foucault's works (Foucault, 1990), is now reached a point in which an ontological illusion of interiority and an epistemological illusion of exteriority define, before social perception itself, how one approaches or defines social perception. Bridging analytic and continental traditions, it is assumed that the clarifying task of philosophy sustained by Wittgenstein (1980), is a call to disentangle what Foucault (1965) described as the category mistake of the 18th century between language and nature, between the order of name (nomenclature) and the order of things (classification). This study couples on Vygotskian constructivism (Vygotski, 1978; Wong, 1999; Shotter, 1996; Berducci, 2004; Holzman, 2006) and Foucault's archaeological project (Hirtle, 1996).

Constructivist realism approach

People's experiences cannot be dismissed; they must and will be investigated in this study. Nevertheless, in the context of the criminalisation of HIV transmission, a social epistemology approach seemed necessary. Reconciling the lived experiences, the observation *in situ* of how people make sense of them and a historical and structural analysis of the context was found possible within a constructivist account of subjectivity (ontology) and knowledge (epistemology). The former leads to the contextualised phenomenological, intra, and

intersubjective accounts whereas the latter investigates the different types and levels of context, and their features (e.g. institutions, norms, and agencies).

The constructivist approach adopted here is based on the will to identify and understand the ontological and epistemological pluralism. In terms of morality, the constructionist premises are applied, in the sense that moral categories are thought to be socially constructed. The question or the deconstruction of their validity, effectivity, truthfulness or degree of normativity is neither the scope chosen nor the aim of this study. The position adopted in the present study might seem sceptical and/or relativistic. If so, it is important to specify that neither a sceptical doctrine or premises nor the ordinary incredulity stances were here adopted. There was no will or intention to prescribe or proscribe any way of thinking, attitudes or behaviours. Instead, the aim was to provide a framework that enables their understanding and explains their diversity. This moderate scepticism leads to an ontological, epistemological, and moral constructivist realism approach (Gunzenhauser, 2006; Cupchik, 2001; Bagnoli, 2002) drawn upon Vygotsky's works ([1934]/1962, 1978) and his upholders (Tappan, 1997; Liu and Matthews, 2005; Turner and Berkiowitz, 2005; Zinchenko and Pervichko, 2013).

Two main pitfalls are inherently related to such a positioning. Firstly, this study might seem as inconsistent as the interdisciplinary field of stigma research, and secondly, it is likely not to provide recommendations or solutions. Regarding the possible inconsistency of this study, the constructionist realism approach enables a non-dogmatic reading and provides a rationale for the theoretical pluralism found in social sciences, stigma studies and perception theory. This also leads one to consider subjective realities and objective constructs rather than objective realities and subjective illusions.

This approach is deemed theoretically relevant and might offer a thorough and interdisciplinary account of conceptual constructs (Sterling-Folker, 2002; Jackson, 2004). As individual agencies are embedded and occurring in a socio-historical environment, constructivist realism allows for both the understanding and/or deconstruction of concepts or practices, and a pluralist investigation (Jackson and Nexon, 2004). Consequently, the methods and tools to be used in this research are based on a constructivist methodology (Mir and Watson, 2000; Pouliot, 2008), combining qualitative and quantitative methods (Morgan, 2007; Zachariadis et al., 2013). Epistemologies and methods frame the practical findings; therefore, practical recommendations will depend upon methodological ones.

4.5 Summary

Based on the transtheoretical overview provided in chapter 3 the epistemological⁷³, ontological and moral accounts developed in this chapter led to adopt a constructionist realism position. While it is often argued that criminalisation increases stigma (Ahmed, Kaplan, Symington and Kismodi, 2011; Adam, Elliott, Corriveau and English, 2014), this chapter rather suggested multidirectional relationships between social perception, stigma and opinions (or expressed thoughts). Indeed, through the concept of *seeing-as*, the moral and emotional components of perception are primary contents likely to orient language and actions. In the context of this study, the primacy of morality on ontology implies that social perception and social categorisation are moral experiences and moral processes.

It also suggests that moral emotions (e.g. shame and guilt) have a primary role. Therefore, this study requires a comprehensive method of investigation able to account for this complexity and for the making-sense process of individual experiences ([Chapter 5](#)). Finally, the primacy of morality on epistemology hints that knowledge and informative inputs are likely to address ignorance and fear, but might not be likely to modify social perception and social experiences. This will be discussed in the light of the findings on the topic of stigma-reducing interventions ([Chapter 7](#)).

Stigma studies were born in reaction to the discrepancies between legal and social equality. The scientification of stigma studies, stigma becoming a medical problem (Corrigan et al., 2005; Goldberg, 2017) embedded in medicine as a new form of morality (Metzl and Hansen, 2014), highlighted the moral rationales behind or at work, whether humanist (egalitarian argument) or utilitarian (reduce pandemics). In this sense, stigma studies are an institutional means to address anomie without violence (through conformity or innovation processes), packaging moral goals with scientific rationales (Chollier and Tassinari, 2017). By the reparation of an epistemic injustice, stigma studies give the ground to otherwise or previously silenced people (Kidd and Carel, 2017). The intrinsic contradiction in stigma studies (science vs morals) leads to blurred lines between the testimonial value (phenomenologically true) and the scientific value (epistemologically true) of the knowledge produced.

⁷³ Complementing this initial epistemological inquiry, a further direction would consist of the mapping of similarities and connections between Vuillemin's classification, philosophical and psychological systems, and psychological theories, whether generic or topic-related. This epistemological work would highlight the philosophical premises at work and the potential discrepancies in psychological theories (Thomasette, 2015).

The analysis provided in this section is not to any extent an attack on stigma studies or an attack of morality. Following a necessary scepticism (Sharrock and Anderson, 1991), this social epistemological inquiry leads to three methodological considerations: firstly, the need for reflective accounts during the research process that took the form a research diary that was used as a self-monitoring strategy and a basis for [section 5.8](#); secondly, a focus on research integrity and related tools in the present qualitative study ([section 5.7.2](#)). Finally, assuming the intrinsic moral premises underlying stigma research leads to ethical concerns, regarding the impact of potential conflicting views between the participants, or between the researcher and participants. The interviewing style and the pre- and post-assessment were respectively tailored to avoid distressing the participants and to assess the impact of the research process (see [Chapter 5](#)).

CHAPTER 5 – METHODS

Based on the four previous chapters and as summarised in the first section of this chapter, a mixed-method design was adopted. The following sections provide information and reflective accounts regarding the research questions, the participants, the procedure, the data analysis, the integrity and I of the study.

5.1 Rationale for the Methods

The following sub-sections refer to issues and challenges identified in the background chapters and related standard recommendations or choices made to address them.

Sampling

The first two chapters presented the context of HIV criminalisation in the UK, with a specific focus on England and Wales, and current debates in health, legal, and community contexts. They highlighted the necessity to involve people living with HIV in this study and experts in connected areas, such as Criminal Law, HIV-related health, and research. Such participants would have meaningful experiences related to the research question and their contribution to the study would be more relevant if they were involved as key-informants (KIs) (Marshall, 1996). Recruiting such participants was achieved through purposive sampling (Onwuegbuzie and Collins, 2007) minimising the potential to confound the validity and power of the study (Onwuegbuzie and Leech, 2007).

[Chapter 3](#) emphasised the necessity to identify i) explicit and implicit cognitive contents, ii) their emotional and moral components, and iii) the social representations enacted when stigmatisation occurs in daily life. The aim of this study could not be achieved by including KIs exclusively. Therefore, participants from the public who were unfamiliar with the topic were recruited using snowball sampling (Vervaeke et al., 2007). In the present study, KIs were interviewed and participants from the public took part in FGs⁷⁴. Both consisted of semi-structured interviews (Merton, 1956; Greenbaum, 1993) that were transcribed and analysed.

⁷⁴ FGs (Merton, 1946) and interview (Chirban, 1996) are comprehensive methods of qualitative data collection. Both have been extensively used in stigma studies since the 1960's (Hunt, 1966; Goffman, 1963).

Design, mixed methods, and triangulation

Given the sensitivity of the topic studied, a Participatory Action Research (Susman and Evered, 1978; Green et al., 1995) was adopted, a type of action research widely used in health and education contexts (Blacksher, 2013; Lewin, 1946). The participatory action research design needed to be adapted to meet the needs of this research but remained the most relevant one. It included comprehensive aspects aimed at understanding, evaluative aspects regarding intervention effects, and ethical aspects (Stokols, 2006). Two main features of the participatory action research were emphasised. Firstly, the consultation of two people along the project who provided input on the overall approach and the materials (Torrance, 2012). Secondly, the role of gatekeeper of one person to recruit potential participants either as KIs or FGs' participants (McCosker et al., 2001). Finally, it is important to clarify that this study was not designed as an intervention as it aimed at identifying the current views and rationales of participants on the criminalisation of HIV transmission, including potential misconceptions to inform potential future interventions.

The [fourth chapter](#) outlined the epistemic and moral values involved in stigma studies.

Research carries inherent biases (e.g. social desirability, self-presentation) some of which may be anticipated. Where they cannot be anticipated, it may be possible for potential biases to be evaluated after the fact (Flick, 2007). Where qualitative inquiry could not provide any account of consistency of findings over time, this study incorporated standardised tools and repeated measures designs (Greene et al., 2005). Mixed-methods were used as part of the action research design to allow triangulation (Denzin, 2012; Hussein, 2015). Triangulation refers to the use of different tools (likely to reflect theoretical pluralism) to observe or assess the same phenomenon (Olsen, 2004).

Qualitative data analysis: context-sensitivity and subjective experience

Following a socio-constructivist approach, this study required a method which would: i) capture linguistic practices and the interactional process of building meaning, ii) take into account emotional and moral aspects, and iii) relate such a process to stigma and social attitudes. Conversation Analysis (Wetherell, 1998) and Interpretative Phenomenological Analysis (IPA) (Smith, 1996) have been chosen to analyse conversations from the FGs and the interviews. CA is nomothetic (orderliness, identifiable patterns in social interactions - see Schegloff and Sacks, 1973; ten Have, 2007) while IPA is idiographic (making sense of one's experience) (Mishler 1986; Braun and Clarke, 2006). CA is a powerful and relevant tool used in

interactional sociolinguistics⁷⁵ (Blanchet, 2000; Auger et al., 2008), in that, it is both context-free and context-sensitive. Indeed, CA allows an institutional/context specification through identifiable interactional patterns as much as the *in-situ* and participant-built ones (Hyden and Bulow, 2003).

Reflecting a theoretical pluralism, from Heidegger's (Larkin et al., 2006) to Harré's ethogenics and positioning theory (Harré et al., 2009; Smith et al., 1995), IPA is commonly used in health research (Biggerstaff and Thompson, 2008), regarding subjective experiences of a phenomenon (e.g. pain; see Smith and Osbourn, 2007). Affiliated with CA (Smith, 2004), the case study approach is emphasised with IPA, based on:) the comprehensive understanding of personal lived experience; the will to understand how people make sense of this experience; hypothesises that emotions modify beliefs and judgements (called Hot Cognition Hypothesis, see Ask and Granhag, 2007). Hence, the coding was informed by CA and IPA and related anticipated codes that were complemented with the integration of new codes along the coding phase. This both deductive and inductive coding was deemed appropriate to ensure the validity of the analysis. Finally, failure to reach data saturation entailing the quality and the validity of the study (Fusch and Ness, 2015) a particular attention was paid to theoretical and inductive informational redundancy (furthered in [section 5.5.2.1](#)).

Ethical concerns

As developed in Chapter 4, two main ethical concerns were raised. The first related to the researcher's subjectivity and morality. Theoretical accounts (ten Have, 2005; Garfinkel, 2001) were considered in the reflexivity process (Lynch, 1997, 2000). Practical precautions were taken. The restitution session offered the opportunity to criticise the researcher's analysis. In addition, the use of a diary as a self-monitoring strategy (Wilde and Garvin, 2007) allowed for personal insights and contributed to the reflexive practice.

Concerns were raised regarding the emergence or the reinforcement of stigmatising attitudes during or as a result of the study. While pre-assessment is often emphasised in qualitative research (Creswell, 2003, 2007), follow-up assessment is weak in existing research (Hohmann and Shear, 2002). Concerns may arise that taking part in this study may contribute to galvanising extreme positions. These concerns were addressed through a pre- and post-

⁷⁵ Drawn upon ethnography and anthropology, interactional sociolinguistics studies how verbal and non-verbal practices produce meaning, guide behaviours (Gumperz, 1992), and aims to identify conversational triggers of emotional reactions and/or social processes. Previous studies on some forms of social violence make this field of research and CA relevant in a stigma study (Fracchiolla et al., 2013; Moïse, 2011).

assessment allowing comparison, and a follow-up restitution session (or debriefing session) as recommended by the British Psychological Society (BPS, 2014) with the participants on their experience or opinions, analysed using a responsive evaluation (Abma, 2000 and 2005, Stake and Abma, 2005, Baur et al., 2010; Visse et al., 2012). The restitution session was also informed by the debriefing session.

5.2 Research Questions

A mixed method study, combining semi-structured FG/Interviews and pre, post and follow-up mixed assessment, was used to answer the following research questions:

1. What are people's views on the criminalisation of HIV transmission, and the rationales justifying these views?
2. What are the social representations of HIV associated with these views? Are there any negative social representations leading to or associated with HIV-stigma that would contribute to participants' views?
3. What are the effects of participation in the study on FGs' participants in terms of HIV perception and stigma? Is stigma research likely to exacerbate or reduce stigma?

The first question focuses on the explicit content and descriptive level of analysis, while the second investigates the implicit content and interpretative level of analysis. The third is both methodological (self-report and repeated measures) and ethical (allowing the researcher to identify changes in stigma).

5.3 Participants

The characteristics of the participants, the transcripts, and details regarding the dynamics (e.g. group dynamics, main interactional pattern) of each FG and interview are provided in the Additional file – Transcripts Notebook. While some participants were open about themselves and shared personal information and experiences, anonymity and confidentiality were ensured through the anonymization of the transcripts and the

5.3.1 Key-Informants

Definition of a KI and inclusion criteria

KIs had to be at least 18 years old. KIs had to show further relevant expertise (i.e. professional activity, publications, public advocacy) regarding the criminalisation of HIV transmission.

Criteria of a relevant expertise for KIs consisted of at least one of the following:

- A minimum of 10 years of practice in a related field (e.g. criminal justice, sexual health).
- Participation in national and/or international consultation panels and/or conferences on this topic, and the presence of peer-reviewed publications.
- Attendance at community and/or public events, volunteering activity and public expression of one's opinion.

Recruitment, participation, and completion

KIs (Pauwels and Hardyns, 2009) were recruited through purposive sampling and interviewed one-to-one (Teddlie and Yu, 2007; Palinkas et al., 2015). To recruit KIs, charities, persons identified as potential KIs, community advocates were contacted in the UK, some of them being met during academic and community events. More than fifty people or organisations were contacted in the UK. Responses either declined the invitation or referred to individual contact details. In total, twenty-eight people living in England and Wales were invited to be interviewed, eleven agreed to take part. People who declined to be interviewed were mostly people living with HIV or people involved in the criminal cases leading to convictions (e.g. barrister of the defendant, magistrate); main reasons, when stated, related to confidentiality issues and reluctance to discuss or disclose professional or personal matters. In total, nine were interviewed.

In the absence of incentive, the doctoral researcher travelled to meet participants where they would feel comfortable and at ease for the interview (Swanson et al., 1997). The interviews took place between February 2016 and June 2017. Interviews were held at the key informant's home (n = 1) in the Greater Manchester area, in their workplace in Cheshire, Cumbria and Greater Manchester area (n = 3), in the facilities of MMU at the Manchester Campus (n = 2) and in a public space chosen by the key-informant in Greater Manchester area, West Midlands and Liverpool City Region (n = 3). The total duration, including pre- and post-assessment, ranged from 80 to 135 minutes. Six KIs were involved in the community either as a professional or as a volunteer; two were sexual health researchers and professionals; one KI was a criminal justice professional. Four KIs talked spontaneously about their experience of living with HIV. The acceptance rate for the participating in the interview was 39%, and the attendance rate (among those who agreed) 82%. One restitution session was conducted face-to-face.

5.3.2 General Public

General public participants had to be at least 18 years old. General public participants were recruited through a gatekeeper and snowball sampling (Jawale, 2012) and took part in FGs. No

incentive or compensation, such as travel expenses, was offered to participants. To allow a descriptive comparison and assess potential sampling biases, a control group of general public participants was surveyed (pre-assessment form only to which was added the sociodemographic information). The control group gathered participants who declined or could not attend to the focus group; some of them referred other participants to complete the survey.

Thirty people were invited to participate. Six FGs were planned but two were cancelled due to late withdrawal and last minute cancellation; participants unable to attend who expressed interest in taking part at a later date were invited to join the next FG. Four FGs were held, with the number of participants ranging from two to five, with 14 participants in total. The FGs took place between September 2015 and April 2017. The attendance rate for FGs was 47%. Of the four FGs, one was held in the London area, in a public space chosen by participants (restaurant), the remaining three were held in Cheshire, in a room booked for this purpose at the Cheshire Campus of Manchester Metropolitan University. The total duration, including pre- and post-assessment, ranged from 120 to 160 minutes. One transcript was returned from one FG with the restitution session form. One FG restitution session was held in-person but participants refused to be recorded. Regarding the two other FGs, participants could not be reached or gathered, and individual feedback was given when possible. In total, seven FG participants completed the full study.

Nine people who declined or could not attend the FG were asked to complete the pre-assessment form (to which the sociodemographic information questions were added), and some of them forwarded or asked for supplementary paper copies for third parties. In total, 14 people completed the pre-assessment phase. This control group was used to describe FG participants and gave a qualitative approach to sampling bias. It was also used to complement pre-assessment data in the perspective of a survey.

5.3.3 Sociodemographic characteristics of the participants

The main sociodemographic characteristics of the participants are summarised in [Table 6](#). All KIs but one were male and White British. Age ranged from 28 to 69 years old. One was a criminal justice professional; two were people living with HIV who expressed interest in taking part in the research; four were working in community settings with people living with HIV; one was a sexual health consultant, and one was a public health and social sciences researcher.

The majority of FG participants' were women (62%) and identified as White or White British (62%). Self-reported ethnicity included the following: British, Black British, Caucasian, Mixed Black and White Caribbean, English, White, White Arab, and White British. Age ranged from 23 to 53 years old. Professions were diverse: nurse, student, finance, retail, mechanic, entrepreneur and one was on sick leave. Four of the participants mentioned knowing someone living with HIV (a friend).

Table 6 Sociodemographic characteristics of the participants

Sociodemographic information		KIs / Interviews N = 9	FGs / public N = 14	Control Group N = 14	Total N = 37
Age	Mean [range]	46 [28;69]	29 [24;52]	29 [23;39]	29 [23;69]
Gender N	Male	8	4	10	22
	Female	1	10	4	15
Education Level N	GCSE ^a	2	3	2	7
	A-levels / Bachelor	3	6	5	14
	Master and over	4	5	7	16
Living area N	Rural	3	5	2	10
	Urban	6	9	12	27
Ethnicity	White / White British	8	10	8	26
	Other	1	4	5	10
Familiarity with people living with HIV	None	1	10	9	20
	Yes	5	4	4	13
	Yes, myself	4	0	0	4
<i>Note.</i>					
^a General Certificate of Secondary Education.					

Globally, the age of participants ranged from 23 to 69 years old, 14 were male and 22 were female. The level of education ranged from GCSE to PhD, and professions covered various sectors (e.g. finance, retail, management, health and social work). Participants were mostly living in an urban area (65%). Descriptively, the control group was similar to the FGs participants, but a reverse gender ratio. KIs were older and less diverse than FGs' participants and the control group.

5.4 Procedures and Data Collection

The procedures were divided into two phases. The first phase consisted of three stages, the second phase of two stages. The full procedure materials are detailed in [Appendix A to E](#).

5.4.1 Phase 1

5.4.1.1 Pre-assessment (58 items)

The pre-assessment ([Appendix C](#)) was formed as a part of the FG/Interview, prompting the participant(s) into the topic. It consisted of:

- Two introductory questions that are also part of the interview guide (*Do you think people are responsible for their own health? Do you think people living with a medical condition should be protected by society?*)? Ratings consisted of a yes/no/other multiple-choice question (MCQ), and a blank space left for comments.
- A 22-item stigma checklist (UNAIDS, 2001), rated on a 4-point Likert scale (where 1 = *strongly disagree* and 4 = *strongly agree*). The scale, which was validated in English (Genberg et al., 2007), was chosen as it consists of three subscales relevant to the topic under study: shame, blame and social isolation (10 items), perceived discrimination (8 items), and equity (4 items).
- Social Desirability Scale SDS17 (Stöber, 1999, 2001): this self-rated scale consists of 16 true or false items, chosen to control for or at least estimate social biases in participants' responses (Borkenau and Ostendorf, 1989; Van de Mortel, 2008). Scores range from zero (low social desirability) to 16 (high social desirability). The inclusion of the SDS17 is a precaution in social psychology research and it is rarely applied in FG or interview context. In this study, its inclusion was considered legitimate and useful, to explore possible associations between high social desirability scores and pre/post discrepancies in attitudes and beliefs.
- Screening habits and experiences (13 items): these self-reported items were devised specifically for this study to investigate screening experiences and potential stigma experienced in healthcare settings.
- Knowledge of HIV (5 items): assessing random knowledge on HIV and recall of the information when given during the FG/Interview. These items are used to control for stigma related to misconceptions of HIV: stigma may prevent recalling information that is likely to contradict an erroneous or stigmatising belief (recall is impeded, as it is a threat to one's self and beliefs).

5.4.1.2 FG or interview

Following a traditional social psychology method, the explicit topic (criminalisation of STIs/HIV transmission) is considered to hide the real topic: participants' reasoning, attribution processes and emotional experience. Asking participants to express their view and/or what they would consider as a crime, leads them to enact their own morality (and moral emotions) and

potentially stigmatising views. Participants were informed about the task and rules of the FG/Interview:

“Thank you for coming today and for taking part in this research. The purpose is to think, reflect, try to discuss, debate on one topic. This is quite a sensitive question, keep in mind you are free to express any discomfort or decline to answer some questions. The question for today’s debate is should STIs and/or HIV transmission be criminalised? Yes or no. If yes, how, why. Before starting, there are a few rules to be told, we do not insult each other, we try to listen to each other, try not to speak over each other and try to invoke rational argument. Here is a stress ball, if by chance, we are not able to listen to each other, we will use this ball as the speech distribution tool.”

Participants were told that they were free to use their own personal stories but that this was not mandatory. The interview guide was a semi-structured interview schedule with illustrative cases to promote discussion with and among participants.

5.4.1.3 Post-assessment (41 items)

The post-assessment ([Appendix D](#)) was given to participants at the end of each FG/Interview. It consisted of:

- Feedback questions (3 items): these questions were used to understand participants’ experience and self-awareness. (*Did you have any opinion regarding this topic [criminalisation of HIV and/or STIs transmission] before the discussion? How do you feel about this discussion on a sensitive topic? Do you think your opinion or arguments might have changed after this discussion?*) Rating consisted of a yes/no/other MCQ, and a blank space left for comments.
- Two introductory questions (2 items): the same questions as in phase one were asked to assess consistency or changes in participants’ explicit views.
- Stigma checklist (22 items) as included in the pre-assessment form
- Knowledge about HIV (4 items): the FG or interview may provide participants with general legal and medical information about HIV. Assessing the recall of knowledge items before and after the interview would help to identify if participants were likely to recall information given during the second stage.
- Reflective questions (3 items): how did the participant experience the FG/interview?
- Socio-demographic data (7 items): year of birth, gender, level of education, living area, ethnicity, professional activity.
- Familiarity with people living with HIV (1 item) (*Do you know any person living with HIV? If yes, who?*).

5.4.2 Phase 2

5.4.2.1 Restitution interview

Each FG and interview participant was offered a follow-up session (qualitative post-assessment, [Appendix E](#)). It consisted of a review of the semi-structured interview or FG following planned steps: the restitution of the qualitative analysis, a discussion on the experience of the FG or in-depth interview and the opportunity for feedback and new or modified opinion. Restitution sessions were audio-recorded with the prior consent of the participant. When a face-to-face meeting was not possible, the participant was emailed a summary of the analysis and asked to comment.

5.4.2.2 Restitution post-assessment (44 items)

The post-assessment of the restitution session allowed for a repeated assessment of the two introductory questions, the stigma checklist, the social desirability scale, and knowledge items.

5.5 Data Analyses

A database containing all of the responses to the pre, post and restitution assessment was created on SPSS 24 software (George and Mallery, 2016; Liu et al., 2007). Audio recordings and transcripts were exported to and coded with NVIVO 11 software (Seidel and Kelle, 1995; Welsh, 2002). A double independent coding was not possible, so two rounds of coding were performed diachronically, a first coding of the audio files of the interviews, then from the transcripts.

5.5.1 Description of the participants and the setting

The systematic reporting of descriptive criteria in qualitative research can provide the elements for a critical appraisal. The COREQ-32 checklist (Tong et al., 2007) was used to describe each FG and interview and sociodemographic information was collected to describe the characteristics of KIs and participants who were from the public. The description of each FG includes criteria specifying the context of the FG and participants' interactions (Kitzinger, 1994):

- Group characteristics: number of participants, degree of familiarity among participants, socio-demographic homogeneity and a possibly sustained group identity (Wilkinson, 1998);
- Degree of structuring: number and content of moderator interventions, the type of information given and type of comments;
- Interactional aspects: interpersonal communicative acts, participants' physical and verbal interactions (number, type) including personal allusions or references.

5.5.2 Qualitative analysis: recording, transcribing, and coding

The doctoral researcher transcribed each FG/interview verbatim. Given the duration of one FG (at least an hour) and the length of one transcription (30 pages) they are provided in a separate document called “Additional File - Transcripts Notebook”.

5.5.2.1 Theoretical and inductive coding

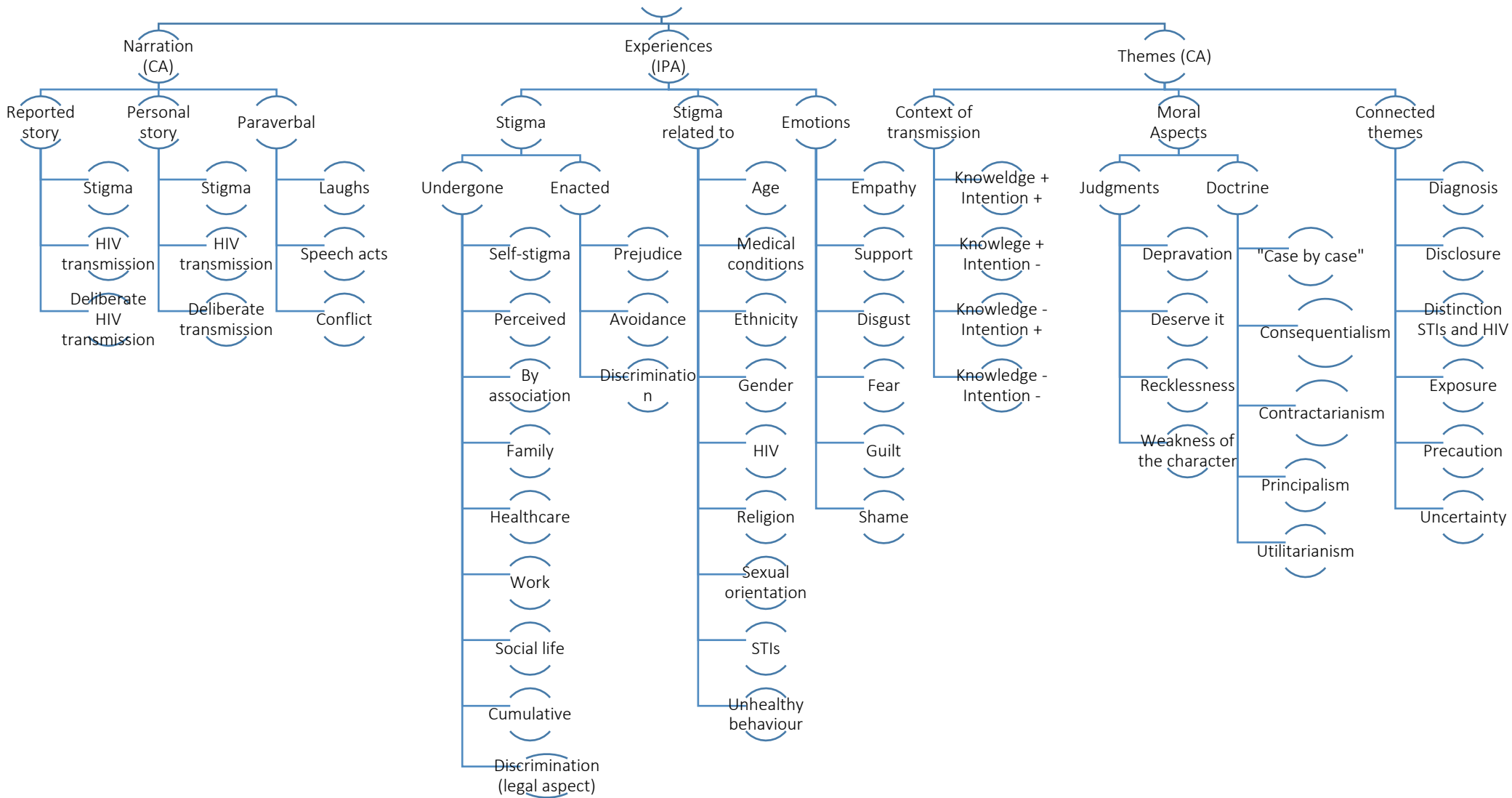
Literature reviews (DeCuir-Gunby et al., 2011) informed the codebook. Sixty-six (66) codes were distributed among four major categories:

- Twelve (12) codes described the types of narratives that included reported story (telling someone else’s story), shared personal story, speech acts and events during the FG or the interview.
- Thirty (30) codes were used to describe emotions and stigma experiences;
- Themes (23 codes) related to the content, divided into three parts:
 - Knowledge and intention combined categories to classify participants views and arguments (5 codes);
 - Moral judgements towards people living with HIV explicitly formed by a participant and moral doctrines that can be identified from a participant’s rationale (13 codes);
 - Connected themes (8 codes).
- One code was labelled as “Other”: this category was left empty to include any unplanned significant themes or elements emerging during the interview.

Using NVIVO 11 software, each audio recording and each full transcript were coded following the codebook detailed in [Figure 2](#)⁷⁶. Along the coding, new codes emerged and were organised according to the following categories: comparison with other conditions, HIV-related policies (e.g. sexual health, sex education), the category “if I...” was used when participants tried to imagine their own feelings or reactions under certain circumstances, personal experiences of stigma, the theme of lies and lying, the life sentence and death sentence, and feelings (e.g. love and rejection).

⁷⁶ For readability, “other” nodes are not represented.

Figure 2 Codebook



Given the [ethical concerns](#) in relation to the impact of the research on participants, a particular attention was paid to data saturation along the coding. Data saturation is defined as reaching a point of informational redundancy (Sandelowski, 2008) and is often used a criterion to stop including new participants (Guest et al., 2006). While the coding tree accounted for a theoretical data saturation, the audio coding phase accounted for the inductive data saturation, referring to the point where no new codes or themes appear in the set of transcripts (Saunders et al., 2018). Data saturation was used as a one of the research integrity (furthered in [section 5.7](#)) and validity criteria (Cope, 2014; Varpio et al., 2017)

The coding tree used highlighted redundant codes coded across all transcripts and codes that were present in some transcripts. Theoretical data saturation was reached at the seventh interview for KIs and the third FG for the public. Inductive coding allowed unplanned themes to emerge. Inductive data saturation was reached at the eighth interview for KIs and the third FG for the public.

5.5.2.2 Reliability of the coding

Qualitative research guidelines (Saldaña, 2015) recommend two coders or a double coding scheme to ensure the validity of the analysis. This was not feasible for this study; thus, the coding was a 2-step procedure (Tessier, 2012). The first coding phase was made on the audio recording, after each interview or focus group (Crichton and Childs, 2005) and the coding of the full transcripts was performed in July 2017. Informed by inter-rater reliability analysis (Gwet, 2014), a congruence analysis was performed between the two sets of coding (audio recordings and transcripts). The number of occurrences of each node or code in each set of data (audio and transcripts) was then compared using a contingency table. Weighted Cohen's Kappa was calculated to assess the reliability of the qualitative analysis. Weighted Kappa was run to determine if there was a reliable agreement between the coding on the presence (or absence) of each code in the two sets of data⁷⁷. A matrix of agreement was built into an Excel file and exported to SPSS 24 software then analysed following inter-rater reliability standards (Landis and Koch, 1977; Cohen, 1968). Kappa value indicated a substantial agreement (Cohen's Kappa = .712).

⁷⁷ Given current standards (i.e. multiple coders), and to ensure the validity of the coding, inter-rater statistical analyses (Gwet, 2008) have been adapted to the context of one rater with double coding.

Qualitative differences in the coding highlighted three main characteristics:

1. If the same codes were coded on the same excerpts, which confirms the congruence, transcripts show one-fourth more codes than audio recordings. This may be due to the ergonomic aspects of the software (less precise and less practical to code an audio file), and the finer analysis of written materials.
2. Interactional patterns (speech acts and events code) were three times more frequent in the coding of the audio files.
3. New codes or codes added in the “other” categories were mostly found in the analysis of the transcripts.

To summarise, double coding was performed as a traditional methodological precaution in the qualitative analysis. An inter-rater reliability test was adapted to diachronic double coding by one coder. The substantial agreement highlighted small differences in quality and quantity that are related to the material. Indeed interactional patterns were more obvious in the audio recordings, and the transcripts were more prone to subtle and more localised codes. The results of the qualitative analysis in [Chapter 6](#) are, therefore, based on both sets of coded data, aiming at a more reliable description and analysis.

5.5.3 Quantitative analysis

Three sets of data were analysed quantitatively:

- HIV stigma score and congruence ratio: Items sum up participants’ views and the development of their views. The sub-scales’ scores and total scores were used as a comparative (before/after) measure to determine the consistency of participants.
- Social Desirability Score: social desirability was used to assess the participants’ tendency to offer responses that create a favourable image of themselves (e.g. over-reporting good or expected behaviour, under-reporting what could be perceived as bad behaviours). Given the sensitivity of the topic investigated, the score might highlight superficial agreement or tendencies to follow a group opinion.
- Congruence ratios were used to assess consistency at each stage (pre, post and restitution) regarding knowledge (pre, post and restitution), stigma (pre, post and restitution) and social

desirability (pre, restitution). Congruence ratios were compared with self-perception to evaluate the explicit (perceived) or implicit (not perceived) effect of taking part in the study.

Eventually, in line with Bazeley's (2006) suggestions, other items were used as qualitative checkpoints and coded as binomial (dichotomisation from the median) or trinomial variables. The knowledge/intention qualitative codes were converted into nominal variables to enable a visual representation of participants' views (Uprichard and Dawney, 2016). Descriptive statistics were performed for all the items of the assessment forms, using SPSS 24 software.

Given the small sample size and the nature of the variables (nominal and ordinal mostly), two statistical analyses were performed:

1. To explore the characteristics of the participants: participants who took part in the FG or interviews were compared to the control group using a non-parametric (associativity) test.
2. To detect biases analysing the repeated measures using dependant samples ANOVAs (Thomas and Zumbo, 2012) and characterise the evolution of participants' responses using non-parametric analysis.

5.6 Ethics and Regulations

The present study was conducted in line with the MMU Ethical Framework⁷⁸, the MMU Advisory Distress Protocol⁷⁹, the MMU Lone Worker Policy⁸⁰, and two professional guidelines issued by the British Psychological Society, the Code of Ethics and Conduct (BPS, 2009b) and the Code of Human Research Ethics (BPS, 2014).

Participants read a detailed information sheet (see [Appendix A](#)) and then signed a consent form (see [Appendix B](#)) before starting the study. They were told that there were no mandatory answers and that they were free to refuse to answer any question, to criticise the material and to withdraw at any time. The information sheet specified that the FG/Interview was audio recorded. Once the information sheet was read and consent was obtained, participants were asked if they had any questions before starting. The recording started from the participants' verbal agreement and included the pre-assessment time. The recording ended when the post-assessment was

⁷⁸ http://www.mmu.ac.uk/policy/pdf/policy_ref_Academic_Ethical_Framework.pdf

⁷⁹ <https://www2.mmu.ac.uk/media/mmuacuk/content/documents/rke/Advisory-Distress-Protocol.pdf>

⁸⁰ <https://www.mmu.ac.uk/health-and-safety/manual/pdf/guidance-lone-working.pdf>

completed. Given the sensitivity of the topics explored, local support resources were identified and given to participants beforehand, to act as referral agencies in the event that the participant experienced or showed signs of distress. To avoid causing any distress or emotional discomfort to participants during the focus group or the interview, the investigator adopted a naïve posture and did not insist on personal stories (i.e. not asking for details).

Sensitive data was treated in accordance with the Data Protection Act and within the policies and procedures of the university: recordings were transferred then stored on a dedicated device and locked in a room. The recordings and transcripts were accessible to a limited number of people (supervisors). Paper assessment forms and signed consent forms were stored in the same place as the dedicated device, in a locked office in a locked draw at MMU. Participants were identified by a code. The paper file with the codes and participants information was stored similarly in a different place to the dedicated device. To ensure anonymity, any information likely to identify the participant (residency, place of birth, work) was not transcribed.

5.7 Research Integrity, Limitations and Biases

5.7.1 Biases

Participation was not incentivised. Two main biases need to be taken into account. Without any reward (money or vouchers) participants might agree to take part because of relational reason (i.e. want to help the investigator) or personal reason related to the topic (i.e. “Yes, I’d be interested because it happened to my friend”), referring respectively to social desirability (Spector, 2004) and self-selection biases (Olsen, 2008; Robinson, 2014). These two biases were integrated as descriptive contextual variables: the degree of familiarity with the researcher and the degree of familiarity with the topic. They were presented for each participant using the COREQ checklist (Tong et al., 2007), and the SDS17 was used to assess the results, controlling for issues such as social desirability and self-presentation biases. The presence of a control group also allows for a better characterisation of the participants and related biases.

Another bias of this study is the absence of an evaluation of participants’ legal knowledge. Hence, while knowledge related to HIV is hypothesised as contributing to views on the criminalisation of HIV transmission, a similar hypothesis cannot be suggested. However, the FGs/interviews being semi-directed, legal aspects when evoked were discussed.

Other biases refer to the data analysis. Given the small number of participants, the statistical significance of the results must be taken with caution; this will be discussed in [section 6.5](#). Other biases are inherent biases in qualitative research, hence specific provisions detailed below.

5.7.2 Research integrity

Traditionally, limitations and biases are expressed in terms of factors altering reliability (consistency over time and representativeness of the sample), objectivity (replicability) and validity (the procedure actually measured what was intended). Most of these constructs are neither valid nor relevant regarding qualitative (naturalistic) research (Norris, 1997). However, Guba (1981) suggested replacing reliability, validity and objectivity with trustworthiness and added four related criteria: credibility, transferability, dependability and confirmability. These four criteria have been extensively used (Anney, 2014, Golafshani, 2003) and a set of provisions for high-quality research have been summarised by Shenton (2004) following Guba (1981) and Lincoln (1985). The provisions made for this study are detailed in [Table 7](#).

Credibility or 'truth-value concern' (in preference to internal validity) refers to the confidence in the findings, reliability of the researchers and of the participants. Transferability or 'applicability concern' (in preference to external validity/generalisability) refers to the possibility to replicate the study. Dependability or 'consistency concern' (in preference to reliability) refers to the consistency of findings over time with the same participants. Confirmability or 'neutrality concern' (in preference to objectivity) refers to the biases, motivations or interests of the researcher influencing the findings.

Table 7 Provisions for a qualitative research following Guba (2001) and Shenton (2004)

Quality criterion	Provisions proposed by Guba (2001) and Shenton (2004)	Provision made by the researcher for the present study
Credibility	1/ Adoption of appropriate, well-recognised research methods	Focus Group and Interviews
	2/ Development of early familiarity with culture of participating organisations	Meeting with community members, volunteering with a Charity since 2015; clinical practice as a registered clinical psychologist and sexologist/professional background, teaching and professional training led on the topics of sexual health, forensic sexology, and clinical practice
	3/ Random sampling of individuals serving as informants	No random sampling; purposive sampling for KIs and snowballing for general public
	4/ Triangulation via use of different methods, different types of informants and different sites	Mixed method study: FG, interviews and standardised scale (stigma and social desirability), but no blind double coding
	5/ Tactics to help ensure honesty in informants	No incentive or material reward, FG and interview lasted at least an hour, the researcher tried to put people in a daily conversation context
	6/ Iterative questioning in data collection dialogues	Paraphrasing, rephrasing extensively and repeating
	7/ Negative case analysis	No negative case but negative aspects were discussed,
	8/ Debriefing sessions between researcher and supervisory team	Monthly peer debriefing
	9/ Peer scrutiny of project	Irregularly
	10/ Use of “reflective commentary”	Yes, see notebook of transcripts and section 5.8
	11/ Description of background, qualifications and experience of the researcher	See item 2 above
	12/ Member checks of data collected and interpretations/theories formed	Yes, transcripts returned
	13/ Thick description of phenomenon under scrutiny	Yes, background chapters
	14/ Examination of previous research to frame findings	Yes, see chapter 2
Transferability	15/ Provision of background data to establish context of study and detailed description of phenomenon in question to allow comparisons to be made	COREQ32, transcripts and full data available
Dependability	16/ Employment of “overlapping methods”	Triangulation and data saturation
	17/ In-depth methodological description to allow study to be repeated	Yes, chapter 5
Confirmability	18/ Triangulation to reduce effect of investigator bias	Pre-, post- and repeated measures
	19/ Admission of researcher’s beliefs and assumption	Yes, see notebook of transcripts and section 5.8
	20/ Recognition of shortcomings in study’s methods and their potential effects	Yes see section 5.7.1
	21/ In-depth methodological description to allow integrity of research results to be scrutinised	Yes chapter 5
	22/ Use of diagrams to demonstrate “audit trail”	No

5.8 Reflexivity and Subjectivity of the Researcher

The investigator's personal account, attitudes and limitations were likely to have a potential effect in the data collection (Berger, 2015; Darawsheh, 2014). To monitor progress and aid in the reflective analysis, the researcher used a diary of investigation as a self-monitoring strategy (Nadin and Cassell, 2006). This diary started before the first FG and ended after the last restitution session. Excerpts and summaries of the diary made during the data collection process are available after each transcript in the Transcript Notebook. For the principle of research integrity, the personal, practical, and intellectual goals are detailed in this section.

5.8.1 The topic

Personal views on the topic are not uniform. As a practitioner, I have been confronted with patients who were experiencing living with HIV in various ways. I have also been confronted by the disarray of some colleagues who were treating, a person in prison who was convicted for the transmission of HIV. This topic was familiar, professionally discussed and dealt with beforehand.

From a clinical and personal point of view, I can understand the feelings of prejudice in acquiring HIV and subsequently engaging in legal proceedings; I can also understand the view that transmitting HIV may reflect a criminal intent, a criminal recklessness, or possible harm, and, therefore, how and why a society would take such a path of criminalising HIV transmission. Extrapolating this argument, it becomes difficult to consider the community of people living with HIV as potential offenders. From a clinical and personal point of view, I also understand the consequences of such cases, when or if generalised, and the feelings of discrimination or prejudice from the community of people living with HIV. Writing this dissertation after completing the study, I still do not know what to think about the current situation.

The interest in the topic and the posture adopted were intrinsically related to clinical practice. First, in relation to the diversity of patients I have been working and volunteering for almost a decade, in community, public or private settings. Having worked with people who committed and victims of offences against the person, I am familiar with the criminal justice, probation services, and prison environment, but with the "victim" side of it. In addition, having worked with sexual and gender minorities and marginalised people, certainly familiarised me with the challenges they face and framed both my approach to knowledge (Chapter 4) and my way of being. My clinical

posture has been shaped according to two main axes, firstly a strong commitment to patients (e.g. being on their side) and secondly, a reliance on the law regarding my practice (regulation of confidentiality, third-party disclosure) and supporting patients (victims or offenders) during legal proceedings or the legal recourses. I am not foolish enough to believe that there is no bias in the justice system, but I believe that my role is to support people in what they experience and use psychological theories and tools to help them achieve the goals (consensually defined in the singular consultation) of a therapy or a psychological intervention.

This was also related to clinical practice as a psychologist in a resources centre for professionals working with sex offenders (and, more generally, in the field of sexual violence). Briefly, the role and mission related to this position are supporting (case studies, clinical and research support) and training diverse professionals who are already working with this population. As such, I do not determine what theories or tools they work with, rather must find the way to support, guide, and equip them whatever their background and practice are. Having this position for many years, and interacting with a wide range of patients and professionals led me to develop an interest in epistemology, pluralism, transtheoretical approaches to clinical work and training, as this may have appeared in chapters 3 and 4.

Questions

What I can state and share are the concerns and questions, stemming partly from clinical practice that led to this study but remain unanswered:

- The likely deleterious impact of such a path, in terms of social perception of people living with HIV and worries regarding self-stigma and self-destructive behaviours in people living with HIV (e.g. perception of oneself as noxious, endorsement of stigmatising views);
- The socio-cultural trends in terms of prosecution and conviction policies:
 - Cultural trends: the current repressive tendency from low- to high-income countries (e.g. Chad, Canada, Sweden). For instance, in France and the UK, first convictions occurred in the early 2000s and more than half of the convictions occurred in the last decade. By contrast, countries for which early criminalisation (before ART) is reported, like Germany and Australia, reported a decrease in the number of convictions.
 - Local sociological trends and their social perception: recent cases of gay male defendants facing charges from several complainants, as it reassociates a sexual

orientation with transmitting HIV and might lead to more stigma for both the gay community and people living with HIV.

- Worries about the normalisation of health, leading to potential deviance and prejudice associated with a condition and/or leading to more marginalisation and potential stigma.

Perhaps, I hoped for having a substantiated claim at the end of the process, but I am still unable to formulate a prescriptive or proscriptive opinion. At best, I can provide a frame to understand any opinion, and identify underlying premises or content.

So far, the primary goal was intellectual and epistemological. The topic of the criminalisation of HIV transmission is at the margin of many more general views, such as, for instance, views on responsibility, justice, health and sex. I was more interested in the core premises and how participants framed the question than in their actual opinion. This related to my own underlying assumption that how one thinks can be as impactful as what one thinks: what one thinks can be modified by knowledge, information, while how one thinks is not always a conscious or deliberate process.

Hence, from that follows the two main goals of this study. The first was to identify participants' rationales and premises. The second was to assess the effects and the self-perceived effects of taking part in the study; this was thought as acknowledging and assessing the inherent effect of social sciences research and the modification of what is studied, not because of aiming at a change but because change might occur contingently.

5.8.2 The study

Conducting the study

As a psychologist and sexologist, the professional and social circles I usually evolve in are familiar with sexual health and sexual violence topics. Relationships with the public are often through public events where self-selection and motivation may make the audience rather benevolent. When starting this study, I was in a completely new environment. Thus, I found myself explaining the study in daily life to people who were unaware and unfamiliar with the topic and more generally HIV and sexual health. I was then confronted with two main situations: people who displayed misconceptions and erroneous beliefs on HIV and people who were explicitly

stigmatising and sustaining erroneous and discriminatory views on people living with HIV, the LGBTQ+ community and ethnic minorities. Similarly, volunteering for a charity, I was confronted with the explicit stigma and rejection of the LGBTQ+ community. This contributed to the will to identify and explore these rationales rather than address misconceptions.

The recruitment phase was a complex and ambivalent process. The people met during professional or community event expressed interest in the study, sometimes asked about being informed of the findings but clearly refused to take part either in the design or as a KI.

Conducting the interviews/FGs, I felt like each of them was quite new and informative, whereas similar content emerged during the transcription and the coding. The digressions I sometimes induced were personally annoying, but similar digression occurred from other participants. This explains the posture adopted, as an interviewer. First, the oscillation between extrapolating the arguments presented by the participants, and providing other examples. Then, the use of the first-person pronoun to prompt participants into a close consideration or even a personal projection of the situation. Some participants asked me afterwards if I was a *victim* of HIV myself or living with HIV, but none of them assumed or asked if I had transmitted HIV to anyone, which, in my opinion, indicated the most unthinkable thing, a blind spot.

Another issue arising during the qualitative phase was the fact that both FGs' participants and KIs stated opinions related to political, religious or social views off-the-record. While documented in general qualitative methods (Warren et al., 2003; Munhall, 1988), the link between these views and the topic of the criminalisation of HIV transmission seemed relevant. When such moments happened, I asked if I could audio-record this ongoing conversation, but participants were usually ready to leave and reluctant to further questions. I did not insist and accepted it as i) this is the regulation for ethical research and participant's consent, and ii) the limits of qualitative research, compared to journalism or clinical practice.

The interviewing style adopted was a conversational tone. As such, I approached these conversations the same way I, concomitantly, in daily life, would interact with lay people or colleagues. I tended to extrapolate the participants' arguments to understand, or rather circumscribe their rationale. This led me to, often, play Devil's advocate, point out contradictions, or reiterate previous words of participants later in the conversation. Following a 'thought

experiment' discussion, I tended to use "I" and "you" to engage participants in a personal thought process. I also found myself, mostly off the record, and mostly after the FG or interview, disclosing personal (or related to very close people) sensitive data, or sharing, with health professionals difficulties or dilemmas.

The posture adopted and my own personal characteristics (non-British, female, psychologist, sexologist, volunteer, and probably many others) have certainly influenced the relationships with participants, in the sense that there was always at least one feature, label, or potential social identity that would facilitate an identification. I used this sort of illusion of sameness to create a safe space and promote a symmetrical relationship, most notably with KIs, insisting on the fact that they were the knowledgeable ones. I tended to share my questions, or what I was surprised by, in an attempt to feed the discussion. I have to admit that being non-British and having fieldwork experience (clinical practice but also satellite outreach) seemed to have been practical, in the sense that to some extent, it might have left some room for political incorrectness and more authentic interactions, such as the "stigmatising moments" during the FGs.

Personal challenges: sensitive topic research and its impact

One of the personal challenges faced during this study was the switch from clinical practice to research's posture and ethics.

The research interview (individual or grouped) was something I initially felt uncomfortable with. I tried to build a posture and an interviewing style that would differ from clinical/therapeutic practice. I would never have wanted participants to feel like patients, scrutinised and/or analysed with a disciplinary grid they might disagree with. In this sense, I approached the interviews on a rather symmetrical basis, in a conversational tone, maybe too familiar sometimes, and shared personal and/or professional experiences with them. Some participants disclosed very personal information that was health-related, but not exclusively HIV-related, or was information regarding their personal life. These moments were always relevant to the discussion, but I wondered, in the moment, how the participants perceived my attitude, as I reacted either questioning or drawing parallels with the topic under study. I hope none of them felt psychologised or pathologised.

The last concern related to the possible increase in stigmatising views among participants and/or the enactment of stigmatising views or attitudes during the interviews or the FGs. Before starting

this study, a literature search was performed to identify potential negative impact of stigma studies and methodological precautions to avoid or at least account for such consequences. The literature retrieved emphasised how to work with vulnerable group (Moore, 1999), adjust or tailor the design of a study (Alridge, 2014), the use of specific methods such as FGs (Farquhar and Das, 1999), and previous risk assessment (Dickson-Swift et al., 2007) in sensitive research topics. However, the publications retrieved also noticed the context-specific aspects of sensitive research. Therefore, the study included a responsive and standardised evaluation with repeated measures, to assess participants' views and possible stigmatising attitudes. This also explains why this study is not an intervention rather a descriptive inquiry, however, it is hoped that this study will inform further interventions (see [section 7.4.2](#)).

Finally, despite this study not being an intervention, for each FG, documentation was prepared and made available to participants after the group discussion; this included where to get tested (in their living area when this information was not known) and leaflets from a local charity working with people living with HIV. While this might entail the restitution session results, it was considered as an ethical practice.

5.9 Summary

FGs and interviews primarily aim at collecting qualitative and comprehensive data. They are often used as research methods and not as interventions that deliberately aim at bringing about change. This study did not aim at an attitudinal or cognitive change, however, it incorporated FGs/interviews in a mixed methods and action research design that included pre- and post-assessments. Two standardised scales and an items checklist were used to allow comparison between participants and global analysis. Limits and biases are inherent to the choice of qualitative research; however, some precautions can ensure a rigorous procedure and analysis. The results and findings are detailed in the next chapter.

CHAPTER 6 – FINDINGS

This chapter synthesises the findings of the mixed methods study. The wealth and diversity of the qualitative data led to opting for a thematic presentation of the findings following the research questions, then followed by sections on limitations and reflexivity. Regarding the qualitative study (Research Questions 1 and 2), quotations were referenced in brackets with the number of the FG or of the interview, and the number of the lines as found in the Additional File - Transcripts Notebook.

Preliminary information on the participants and the FGs/interviews

Three out of five participants attended the first FG. In FG1, participant 2 was the core of the group, being a friend of participant 1 and the girlfriend of participant 3. Participant 2 was the most talkative and was almost organising the debate (e.g. questioning participant 3 when he was silent). The familiarity among participants was obvious, so were their tendency to sarcasm and their past common references. Their arguments developed were mostly based on their representation of what happened to one of their friends who had been reportedly transmitted HIV deliberately.

Only two out of six people invited attended the second FG. This FG was the longest and the discussion was intense. The first third of the conversation was mostly taken over by participant 1, and I felt like participant 2 did not feel listened to. Participant 1 having been referred by a third party (see methods), and having only had an email exchange with him, I was surprised by the knowledge and strong opinion on the question. The content of this FG was the most grounded and the most developed. Participants committed to the task and involved their background, knowledge and personal situations to disentangle the moral dilemma they initially, and very early on, identified. I felt like a spectator rather than a facilitator, but this was due to the quality of the discussion. There was no animosity between the participants, they engaged in a philosophical debate and were both aware of their own premises. The essence of the discussion can be summarised on the question of one's responsibility towards oneself (participant 1) and one's responsibility towards others (participant 2).

FG3 and FG4 were similar in terms of interactional patterns and content: some participants were leading the conversation (P4 and P1 for FG3 and P1, P2, and P4 for FG4) while some remained silent. All participants but one in each group had little knowledge on HIV and displayed misconceptions that were addressed by other participants during the discussion. During these two FGs, participants displayed preferential and stigmatising attitudes that they were able to question and analyse.

At the beginning of each interview, the reason for choosing the person as a KI were elicited ([section 5.3.1](#)). KIs sometimes added further competencies, skills or aspects of their identities that might contribute to their views. Three KIs explicitly stated they identified as gay men (KI3, KI5, KI7) and four declared living with HIV (KI1, KI3, KI5, KI7). KIs tended to share their uncertainty or questions and, in that sense, the interview were mostly based on KIs experiences and their intellectual views.

6.1 Research Question 1: Views on the Criminalisation of HIV Transmission

The following section details the main views on the criminalisation of HIV transmission, their arguments, and their knowledge of the law for GGs participants and KIs, before synthesising the common features.

6.1.1 Opinion and rationales from FGs' participants

Views on the criminalisation of HIV transmission

The four FGs differed in the way they addressed the moral aspect of the question. Two participants from FG1 explicitly stated a contractarian view of relationships. The discussion ended when reaching the point of moral views. Contrastingly, FG2 provided in-depth discussion about the moral foundation of such opinions and debated connected themes such as justice and responsibility from an ethical point of view. FG3 and FG4 focused more on participants' reactions in cases of HIV acquisition and transmission and was mostly based on relational scenarios. Among FGs' participants, three main views were developed: a pro-criminalisation view for the transmission of (and sometimes exposure to) HIV, an anti-criminalisation view on principle that might accept exceptions, and an anti-criminalisation view based on consequentialism. Two participants did not express a clear opinion (FG1P3 and FG4P1).

Pro-criminalisation views

Eight participants (from FGs 1, 3, and 4) adhered to the pro-criminalisation view when an HIV-positive person is aware of their status. Different rationales were provided, and each group developed a singular argumentation. FG1 started with the reported story of a deliberate transmission of HIV to a close friend of two of the participants:

P1: My friend who had HIV it is exactly what happened to him. The guy was in love with him. (...) And because he wanted to keep him, and he is a sick mind, he decided to give him the virus as well. So he did not tell him that he had it, he said he was safe, they had sex on a drunken night, did not use a condom and my friend ended up being infected. And when he called him, he asked him and the other guy was like 'yes I know, I did it on purpose so we can be together'. (3s)

P2: This is a crime!

P1: This, this for me, this is a crime.

P2: But it is. Anyway, it is already...

P1: This is used as a... To me, it is, it definitely, how do you call it? You know like attacks with virus.

FG1, 42-54.

The discussion during this FG was, therefore, articulated around this known situation. Participants showed high empathy towards their friend and high disapproval towards the person who transmitted HIV to him. This influenced the whole conversation towards a duty to protect the others, and the case of this friend now living with HIV was taken as a worthy model:

P1: My friend now he is making the point to protect himself whenever he has sexual intercourse with anybody else, because he knows he has it.

FG1, 385-386.

Participants looked for analogies with other offences against the person. The most frequent one was comparing the intentional and reckless transmission of HIV to murder and manslaughter, with a strong emphasis on the outcome:

P2: Oh no but yeah, the problem is intentional or reckless. Because reckless is... It could be an accident. There is intentional, I know I want to, reckless is I forgot, I have not been careful enough, but it was not my intention, which is like the murder or the manslaughter or something. You know it is kind of a different scale.

FG1, 65-69.

P4: Yeah. I think you can only base something on the outcome really, because anyone could have the intent to kill someone, but not everyone is going to act it out. So, I do not think it is the thought process, I think it is the actions.

FG3, 740-743

P2: Just because you did not mean to give someone HIV, it does not mean you did not give someone HIV. So if you accidentally murder or kill someone, you still get done for manslaughter.

P4: It is exactly the same thing isn't it? And someone knowing and transmitting HIV that is basically manslaughter, it is not murder, but it is attempted murder.

P2: Attempted murder.

P4: Yeah. Manslaughter. It is the same as someone giving you poison.

P2: But if you transmit it without knowing you had it, then it is manslaughter, because you did not mean it, but you still did it.

FG4, 166-174.

However, in FG3, the argument switched from the perspective of the outcomes to the consideration of intention and possible attempt:

P4: Oh, I see what you are saying. You are basically saying if someone did not succeed in transmitting HIV, would it still be a criminal offence? Yes. Yes, definitely. You can try to kill someone and not succeed. So yeah, I think it is the same for me.

P5: But if someone's got HIV, and you do not know you have HIV yourself.

P4: Yeah, I think if you do not know, you do not know. But any informed, if that person knows, do not take precautions and does not inform, and transmit HIV...

I: If it does not, if there were no actual transmission, would you allow the complaint for attempt?

P4: I think that'd be down to the individual person, but I would still see it as intent, I'd still interpret it as someone intending, however, it would be difficult to prove if you are not infected with it. Do you know what I mean, how do you prove you even had sex with that person, how do you prove the intention. I think it should work like that, but the law does not work like that, it just would not work.

FG3, 763-774.

Parallels with other conditions, whether communicable (flu, STIs) or non-communicable (asthma, cancer) were drawn:

P2: I mean, it is still the same, deadly, willingly it is all about this. If you give me something annoying but...

P1: Ah, like a flu!

P2: Yeah, but like, flu is too common, because everybody gives each other the flu.

P1: Yeah but there you go. It is supposed to be something but because you do not die from it.

P2: No like, imagine, I give you asthma. Imagine. Because it is impossible, we know that. But it is a condition, it can kill you, it can, especially when you are not used to it. So what do you think, would you file against me? I knew I had asthma, I gave it to you?

P1: Yeah I would.

FG1, 482-495.

P4: That is the difference with cancer, for me. Cancer can be treated. That, when it gets to that point, I mean for me, I just think it is a death sentence. When it gets to AIDS, I personally think it is a death sentence.

P5: It is the same with cancer, once you have passed a certain stage.

P2: But you can live a normal life with HIV. You just got a disease and you live a normal life.

P4: But there is no guarantee it does not turn into AIDS though.

FG3, 178-183

The criminalisation of the transmission of any disease led to incurability as a criterion for possible criminalisation, subsequently, other STIs were included using this rationale. Pro-criminalisation

participants mostly perceived HIV as a death sentence, even when conceding it was a manageable long-term condition.

P2: Yes, it is a manageable condition but it does not matter because your life is not normal anymore. Because of the treatment and so on.

P1: It is still a death sentence.

FG1, 181-183

P4: That is the difference with cancer, for me. There is, you know, cancer can be treated. That, when it gets to that point, I mean for me, I just think it is a death sentence. When it gets to AIDS, I personally think it is a death sentence.

FG4, 176-178

Anti-criminalisation views

Four participants (FG2P1, FG2P2, FG3P1 and FG4P4) expressed an anti-criminalisation view. Two of them adopted this viewpoint as a principle emphasising one's responsibility not to acquire HIV, conceding exception in case of intentional, deliberate and malicious acts. The two other participants expressed a consequentialist argument against criminalisation. Arguments were based on either a feeling of regression towards an oppressive past, most notably regarding the gay community and the early days of the pandemic, or worried speculations and the fear of a form of generalisation, referring to a "can of worms" (FG2, 180) or an "Orwellian world" (FG2, 906). These participants used extensively the expression "Where do you draw the line?"

P1: I mean I think it is a ridiculous assumption (...) to criminalise people on the ground of sexually transmitted illness. Certainly, HIV I mean, it is like going back to 70s early 80, you know when HIV came up and people, mostly gay men were seen as evil sick propagators of all kinds of depravities, illnesses and cetera, basically pretty much. (...) So, I think, if we ever get to the point, we are actually going backwards, you know even beyond barbaric times. I mean other forms of ST illness have become much more common place in society, people have a much more laid matter of fact back attitude towards things like chlamydia, and gonorrhoea, and syphilis. It is just like, oh well, got one-night stand, got chlamydia, go the clinic and get treatment that is it. But I still think the main stigma is still HIV and AIDS. (...) Well, for me again, it is ridiculous. You know it is because I believe, something I put down on my you know questionnaire; I do completely believe health is a person's responsibility. And to actually criminalise someone on the ground of it, I think it is completely preposterous.

FG2, 9-38.

P2: For the argument, I split it in two parts. From the practical point of view, I am against criminalisation because I am aware of the consequences. From the theoretical point of view, the assumption, I think, I feel, I feel so I need more time, just to be able to argue, but I feel that it would be right.

FG2, 290-293.

Two main themes arose from three participants that were not present in interactions with or between other participants: the distinction between the moral responsibility and the criminal liability, and the extension of the debate to other forms of health-related risks, or other consequences of sexual activity (i.e. pregnancy). Two participants mentioned the example of food poisoning:

P1: You have a choice. Very simple thing. For example, if I go to see a doctor, and that professional does not give the knowledge and competence that I need to solve my problem, I will not take his advice. If I walk into a shop, or a restaurant to eat, and I see the standards, or the service is bad, either I stay or I go. If I stay, get a bad meal and I am sick the next day, or Delhi-belly - (I do not know if you can say that anymore, maybe it is not really politically correct, I said it anyway) - am I going to blame the restaurant? Because of their poor quality food, poor-quality hygiene? No! I decided to stay. So that is why I agree with what you are saying on the consequences, but I cannot agree on the moral basis of it.
FG2P1, 960-968.

P1: I would just say, as a society, you just have to take the risk. You just have to take the risk, if you do want to have sex. It is like, just, you just assume, it is like in a restaurant, you just assume the kitchen is clean, and, you have to take it if you want to. I mean, my grand dad, he passed away, but, my family said he never ate out, he only ate home-cooked food, he did not want to take the risk of eating out, so he missed that opportunity because he chose not to. It is like having sex, you have chosen to have sex and you accept at some point this chance or not at all. So you just have to take the risk.
FG3P1, 565-571.

Globally pro- and anti-criminalisation views are respectively based on arguments that focus on, the responsibility to protect the others (not to transmit) and the responsibility to protect oneself (not to acquire), respectively. Moreover, all participants holding anti-criminalisation views made the distinction between the criminal and the moral responsibility, arguing that if there was a moral fault or prejudice; criminalisation was not an appropriate response.

Knowledge of the law

While this was not assessed directly, FGs participants' knowledge of the law was consisted of misconceptions and information from the media and press releases, the latter being not specific to the British context. However, some participants (FG1P3, FG2P1, FG3P4) showed basic knowledge related to the offence under which HIV transmission would be prosecuted,

P2: Would you put me on trial for risking your life?
P3: For transmitting HIV to me? What in the law would you file for? What does it come under?
Causing bodily harm,
P3: So if I wanted to (noises) I have the right I could (noises)
FG1, 321-323

Others were aware that disclosure is not a requirement and informed other participants,

P2: I think that if you are going to have sex with someone you know living with HIV, obviously, it has to be protected. And you should probably tell him that you have HIV.

P4: You would have to... I think even if they are protected, yeah, you should.

P2: You should, but do you have to?

P4: If you got HIV and you still get protected, you should still consult the person... That you have HIV.

P2: Yeah you should, but you do not legally have to.

FG4, 184-192

It appears important to note that one participant, with a pro-criminalisation view, thought that HIV disclosure was a legal obligation,

P5: It is illegal when you got HIV or AIDS and you do not tell that person.

FG3, 26.

In each FGs, participants recalled cases they heard or read about in the news, but it was used as an illustration to their point more than a rationale,

P1: Yeah, unless, in cases like. I have heard cases of people that were, that had HIV and they were literally going to have sex with people to transmit the disease (P4: What!) Because they were very annoyed, because someone did that to them. So in this case, yes. They should be punished as doing any harm for anyone. But I think that just having sex with someone, it is both people's responsibility. Even if the person knows s/he has HIV and did not tell you, it is your responsibility as well because you had unprotected sex.

FG3, 278-283

Finally, a certain mistrust in the judicial system was also found, though mostly in FG2,

P2: Yeah, that is the point... I saw this in many cases, so I think that, in this case, if we take this from an individualised perspective, in theory, we think we are doing the right thing. In theory, from the theoretical point of view. But, from a practical point of view, I think it will come down to incomes, money, just this kind of things, the best lawyer wins.

FG2, 283-286.

P1: (...) The law unfortunately does not look at individual cases.

P2: No?

P1: No, never, believe me

P2: It is supposed to be, actually, like this, this is why we have a lot of different outcomes.

P1: It depends on what the law says, you see, it has nothing to do with the circumstances.

P2: There is an interpretation, so I think that is very individual, that is the point. Maybe I am just talking from an XXX perspective, but it is very, very, individual, because the law...

P1: Not really, in any country, because what you have is an exercisation of law, not justice. It doesn't matter what circumstances, whoever can argue the better case, it doesn't matter what evidence you have, it is how the case is argued, and how it refers back to the Law, whether you are guilty or not

FG2, 343-356.

Maybe the most interesting finding in relation to the legal knowledge is that participants were poorly informed but did not ask as many questions as they did for instance regarding HIV (see [section 6.2.1](#)). As the task was framed as a thought experiment and based on their personal views, it might not have left much room to question the legal aspects of the question or spontaneously demonstrate their knowledge of the law. Therefore, the views and concepts developed in this chapter are based on participants' personal constructs and (mis)understandings.

Other themes

Sexual health education

Several secondary themes emerged across the four FGs, centring on the justice system, health education or sexuality in general. Several participants highlighted their educational needs regarding sexual health:

P5: But to be honest, it is about all diseases, it is like cancer, people are educated on it, HIV, no one is really educated on it.

P2: But then, can you be educated on every single disease, it is very difficult to, like educate someone about everything that goes on in life.

P5: But why does it have to be like, why cannot they focus educating on other things. That is my personal opinion. For cancer, all you see is like cancer research, fundraising and...

P3: Check your boobs, and they tell you what to do...

P5: Why can't they focus on other diseases? Like diabetes, HIV, you are not really educated on it, that is what I think, anyway.

FG3, 344-352.

P1: And I think I disagreed with you because you mentioned things like education, income, et cetera... I come from the other perspective, the sociological perspective that human, even, it does not matter how liberal they think we are, we cannot deal with sexuality. Even nowadays, in 2016, we cannot deal with sexuality. Sexuality for me is very much a need like eat, drink, sleep, defecate, urinate, rest, it is a basic need. (...) But people do not see that. They think that sexuality and sex, it is something primarily either something sacred due to religious beliefs, or to family values, or social values, and that is it. It is still something dirty. Something that you do not deal with. Something you suppress, something you do not have.

FG2, 259-268.

Participants, whatever views they sustained, engaged with the topic and tried to understand the external of structural determinants of HIV stigma and criminalisation. They were also able to point out the discrepancies or contradiction between what they hoped or expected and the actual outcomes, mostly in relation to health and/or sex education:

P2: I do not think it is to frighten you. I think it is just to make you more aware of what is going on. I do not think their intention is to frighten you. It is just that you need to know those things if they do not tell you are not going to know.

P5: From a teenage, from a young teenage point of view, it does automatically goes there, you are going to think oh shit... You can get all these...

P2: But again... You do not use condom still... (...)

P1: I think it is very risky and almost dangerous to talk about health when it comes to schools, because again, my thing is where do you draw the line, if you really want to get deep down to it, you shouldn't have pizza in your life, never go to McDonalds in your life, you know it is like, you might want to have a fruitarian diet... I do not think you can fully teach kids or young people health, knowing that most adults are not following a completely healthy lifestyle. It is very, you know, I do not think... (...) So in terms of sex-ed, where do you start? You know sex is bad, your teachers are telling you things, and have McDonald's on a Friday, where do you, how much can you teach about health, just have fruit and salad for the rest of your life, it is not even good.

P2: No, it is not.

P1: You know, it is... I do not think, as people, we can be completely healthy. There is so much pros and cons for everything, even being a vegan, it is very risky telling people what is best for their health really, I think.

FG4, 391-418.

Consent and Trust

Despite lacking in specific knowledge, participants committed to the task and tried to give comprehensive insights to justify their arguments. The debate was connected to other themes that were diversely explored but relevant and already discussed in the background section of this dissertation. Finally, it is important to note that the majority of participants (except in FG2) highlighted the practical solution of disclosure and informed consent, leading to the assumptions made about one another as being HIV free or STIs free. The conversation during FG3 revolved around trust, and one participant contemplated the possibility to prosecute in the case of deception. At the very beginning of the FG4, P4 stated a pro-criminalisation view and the fact that she was systematically asking her partners and explained,

P4: Do you know why I would ask? Because if I get infected, and thought do you know what, I am going to prosecute this person, legally, it is the reason I have asked him, I gave him the chance to tell me. (*Laughs*). You see what I mean, you see my point. I gave you the chance to tell me because I asked you. Then that is back on to him then. That is why I would ask.

I: So is it in your mind every time you consider having sex?

P4: Honestly, yes it is. Most definitely.

FG4, 229-289.

In FG3, P4 later mentioned that disclosure should be mandatory, while other participants agreed in the first place, taking the perspective of a person living with HIV mitigated this view and P1 expressed the possible unfairness of such an obligation:

P4: I think a person should be legally obligated to notify a person that they have HIV before they have sexual intercourse. Because, and the reason I think this, is because even if you can take precautions for safety, and we both might agree to do that, a condom is not 100%. It cannot,

you cannot guarantee the other person 100%? So I believe you have to give the information to fully make that decision.

I: Do you think this is feasible, in daily life, every time you are likely to have sex with someone to disclose your full sexual history?

P4: I do not think a full sexual history is necessary, just the fact they are HIV positive or not. I think it is quite easy to have a conversation and say 'before we have sex, I have to inform you, I have HIV'.

P5: Yeah, I do agree with you.

I: So now, imagine you are a person living with HIV. Would you feel like doing it?

P3: It would be hard, wouldn't it?

P2: A lot of people are ashamed about that. That is the problem. A lot of people do not want to tell people that they have got it. So it is probably hard for this person to open up and tell them.

P1: I agree with what everyone says so far. But I feel like it is very very risky, I do not know if it is actually fair, for people who are infected with HIV. I do not think it is fair to them to legally disclose. I mean, where do you draw the line? Is it just HIV, or someone with chlamydia needs to disclose, or gonorrhoea, you know, there is a massive continuum of diseases, like... Are we saying that HIV is the worse? I mean, is it something worse? Personally, I do not know. Where do you draw the line? I do not think someone with HIV should have to be legally obliged. Yes, it could be nice, but do you tell somebody if you have a cold, you know what I mean; I think it is very sketchy where you draw the line.

FG4, 64-75

Furthering his argument, FG3P4 insisted on personal responsibility,

P5: You are not going to go, before, asking someone else have you got any STI.

P4: I do! (*Laughs*).

P5: There is no such a conversation, in the moment. Oh by the way, before I sleep with you, do you have HIV?

P1: You could do. So, that is my point, so if no one would but P4, I mean, you cannot blame the person, if you do not ask you cannot blame them.

FG4, 244- 251

While participants of FG3 and FG4 thought that informed consent was a practical solution to protect people not living with HIV, participants of the FG1 insisted that the contractarian aspect of relationship could also protect people living with HIV:

P2: Yes, either you sign the contract, we are together well stay together.

P2: No I mean like between two persons... it is like you say "ok I have it ,ok I do not care because you and me we are going to spend the rest of our lives together", then you want to leave, he wants to leave, doesn't matter it is too late.

P1: Yeah you are stuck with it. No as long as you made an informed choice, I think that becomes your own problem. I do not think you should be able to go...

P2: This is all the same, actions and their consequences.

P1: Because it is awful to be the other person, imagine I have AIDS and I tell my partner and my partner say I do not give a shit and then two years after he take me to court because we broke up... Like what am I going to do? I told you I did everything I could on my part and you still agree to go for it. You know like, how fair is it towards me?

FG1, 884-896.

Finally, participants of FG2 seemed more uncomfortable with the possibility of informed consent as a contractarian solution to ensure trust.

P2: It is not informed consent. There is also some values... For example, trust. For example, you trusted me that I would be able to come this morning, there is trust...

P1: But...

P2: I'm just talking about the moral point of view. I think there is a split in our society between morality and practicality.

P1: Absolutely, I totally agree with that. But... People lie.

P2: I know. This is the point... So I know that people lie...

FG2, 411-417.

Lies and deception were considered from different point of view but also related to different contexts, whether the relationship was a long-term one or a new one. Views on informed consent allowed participants to consider the possible impediment to disclosure and elicited different stances on responsibility.

6.1.2 Opinion and rationales from the key informants

Before detailing the views of KIs, it seemed important to report the feelings of two KIs of a lack of consultation of the community of people living with HIV on the topic of criminalisation:

KI5: This is the, the thing about it is, it cannot be a certain type of people discussing it. It should be the people who make the law, the people who look after like the doctors and us, the people who has it. And you know, it has to be a triangle; this does not make a circle. It is going to be these three.

I: So health sector, criminal justice and people living with HIV?

KI5: Yes. Like I said the government is thick, you need all the professions, their relevant bosses, and the people. And hopefully discuss it.

KI5, 381-387.

KI7: Too many times, decisions are made without people living with HIV as well. So there is no like voice. Decisions are made on their behalf, and without actually consulting us.

I: So would you consider like a huge consultation panel of people living with HIV on the topic of criminalisation useful?

KI7: Yeah, that would be very interesting. We would get a real balance of real people. That would be interesting to know what other people's views are. Especially, people who may be like, kind of the demographics. So like, I would be interested to know the opinions of, for example, white heterosexual woman, they might have a different take on it. I think, as a gay man growing up in the UK, it is always kind of there, even if you think it is not for me, I'm not that kind of person. Yeah, I would like, I would like to know what is your opinion, if you are not one of the typical populations, like it could come out completely out of the blue. You know... That would be really interesting.

KI7, 103-155

KIs tended to be more argumentative and to voice substantiated views. All KIs agreed or implicitly stated that living with a chronic condition was a prejudice or something uneasy to handle. Two participants sustained the pro-criminalisation view in the case of reckless and deliberate transmission. Five participants adopted the anti-criminalisation stance on principles. Two participants adopted a “prefer not to say” stance, but during the interview appeared rather anti-criminalisation. The criteria of intention to transmit was acknowledged as the most relevant for criminalisation, whether participants were pro- or anti-criminalisation. Comparison with other health-related conditions or states included pregnancy (KI6), cold or flu (KI2, KI3, KI6, and KI7), cancer (KI4) and other health-related risks (KI2 and KI7) such as smoking (KI4, 74) or surgeries (KI6, 57); were also found comparisons or information related to other national contexts (KI1, KI3, and KI6).

Unanimously, and independently from their views, KIs pleaded for education on HIV and support for the people living with HIV, as KI9 extensively insisted on. Several cases were evoked during the interviews, most notably the herpes case (KI1, KI2, KI3, KI5, and KI6) and the upcoming trial of Daryll Rowe (KI5, 112 and KI7, 90). Many common themes (but divergent views) emerged across the interviews; some of them will not be explored as they were less directly connected with the topic investigated. It still appeared worth mentioning that moralisation attitudes from health professionals (KI2, KI3, and KI6), how criminalisation affected professional practice (KI6, KI8), the PrEP debate (KI3, KI5, and KI9), and the social construction of the “other” (KI3, KI4, and KI7) were developed.

All KIs showed awareness of conflicting goals, values and interpretation of what the common good is or would be. Hence, their rationale revolved around striking a balance, whether a pro- or anti-criminalisation view was argued:

KI3: As I say, I think it is difficult, because you have a question of justice and you also have questions of public health, and I think those two things are... (*Hesitation*). You are asking two different things really. The justice argument is about harm, and violence, either psychological or physical and then you have the public health arguments that are what harms are being caused and what harms are being caused by criminal activity. And I think, it is very difficult to, I think, it really has to be on a case-by-case basis.

KI3, 421-427.

Pro-criminalisation views

Pro-criminalisation views were sustained by K12 and K15. The rationales provided revolved around the idea that living with a long-term condition is a prejudice, a harm when inflicted. While K15 emphasised the consequences of living with HIV through personal and reported stories, K12 developed analogies of criminal liability for any foreseeable harm:

K12: That is fine, if they want to do that, again, that is fine as long as you get the right answer, the truthful answer. Again, I do not have any problem with that. But there is a responsibility when you have an STD and to go to a party to actually carry condoms, because you are not, it is almost like sex, there is no such thing as a terminal erection, I wanted to have sex and I just lost my mind, there is no such thing as that. So, that person has to take responsibility for others, for safety and health of others.

K12, 257-263.

The argument was extended to conditions (mental health disorders) leading to the possibility of harm but also compared to domestic violence, highlighting a definition of bodily harm. Finally, K12 elicited one possible rationale for disclosure and questioned the possibility (and relevance) of a mandatory disclosure scheme using the comparison with the aforementioned disorders or type of violence:

K12: Ok, I am taking it to its extreme. Are you saying that if I have if I have a chronic mental illness, like schizophrenia, and I suffer from delusions, hallucinations, whatever, and I'm likely to act out a killing. Therefore, I might stab you. Despite our beautiful relationship, I might harm you. So is it the kind of scenario I would debate? I think if I was such a risk to society, I'd probably have to... It would be a good plot for a drama. That is for sure. Well, we can draw a parallel with paedophiles. Nowadays, a paedophile has to tell the police where they live. And now the question is, are the people in the street entitled to know about this person's behaviours? So there is a potential for informing the people about the risks? And also there is parallel to be drawn within the area domestic violence. Should, and I do not have the answer or know what the outcomes would mean, but the question should certainly be is the new partner entitled to know the past of their partner when he or she severely beaten someone before. And I would say yes. I would. How that? What the mechanics of that are, if you are my daughter, and if you are getting into a relationship with a partner, who in his previous relationship had beaten his previous partner to the point of going to the hospital, I think I want to know that. I think you want to know that.

K12, 270-283.

When questioned on the possibility to prosecute someone for attempted transmission, K12 dissociated the moral from the legal responsibility:

K12: So if for example. I have HIV and it is my intention to pass that onto my partner, my girlfriend. It is my intention but it does not happen. Are you asking me then do I see that as a crime? Well, morally, the person has some case to answer. But, criminally, it is a very difficult one. Because you can have attempted crimes of course... Certainly, I would be surprised of a conviction. I might be wrong. But in this country, I do not think you would get a conviction.

While K12 developed a legal rationale, K15 shared his personal story and feelings at the time of the diagnosis. The pro-criminalisation view was conditioned to the knowledge of one's HIV status and the non-disclosure. This is similar to the informed consent developed by FGs' participants:

I: Have you considered complaining when you were first diagnosed?

K15: Have I ever... Well I did. But they said you have to go public, and I said no. And you know. No. my treatment has been fantastic. It is my own fault that I picked it up. It is my own fault. How can I complain? When I go to *XclinicX*, I have a way of a good time; always have a laugh and a joke. My treatment there is great. From the very first moment, I ended up in hospital. It was great. I was seriously ill, and I had a laugh. (...)

I: So do you know the person who transmitted it to you?

K15: No. I do not. No. Because it was a, I have had it for a very long time. That is why I ended up in intensive care. If so, then I would have gone after him. Really. I would have gone after him. Because if he was diagnosed, if he knew, I would have took him to the court, because he did something morally wrong. Because if you cross principles, then you will not be honest.

K15, 133-147.

However, at the end of the interview, K15 seemed to have a more mitigated view, focusing on the deliberate transmission exclusively, and considering different factors likely to impede disclosure (i.e. mental health difficulty):

I: Do you think that in the community, people tend to be for or against criminalisation?

K15: To be honest, I do not know. I am against really unless, like I go back to that, young lad having sex with eight people⁸¹ giving it knowing he has it. But if you have gone out without the intent, like you accept but you do not really accept it, you got that mental... You cannot really prosecute because at the end of the day that is something wrong, they have not accepted it.

K15, 395-398.

Anti-criminalisation views

Anti-criminalisation views were affirmed at the very beginning of the interviews:

K16: Personally, I think it is wrong, the criminalisation of STIs and HIV, I think it is a stigmatising act in itself to criminalise these things. And I think it takes very little account for the complexity which sexually transmitted infections are both transmitted and acquired. And I think the criminal law, in particular, is an inappropriate tool because it has no sense of mitigation. No grey area. And, contrary to public health, messaging where everyone should be protecting ourselves, criminalisation firmly claims to place the blame with one person, rather than both.

K16, 17-23

K17: I do not think it is helpful, that it is criminalised, it adds to the stigma. And, if you look at, in the same context, other conditions, they are not criminalised in the same way. So I do not understand why this is a need for criminalisation around sexual health. It is kind of like when you are living with your family and a cold passes around, why do you then feel the need to blame anyone?

K17, 3-7.

⁸¹ This was an allusion to the case of Daryll Rowe, a few weeks after his first interrogation in Brighton.

KI8: Oh totally against. Hum, it does not, it will not support the message that charity and health organisation are trying to put out there that HIV is a long-term condition. It stigmatises people living with HIV more and also put some blame on people living with HIV, and reduces that need for everybody to take responsibility regarding their sexual health.
KI8, 3-7.

The main arguments developed were based on principles and consequences of criminalisation.

The main arguments were also related to stigma and HIV exceptionalism:

KI6: ... The philosophical question is why did you hand over all care of your body to someone else. We do not even do that if we are going in for surgery we have every implication details we have to sign a form. So what makes you think that this person who you know in a sexual way. Why did you hand over responsibility for your own integrity corporal, physical integrity to them?
KI6, 62-66.

One KI evoked his own story to explain his stance:

KI7: I think... When you are, when I was newly diagnosed, again, there is too much going on. But then, a few months later, I start thinking about it and it could be two people so I contacted them. And one of them was like I know I have been tested since then and I know I am ok. The other guy was like really defensive and was like “no, why the hell do you think it is me” and this kind of stuff. And about a week later he contacted me again and was asking me all sorts of questions, like how did you know, what made you go and get tested and that kind of stuff. And I thought, I might not have known and seemed for him to cope... And I guess I just thought for a while I could be angry, and I guess I was at a certain point, but you just have to get on with it. Being angry with that person does not change anything. And I think, my case was, like he had no idea. But I imagine some people, are really, you can almost, you can use your energy and fight it. And actually, if you are fighting it, HIV is going to become a bigger part in your life than it needs to be.
KI7, 50-61.

Finally, rationales (KI4, KI6, and KI8) were developed on the basis of an ideal of justice and society, contrasting with the mistrust of FGs’ participants:

KI4: I have a great deal of sympathy for them and their circumstance. I can empathise with the anger and shock, finding out that they have acquired HIV, and I would wish to support them, to come to terms with that infection. But I would not and do not believe that a criminal prosecution, as a society, is the most productive next step. Because everyone living with HIV has acquired it. They have acquired it from someone else. To say that the circumstances by which one person acquired HIV over another, somehow, require prosecution does not fit with me comfortably at all. And that is the difference between, hum, vengeance for some, that personal sense of victimisation, and wishing to do something about that, and a society saying, “well actually, there is something else to do about this”. And we can punish the individuals, as a society. It sits with me in the same way I would view death penalty. I can well understand for those who had, a family member being killed, being murdered, wishing to seek a personal sense of vengeance and retribution against someone else, but that doesn’t mean to say that as a society, we should say that we believe that death penalty is a suitable course of actions to take in that circumstances. That is where I think society is far more powerful than individuals are. Anyone who has been infected with HIV has acquired HIV, and feels a personal sense of anger

about that. Do I think that they are right to then say they were a victim, personally violated in some way? Unless we are talking about cases of rape, and even then, whether HIV was involved, I still do not think that elevating it up to a different level in terms of crime and punishment whether they acquired an infection, is a feature of that. I do not think it should take this circumstance to a higher level. Therein, for me, lies the rub. An individual, yes I can understand your feelings about this, but as a society to say no, and use the tools of the law to then prosecute, not at all. Because that victim, as soon as they have acquired HIV, is now... An offender. And they will have to live up to those particular standards.
KI4, 99-128.

Knowledge of the law

KIs expressed their opinions on several of the conviction cases in the UK. Some KIs demonstrated deep knowledge and showed a critical reflection on conviction cases. KI4 developed the concept of otherisation,

KI4: Whereas, when we look at people living with HIV, what we are talking about, very much, we are not talking about the HIV biologically, when we look at prosecutions, it is very particular individuals, where cases are brought. And usually, the personal circumstances of those who are prosecuted are more marginalised than the rest of the population. More stigmatised. The kind of demonization of these individuals is greater than what we find in the general population. And that is why I think that you cannot divorce HIV as a health issue from the social values of the culture within which it is in place.
KI4, 88-94.

KI6 spotted the sociodemographic mismatch and cumulative vulnerability of the people involved in the criminal cases,

I: So what do you think of the 27 convictions in the UK?
KI6: Terrible. They are awful. I think... It is hard to differentiate if they came from stigmatised subgroups because of course Stephen Kelly was a prisoner himself. Prisoners have the official stamp of Justice to say that they been in a stigmatised group, Konzani and Dica, Black Africans, with its lovely white women who innocently call these infections. I think I did not like that aspect to them. I did not like the fact, the aspect that there was not a shared responsibility. It was definitely an accusation that someone had transmitted a disease. There is no acquisition. No accusation that someone has acquired an infection.
KI6, 33-40.

Furthering this view, KI6 evoked the possibility, if any, of a legal recourse on the basis of Tort law rather than Criminal law, hence suggesting a shift from retributive sentence to restorative justice:

I: So the knowledge of one's status is not entitling any more responsibility.
KI6: In my mind no, in my mind no. No, it just is not. Nothing criminal law. But. Wait. No one has even touched on tort, or negligence or mitigation. If that sort of things were happening. . I think there is a case, because it is mitigation.
I: Ok, so it is against the criminalisation but not against any legal action?
KI6: Yeah, not against anger. Because, Law is about anger, isn't it? It is about you trespassed on my rights or what I thought was my rights. And the law colludes and say, "Yes it was your rights

and I did that". Hum. And. I am against in principle. I still think it should be that person's responsibility. But I think it makes more sense in civil liability when you say, "actually, you knew a bit more than I did about that. So actually I want to see for thousand pounds or whatever X amount of money because you did know that and you didn't insist on the condom use".

I: So you would rather take a restorative justice line?

KI6: That is the only point of it, yeah. Because. It is about restoration and then I cannot spend my whole life saying HIV is the same as anything else. People should be treated the same. Well that is true. But if you know that a beam of wood is going to fall on my head and you see that and you know it is going to happen and you let me stand under it, well, come on you knew that. Where is the fairness? That is restorative... Criminal justice, well it is not even justice in this case in my mind. Criminalisation is unhelpful.

KI6, 67-85.

However, when later questioned about restorative justice, KI6 explained it was a solution by default:

KI6: Ok. So I am utterly against, utterly against restorative justice but I can see how it would be applied more fairly. (...) I am against both of them if I can say anything. But... I am against both of them, but what I can see is that restorative justice is a fairer tool for the job, if that makes sense. Hum. Because restorative justice is about someone saying, "something happened to me. I do not think it should have and I would wish to have reparation". And we can do that for everything, I can do that because I have been exposed to asbestos at work. I know there could be asbestos because there is a roof but I did not know there was asbestos so I could have worn a mask.

KI6, 151, 163.

Shared responsibility

KI6, KI7, and KI8 insisted on the shared responsibility. KI1 and KI5 insisted on disclosure; one of them insisting on signing a consent form before any sexual relationship, highlighting the fear of onward transmission and reprisal,

KI1: That is why they have to sign. No he has declined to use condom, I insisted, he said no, he said, I agreed, I have consented to... sign and date, and give me a copy. Once it is written down, you cannot take it back.

KI1, 332-334

Shared responsibility was uniformly defined as both protecting oneself and protecting the others (KI4, KI6, KI7, and KI9),

KI6: For a sexual doctor that is the way I came forward... for sexual act. The input and output from that sexual act should be, in my thinking, a shared responsibility. So seemingly quite comes from feminist argument that pregnancy is not a woman's responsibility, it is a shared responsibility. We never talk about a man transmitting a pregnancy do we? But probably that's the same as transmitting a STI. (...) Certainly not at the time of the Kelly conviction, I mean it was 2001, was it? I mean really, what on earth is going on here. So shared responsibility is about both participants looking after, looking after themselves really, rather than being a requirement for the other person.

KI6, 37-47.

Finally, some participants extended their views to the exposure to HIV and/or the non-disclosure of one's HIV status. Questioned in the light of responsibility, the criminalisation of non-disclosure of HIV status seemed to entail the shared responsibility stance:

KI3: And I think, the thing is, again, this is my issue around prosecution of non-disclosure, is, if you create a situation in which people are so frightened, what they tend to do is just go underground, and actually, it works against people being open about their HIV status. (...) I think the thing is, what is the point of disclosure? What are you protecting, who are you protecting? What is your aim in terms of disclosure, mandatory disclosure? What kind of disclosure are you talking about? Are you talking about compulsory disclosure here?

I: Yes, to any sexual partner.

KI3: Yes to any potential sexual partner. Right, I think the problem with compulsory disclosure is that the entire onus is on the HIV positive individual.

KI3, 295-325

The disclosure stance was also evoked in the context of an accidental non-sexual exposure situation:

KI5: Back to it, you have to be going for it and thinking about other people. If you cut yourself, you have to clean it up. If someone is here, you have to tell them. I cut myself, but everybody will be safe. I am undetectable; the medication I am taking is working. It happened at work, I told them. Everybody is going to be safe.

KI5, 314-318.

Compared to FG participants, key-informants were more knowledgeable, more aware of causal or contingent aspects involved in the criminalisation of HIV transmission, and provided more substantiated arguments. The common feature across all interviews was the distinction between moral liability and criminal liability, even in key-informants who had pro-criminalisation views.

6.1.3 Common features between KIs and FGs' participants

Four main common features were found in both FGs and interviews with KIs:

1. Living with a chronic condition as a prejudice (mostly as a ground to criminalisation);
2. The emergence of the informed consent (knowledge and disclosure of one's HIV status to potential sexual partners) as a common theme and solution (FG1, FG3, KI1, KI5), protecting both partners. As pointed by several participants (FG2P2, FG3P4, KI2, KI5, KI6), the informed consent relies on trust or honesty (KI3), and the risk of deception was anticipated;
3. The link between stigma and criminalisation;

4. Finally, the representation of the one who would deliberately infect someone else as “half crazy” (FG1, 37).

The former two have already been developed in the previous sections; the latter two are explored below.

Stigma and criminalisation

Unexpectedly, spontaneous explanations of the legal recourse or its absence in relation to stigma emerged in both FGs and interviews with KIs. The main stigmas alluded to were homophobia or stigma against sexual minorities (FG1, KI3) and racism (KI1), with a strong awareness of cumulative stigma. Participants in FG1 explained the absence of legal proceeding by their friend’s fear of publicity (also evoked by KI3, 127) and potential consequences:

P2: Did he sue him?

P3: No.

P1: The thing is he works in a very environment let us say, where it was already hard to be gay... So, it was very hard for him at first to face the problem, so going to the police and stuff and the thing he was very scared that this was going to be known by his employers, and that is why he did not do anything. But he truly wanted to kill the guy obviously.

FG1, 84-90.

I: How do you explain the fact that there is almost no gay men prosecuted or convicted?⁸²

KI5: Because they are too scared. You know they all say, it is not a gay thing, but yes it is. And gay people gets it because they have been irresponsible. You know. And it is a case of, it is just a question of habit. (...) At the time, before, the gay person was blamed, and discriminated. The gay people, we were underground, and you know, who want to be in the headlines?

KI5, 243-248.

One KI referred to the cultural relationship to legal recourse and to the public disclosure possibly related to a criminal procedure:

KI1: I am just wondering why there are no black people complaining. You know that could be that people who have been infected, but because of our culture we are not used to legal recourse. Not sure we would encourage or be encouraged to report. (...) Tend not to take things not too serious, too personal. I see white people worry for very little thing. Though it is a big thing, I think, people would not like to be, you know do not want to be in the newspapers... Also maybe there has been some complaints but no further legal stages. I am surprised there is not a lot of Black women.

KI1, 202-210.

One KI also developed an opinion on the gender bias:

⁸² This interview took place before *HM v Rowe*.

KI8: I mean there has been so few cases. And I know, predominantly those cases have been weighed in heterosexual couple, and I think there has been a few cases for gay men. So I think it is an element of what is going on in the position of women, as victims, and that the judges tend to sit more favourably for a woman than for a gay man. And I think... It is also a very old piece of legislation. The assault. Yet we know there is more gay men living with HIV.
KI8, 43-48.

Two KIs developed a socio-historical analysis of HIV according to which the LGBT+ community was stolen ownership of the history of HIV and AIDS; KI3 insisted on the pink-washing, while KI4 developed the medicalisation of HIV and AIDS. For these two participants, HIV stigma is intrinsically related to the stigma against sexual minorities. While stigma within the community was evoked (KI3), the underrepresentation of the gay community among the conviction cases was related to anticipated stigma from the judicial system and reluctance to legal proceedings due to negative impact on the communities in terms of public perception:

I: How do you explain the under-representation of gay men among the conviction and the prosecution cases?

KI3: I think there are several different things going on. I think that within the African and Caribbean communities, HIV, generally, has a higher profile of shame and stigma. It is been a while since I have done work with people from that community but certainly when I did do work with that community, it is really difficult; you know it reflects on their families the communities are very close. So if somebody is found out to be HIV positive, it quickly goes down the entire pipeline and it is a source of great shame.(...) I think that, gay men are more realistic about HIV transmission. I think that they quite often do not see themselves as victim in quite the same way. I think also they also think they're not going to get... if they are exposed to deliberate onward transmission, I think that they, quite often, think they're not going to get a fair hearing from the authorities anyway. Hum, so I think that is part of it. Hum and I think that also, from a personal perspective, I think there is almost a certain amount of honour among thieves, we do not snitch, on each other. If that makes sense. I think there is a certain amount of that, though I think, perhaps, also a desperate desire not to have that kind of tabloid sensationalist press around gay men.

KI3, 158-171.

KI4: And it think the whole history of HIV, fits with that, as far as I am concerned. because you start off with, in the 70's and 80's, the rise of gay pride of challenging the perception of society on what it means to be LGBT, and people discovering pride and begin to stand up for themselves, and suddenly comes along this infection that decimated the gay community. That is what happened. It is God's will, God's judgment that those who are living with this infection are those who are L, G, B, or T and now there is something that proves that they are deviant. That is what happens if you do deviant things with other people. You die. And you should die and we should be protected from you. And in the end, they will all die. And one can see it in terms of how the pattern of health care developed, and it was not until HIV was established in the heterosexual population that it was recognised to be a public health issue for the heterosexual population, that the government of the day began to say, "We should do something". (...) And that sense of stigma, that sense that we need to protect the normal majority from the abnormal aberrant minority, and we will find ways to be able to do that. And we will find systems that

allows to do that and still say we are acting responsibly. And that is why I think that stigmatisation cannot be separated out from the social and cultural values of society at the time. So criminalisation is an expression of that isolation of the other
KI4, 177-198.

Nevertheless, views sustained by KI3 and KI5 did not represent a homogeneous standpoint from the members of the gay community or the community of people living with HIV. For FGs' participants and KIs considering that HIV was still a life sentence (KI5, 166), the harm to one another (transmitting HIV) and the harm to the community (stigma) were two different concerns:

I: Do you think, some people think the criminalisation is feeding the stigma, do you agree with this?

KI5: Well, I would say, that, yes and no. Because people know that you can survive and live, and it is not a bad thing. But, people do not follow the simple rule of "you must wear a condom", if you are infected, and you must disclose. And in that one, because he knew fully well what he was doing. So in this case, I agree with what people think about it. I totally agree with it. I could not do what he is doing. No way. You know, because he is breaking the law, it is in the law that you must disclose. At the end, you just ruin one's life. So that is what it is. I could not do that to another person. No, that's, he get me annoyed for what he did. He knew damn well what he was doing, and turn around and stuck his two fingers in other people. And that to me, is wrong. He deserves everything he gets. Even though he will be segregated in hospital, been imprisoned and he will still get his medication, if he chooses to take it. So, you know, I agree with what some people think on what he has done.

KI5, 170-182.

The social perception of HIV and social discourse on HIV were also pointed out as the roots for a sense of prejudice in the acquisition of HIV:

KI6: They are angry. This is a disease everyone is telling me I am not part of. I am furious and I am going to take that all the way to court. And get that through. That is a hypothesis, and I am talking at the top of my hat. But you know, it is a hypothesis. Whereas, a homosexual man, perhaps there is an understanding. That is where the epidemic is, that is where the epidemic is. That is where the targeted thing is. So perhaps... What we are seeing is the translation of responsibility on the ground. So that translates into responsibility, like "I got HIV, maybe it was something I did or didn't do". Why would I take that person to court? It could be more sinister than that. That they could be afraid of recriminations from gay groups about not protecting their cause and not being part of the gang, to then take it to court. Because of course, what we are saying is the court is just the tip of the iceberg. Perhaps, they are afraid of the backlash.

KI6, 121, 132.

"Sick" or "bad" or the SR of the one deliberately transmitting HIV

Another common feature was the recurrent depiction of the responsible one as one who would transmit deliberately HIV as "sick mind":

P1: Yes, it is all about intention.

P2: Like if you have someone who has half-crazy and knows has HIV and is like "ok I'm going to spread it". (...)

P1: My friend, my friend who had HIV it is exactly what happened to him. The guy was in love with him. (...) And because he wanted to keep him, and he is a sick mind, he decided to give him the virus as well. So he didn't tell him that he had, he said he was safe, they had sex on a drunken night, didn't use a condom, and my friend ended up being infected, and when he was, he called him, asked him and he was like 'yes I know I did it on purpose so we can be together'.
(3s)

FG1, 36-49.

K11: I do not think imprisoning is... I also think that taking people to prison is going too far. Too far. But at the same time I do not know what kind of punishment should be. *Hesitation and silence*. You know, if somebody does it really deliberately. Deliberate, so that I really want to infect people, I do not want to be alone, that is wicked. That person needs to be locked up. He may not be well in his head, there would be some problem.

K11, 128-133.

Mental health issues were discussed in FG3, in relation to disclosure and the debate revolved around an outcome-related or a mitigation view. As neophytes, participants were rather subtle in the way they approached forensic and mental aspects related to transmission, considering both individual difficulties to disclose or the criminal procedure. They started by acknowledging the difficulty to disclose and cope with the diagnosis:

P2: I can understand mentally. *Voiceover*. But the other person would not see it that way, you put them at risk. And that is not fair on the other person.

P5: It is not fair on the other person but...

P3: It is not fair... You are living with HIV and you are not going to tell them... But you should.

P5: I can see the other side, because, mental health is a bit down the line. Mental health is a bit of an issue in itself.

P3: Yeah mental health issues...

P5: Will you stop interrupting me! (...) Mental health is a big issue in itself that can cause a lot of problems, in itself, so I can see it from both. You do not want to infect him, but that could cause you even more...

I: Distress?

P5: Yeah, and, it is like a 50-50. You do not want to get him done, so you are not like intentionally out there, uh, I am going to transmit HIV, but on the same respect... Everyone gets sexually frustrated at some point. And it is going to be upsetting, when you get HIV. I suppose you do not want to tell anyone you have it, but, I suppose you are going to have a lot of mental health issues about it. It is a big one.

FG3, 669-774.

While participants displayed empathy with people living with HIV and mental health difficulty was mentioned as a reason not to disclose, P4 stated that this should not entail the criminal liability, however, the conversation went on the alleged mental health difficulty, eliciting doubts on the veracity of mental health difficulty claims:

P4: I think that, regardless of someone mentally ill, it should be treated, under the law, it should be treated the same. So the prosecution should be the same, the rehabilitation should be different. So, if it is deemed that what has happened is the result of that, then maybe, whatever, not punishment, but whatever sentence they get should reflect the treatment incorporated in it. But I still think that in principle, it should be treated the same. Initially.

P5: Good point, to be fair. But, in all respect, there are some people out there who can just claim they have mental health issues...

P2: Some people just blame the mental health on everything though. They use it... I think a lot of people just use it as an excuse, a lot more than they should. (...)

P5: Yeah, but it is not only that. Some people, have they done something wrong, they will just go, oh, I have mental health issues. *Voiceover*.

I: You still have forensic expertise in judicial context. So, you will be evaluated at some point.

P3: I do not remember, but this case, half of the team was saying that he has mental health issues and the other said he did not. I do not know, but it was a case like that. So what are you supposed to do then? It is not always this clear.

FG3, 717-722.

The question of mental health issues was developed by KI5 when discussing the exposure to HIV:

KI5: It is like I said, it is their mental state. It is got to be their mental state. Because if they are not fully understanding the consequence, no, no. Should not be. There is a mental health issue.

I: So someone let us say, living in the denial of the condition?

KI5: Well I do not know how you can live denying it. Because if you are denying it then you are not taking your medication. If you are taking medication, you cannot deny it. To me, if you are in denial, then you are not taking medication. You know sometimes I forget but I make sure I catch up. You know it is always going to be about the outcome, outcome if you take your meds and if you do not. I will argue that, I mean, it goes back to if the person is in denial, they are not taking the medication. If the person has accepted it, they are taking their medication.

KI5, 294-303⁸³.

Finally, one KI stated that there might be a mental health issue when the transmission was intentional:

KI7: (...) I think anyone who does do it there must be something wrong with their mental well-being at some level. Hum (...) I do not think you can be, I do not want to say like a sane person but. It is not normal to want to hurt other people like. Whatever it is.

KI7, 77-81.

6.2 Research Question 2: HIV-Stigma, Social Representations of HIV and People Living with HIV

For the purpose of this study, this section summarises stigma-related features and perceptions of people living with HIV from FGs and interviews.

⁸³ Despite anachronistic, this excerpt is quite interesting to relate to the Daryll Rowe's case and the debate or claim of denial of one's condition. KI5 alluded several times to this case, before it was ruled (Spring 2017).

6.2.1 FGs' participants from the general public

Knowledge of HIV

While the routes of transmission and use of condom as protective strategy were known, participants insisted on generic sexual health educational needs. They also acknowledged their lack of knowledge regarding HIV:

P1: I think with HIV, is like... I think people fear more. I do not really know that much about it. For me, for me it is like game over, I think maybe because we are less educated. A cold is like, not that feared...

P2: I think people are not educated enough when it comes to HIV.

P3: I do not know nothing about it. *Voiceover*.

P2: I do not know a lot about it all.

P5: When I had the questionnaires, I just put down numbers but did not have a clue.

P3: I was just like, going to write anything down, that...

I: So what do you know about HIV?

P2: I know it is an STI and that is as far as it goes really. *Voiceover*.

P1: Human immune, human immu-no-de-ficiency virus.

P1: I just know it just weakens your immune system. Like you can have HIV and die from a cold, you know what I am saying. That is the cold that killed you, but it is HIV that brought you down in the first place.

P2: I get that... because you can be positive, can't you? I do not get it. That is what I do not understand.

FG3, 103-119.

P2: If you give birth, you can pass it on to the baby.

P4: Yes, but they had unprotected sex before.

P2: But the baby did not. *(Laughs)*.

I: Actually most of the women giving birth, I mean, women living with HIV, give birth to non-HIV babies.

P2: Really?

I: Yes, because the treatment during pregnancy is preventing vertical transmission.

P4: I thought you just had a C-section.

I: You have fewer risks, but still, you will give birth to a healthy, not living with HIV baby.

P4: I am ashamed of my answers. I have no idea.

FG4, 6-15.

P4: It is curable, to a certain extent, isn't it?

I: It is not curable, but it is a manageable chronic condition.

P3: I think someone has been cured from AIDS. Or HIV?

P4: I thought if you caught it early...

FG4, 82-86.

The participants were asking questions and seemed surprised by some medical advances, for instance regarding the prevention of vertical transmission. However, even though this information promoting the idea of HIV as a manageable condition was given, participants expressed strong feelings when imagining themselves acquiring HIV.

If I was acquiring HIV...

When imagining being diagnosed with HIV, participants tried to foresee their reactions. These moments were those with the most intense emotional content, participants evoking shame, anger, guilt, self-blame and despondency; shame and anger were the most frequent. In the FG1, there was even a debate regarding what emotions one should feel:

P2: Ok, if tomorrow I get, I do get it because I had sex with a random guy... It is hypothetical darling (to P3). I would be ashamed, not because I have it, because I've been silly, because you know the risk, you do not know everyone and a lot of people are just going out and sleeping with guys maybe one day they wake up they'll be tested and they will have AIDS. (2s) And I, if it was me I would be ashamed because I have been silly. I ruined my life because I slept with this guy

P1: I would not be ashamed, I would be very mad at myself. There is nothing to be ashamed.

P2: I would be ashamed for having been silly.

P1: I would be mad at myself.

P2: Yeah mad as well, but it does not mean I will not be ashamed (3s). You can be both actually. I would be furious at myself but I would still be ashamed, not because of the fact that I have it, because of the way I got it.

FG1, 148-159.

P5: See, me, from a personal perspective, if I got HIV, I would not have sex with anyone anyway. Because I would not want them to go through what I have been through. So I would just not have sex for the rest of my life, and just deal with it the best I can.

FG3, 749-751.

P4: My only issue would be, if the person knew they had it, even if we were protected I would still be angry that he did not say anything. You know what I mean. Because they took a risk with my life. Not necessarily death, but it is changing my life without consenting with me. It would be the same like if cancer were transferable.

FG4, 444-447.

Across the four FGs, some stereotypical features appeared as to how participants characterised the people acquiring HIV, enacting judgements regarding the route of acquisition. These stereotypes included the reckless person, the stupid person, the uncertain or concealed person, and the liar, or a combination of these:

P1: Very important. And one thing I always had in the back of my mind was my parents... I would hate to think that I gave my parents that pain, and die young of a very reckless act. For the sake of what? 30, 40 seconds of pleasure? That is mostly what male orgasm may last...

FG2, 689-691.

P1: That is the bisexuals! (*Laughs*)

P2: Hum?

P1: That's because of the bisexuals!

P2: Ok we know who to stigmatise now! *Laugh*

P1: There you go you do not know where you are, the men, the women, there it goes... (*Laughs*).
FG1, 226-234.

P2: (...) Because I'm an adult, I'm a sane mind, you know I have a fully conscious mind and all my cognitive process is working very well, I have no reasons to find any other, you know, avenue to blame for my own infection apart from myself and my own carelessness. Right? There is another issue which is very very complex, which, as I said, I think most of society is unaware, including the aspects of heterosexual society, which is the enormity of heterosexual men, inverted comas, who are having sex with other men, and their female partners haven't got a clue about it.
FG2, 90-96.

P4: So you could argue that you did not know.

P2: Yeah, but those individuals just do not get tested. And continue to go around having unprotected sex.

P4: Yeah.

P2: In that case, they are doing something wrong because it is careless. Their excuse is oh, I just did not know, when it is quite easy to go and find out. Yes, they should be criminalised in that instance.

FG4, 73-79.

P1: I think you are responsible for having unprotected sex in the first place.

P2: Yes, but I cannot kill myself for each mistake...

P1: Of course.

P2: So, let us say, I do not kill myself. The next step, I realise that I made a very stupid thing, so I realise this, next step, I am still alive, so, next step is just to go to the clinic. So the fact that I am aware, or not aware, if I know that I could be positive, or negative, makes me responsible. It is not to know or not to know, it is just what I do not know but could. If my partner lies to me, it is another thing. But if I had unsafe sex, this is different for me.

FG2, 974-988.

Through these stereotypes, an archetype of the reasonable person is implicitly sketched.

Developing their views and feelings on HIV acquisition, participants enacted judgements related to unsafe sexual practices (e.g. irresponsible, reckless). Conceding their own unsafe sexual behaviours, some participants accepted to be considered as reckless and were even self-judgemental, while some reaffirmed the stance that disclosure should be mandatory as a solution to possible HIV acquisition. The emergence of potential prejudicial or stigmatising discourse and/or attitudes during the FGs has to be better understood through further research.

Stigma and the precedence of personal experiences

Stigma was primarily expressed through personal experiences and reported stories, most of the time unrelated to HIV. The precedence of the participants' own experience seemed to put HIV stigma in the background, stressing the primacy of personal experiences even when the topic is unrelated.

Stigma was not explored *per se* from the participants' perspective, however, it spontaneously emerged in all of the FGs. Participants were primarily talking about the stigma they experience(d).

Personal experiences of stigma covered a wide spectrum of features, such as smoking:

P2: I am waiting for the day, someone's going to file for that, believe me I do not think they will prove anything.

P1: Yeah that is true though.

P2: I wish, I almost wished it would happen to me, because smokers are stigmatised. (...) People insult you in the street.

P1: Yes or they pass you in the street and (*coughing exaggeratedly*).

P2: Yes, you could say it is harassment, it is the same, and air belongs to everyone street belong to everyone, you see me smoking, you have the choice just pass your way, as simple as that. It is not like I am hiding when I am smoking... To me, I am thinking one day, if it ever happens to me, I will be like... prove it!

FG1, 661-673.

Eventually, stigma related to sexual orientation

P1: (...) Actually, in XXX, I was called into the office, because I had, you know, little illnesses, one after the other, you know, I had a cold then an infection, then I had this then I had that. And for about 3 months, I was ill at work and my boss actually called me, and said there were concerns. I know what it is, I was ill, I had just been through difficult times, and it probably affected my job, and he said yes, but the people at work are concerned because they think you have AIDS. And I was absolutely horrified. Horrified! Because, I knew I did not have AIDS, I knew I was not HIV positive (...) But immediately just because I was gay, I was stigmatised because of that. You see anybody else in the group, it was not a hospital, it was a home for people with learning disabilities, if they had gone through the same, and the thought would not have crossed their mind, because they were heterosexual.

FG2, 674-696.

Personal references were used by participants in comparison with or to understand the stigma experienced by people living with HIV. Off the record, some participants shared the stigma they experienced in association with mental health issues but also cancer. While in FG1, participants were sarcastic and stated that stigma was inherent in everyday life. Participants who shared a sexual orientation and health-related stigma showed more identification with and understanding of people living with HIV.

Perceived stigma

All the participants showed awareness of HIV stigma (perceived stigma), mostly in reference to the gay community, but also due to the routes of transmission and judgements on behaviours likely to lead to the acquisition of HIV:

P5: It is like P4 said. There is a difference between your behaviour and how you are born with something. You always see on the news, and films, drug users they are tested for HIV when they have a baby.

P2: Gay people are pinpointed for AIDS as well a lot of the time. Gay people are associated with having AIDS, not so much because it is... But obviously, years and years ago, gay people were disgusting because they were associated with AIDS.

FG2, 854-859.

P3: I think it is more about the label. Because if you know you have HIV/AIDS, you are going to be labelled by society. *Voiceover*. Basically, we can say that nobody really like people with HIV/AIDS. That is just the case.

FG4, 379-381.

P1: Yeah because, obviously having HIV is still something that is, a lot of people feel ashamed about it, they do not see it as a normal sickness it is not like cancer where, when you get out of it you are seen as a hero 'oh my god you got cancer' when you get HIV you are a nasty dirty person basically.

P2: Oh, no, no you are an unlucky person.

P1: Hum. But in the eyes of society, until not very long ago and still today... (*Restaurant noise*).

I mean still today there is a lot of unsaid about HIV, people still feel ashamed of it

P2: It is because of the way it is transmitted.

FG1 96-103.

P1: In the collective conscience I am quite sure AIDS is a shame because it comes from the gay world (P2: Hum) the same way syphilis from the whores.

FG1, 245-246.

While participants were able to perceive the stigma experienced by people living with HIV, they also enacted some forms of stigma, most of the time when making jokes or sarcastic comments.

Possible stigma enacted during the FGs: avoidance and distancing

During the FGs, there were moments that could be considered as the emergence of stigmatising views, or prone to giving rise to stigmatising attitudes. It was chosen not to intervene for two main reasons:

1. The aim: this study is a research aiming at capturing and understanding the relationship between stigmatising and criminalisation views, not an intervention aiming at addressing potential stigma. Furthermore, the phenomenon studied is mostly a silent one and it cannot be addressed without a thorough understanding of it.
2. The safe space of the research FG: participants agreed to take part and share their views, and they are entitled to be authentic and/or not politically correct⁸⁴, whether related to language use

⁸⁴ That goes without saying that the law constitutes the limits of what was acceptable or not; verbal abuse, incitement to hatred or any other discriminatory behaviour would have been reported.

or the development of personal views. It was also considered that given the sensitivity of the topic, the expression of such views could be discussed and questioned by the other participants.

In terms of language use, the use of the adjectives “clean” or “clear” to mean HIV-negative was recurrent. Participants were also using idioms such as HIV people, positive people, AIDS, but at the end of the FGs, some of them had implicitly adhered and were using the idiom “people living with HIV” (FG3, FG4). This sort of language permeability highlighted how linguistic practices fall short of intention and can be influenced. It also captured the perpetuation of language use considered by others as offensive. Eventually, the use of the adjectives stupid, mad, sick mind, reckless, careless in relation to acquiring HIV had strongly negative connotations.

Induced by the theme of the sexual transmission of HIV, the theme of intimate relationships arose initially in the context of a sexual encounter:

- P5: (...) But then, are they going to tell you, especially in the moment, you know, they're not exactly going to turn around and say, yeah I have HIV, because that would be awful, no one would sleep with someone living with HIV. Well, it is my personal opinion. Because I would not sleep with someone who has HIV.
- I: Would you not? Even with condoms and knowing the person is treated and has a low viral load and risk of transmission?
- P1: I would not either.
- P3: No.
- P4: No
- P2: Because there is still that chance.
- P1: So, the orgasm is not worth it, you know what I am saying. I would rather have a wank.
- FG3, 272-282.

The same topic was evoked again later, in the context of a long-term and loving relationship:

- I: So it is not just about sex, if someone you learnt to know the person, and before having sex the person you are falling in love with is telling you, “we have to talk, I'm really sorry I didn't tell you before, I was afraid of telling you, I'm living with HIV”. What would you do?
- P3: I think that is good.
- P1: I know it sounds bad, but I would personally stop it... I feel sorry for people, I do feel for you, but it is for me, it is like someone with a criminal history, you know someone saying like I'm a criminal, I'm an offender, it is the same thing, I'd personally, I guess, I would, no disrespect, but there's too many women out there. It is, I wouldn't, as sad as it is, I, I, I wouldn't actually go away, I'd still be friends with that person, but I wouldn't want to take it any further.
- P2: It is difficult because you do not want to shame the person, at the same time, you do not want to put yourself at risk. Then... It is difficult. Because you do not want to hurt the person either, but I would just walk away.
- FG3, 293-304.

Instances in which participants were questioned about their stigmatising views or attitudes became a point of interest. Two moments have been chosen on the topic of having a relationship with a person living with HIV. At the end of FG3, one of the participants was asked about his potentially stigmatising attitude:

I: So you were saying that you would not have sex with someone disclosing she is living with HIV. Do you feel like you are stigmatising the person?

P1: It could be seen as that, and if it does I do apologise to that person but, it is a case of, I am meeting with a human being whereby I am so sexually attracted to, and all I have to do is... For me, sex is great, but it is not like I need to do it. I would rather not... It is not worth the orgasm.

I: But you can consider, you would admit, it is a form of stigma?

P1: Yeah, I do appreciate it can be, and I am going to apologise, you know, I have to look after myself primarily and unfortunately, and if looking after myself I am stigmatising, I will apologise to that person. Again, I have nothing but sympathy, honestly, sympathy for people who are in that situation, but for me personally sex is not worth it, in the sense that I do not like it enough to do that. So... Does that make sense?

FG3, 819-829.

P2: (...) What would you do if you were on a date and the person would say something like that?

P1: I have no idea. I would like to say that I would not care and, but I do not know. I cannot say that now, because I would be lying. This is what I would like to do, but I do not know. On the other hand, of course I would be afraid of... Well, if it were someone I really really like, someone that I was in love with, maybe I would consider it more, but as P4 said...

P3: I would not be in love anymore. Seriously. I am just honest.

P1: I do not know, I just think that is something that we can only say when we get through it.

P3: That is sad.

FG4, 589-597.

In these two FGs, all but one of the participants agreed that they would walk away from someone living with HIV in the context of an intimate relationship. The fear of *being given HIV* is to be differentiated from the fear of acquiring HIV, in the sense that the speakers in the former situation are considering themselves as passive. It also localises responsibility on the transmitter rather than on the acquirer, which refers to the stances adopted on responsibility discussed previously.

Eventually, the presence of the innocent-guilty dichotomy has to be noted, as it seemed to guide how participants might perceive someone living with HIV. Such a view was espoused at the outset of the conversation in FG1. When FG1 participants were asked to imagine the situation in which their friends would transmit HIV onward, they were puzzled. This was an unthinkable situation; FG1P1 and FG1P2 insisted on his safe-sex practices, the only possible context for transmission being the bad luck of a condom accident. One participant in FG3 tried to respond to the moral stigma attached to it. FG3P4 was responsive to the interpretation suggested, and linked the innocent/guilty dichotomy to the one's actions leading to acquire HIV:

I: So would you relate the context of transmission to any moral judgement?

P4: My moral judgement? (...) Yeah, I think there is a moral judgement there. I think there is like... Is it moral judgement like in am I judgemental? When I say that, or is there any preconceived notion behind that?

I: I think it would be both because, in what I understand from what you are saying, when you say born with it, there is no, as you said, action of the person. However, if there is an action of the person, we were talking about responsibility, and it is her/his responsibility because of her/his actions. (...). There is a step further, the guilt or the fault the person would have done. (...) The innocent and the guilty one.

P4: I think if you word it like that, then yeah. I think, I do not know, it is just personal experience. I am not saying not guilty and guilty, or innocent and guilty, but there is a proportion of people within that went out did not use a condom, had sex and got HIV. In addition, I think that is completely different to someone being born with it; it is just what they have been born with. FG3, 789-807.

6.2.2 Key informants

This section regarding key-informants is synthetic. KIs' substantiated views were based on an accurate understanding of HIV (medically and socially) and/or an accurate and comprehensive understanding of the Law. All but one (KI2) provided insights on the lived experiences of people living with HIV, whether personal (KI1, KI3, KI5, KI7) or reported (KI4, KI6, KI8, KI9), whether focusing on the daily management of a chronic condition,

KI1: (...) It is a life sentence we are talking about. It changes the whole life of yours. Your life will never be the same. You are going to have to think about so many things. Some things... Sometimes you find yourself isolated, you cannot socialise, because you have to go back and take medication. And your medication makes you feel bad. And the thing with being positive, for some people it is not only HIV, you have other complications. You take other medication for other stuff, so it is double problem, on top of HIV. So it is not a good thing to infect people. KI1, 156-161

The social stigma,

KI: Yes, yeah. It is not only the medication for life; it is also, with what goes on with the condition. There are a lot of things, like stigma and all that. You know. Because, the condition is associated with many things, like prostitution and that kind of things, so really. KI1, 188-190.

Or specific aspects such as perceived stigma and the innocent/guilty dichotomy, (KI3, KI4, KI5, KI6), anticipated stigma, loneliness (KI3, 306) and stigma experiences,

And as you go out, into places like, where I live in *XcityX*, I think that I wouldn't, I do not really go out in the scene in *XcityX* anyway, but I think if I did, I wouldn't want anyone to know about my HIV status. Because it is a very small scene, and gossipy. I think that, again, there are very judgemental attitudes. And I think, then again, when you go further out in smaller regions... You know. I remember somebody who was a volunteer at *XnameX* a local gay charity in *XcityX*, he'd

go around on world AIDS day with a bucket for money in *Xsmaller cityX (coughs)*, and some guy came up to him and said “yeah, but they deserve it really, do not they”, in a gay bar.
KI3, 69-75.

Mirroring the rejection of a partner living with HIV (FGs), the experience of rejection after disclosure was pointed as silencing:

KI7: You mean why do people not talk about it? I think it is fear and it is the stigma, which in itself can be quite hard to think about sometimes. So sometimes, I mean, there is that fear of being discriminated against or being persecuted. And the fear of being alone. Because if you talk about it, people, no one is going to want to know. And. I think. That is why people do not share their status. They do not talk about it, or they will just tell some people. Because it is just, you are already in that perception and prejudice. However, when you actually go through, hum, talking about it, to have that rejection, that is the actuality of what is happening. And once they have experienced that once, they do not want it again and they just close up. And they will not talk about it.
KI7, 32-41.

Eventually, structural stigma was denounced:

KI3: (...) So, that’s also kind of what happens with HIV, with an idea of quarantine, with you know, I could not travel to the United States, I could lie but... And if I was carrying medication, there is always the possibility of somebody stopping me and sending me back home. And you know even now, you require HIV test to get into Russia for example, there are plenty of other places, so there is still quarantine type laws around HIV. And it is still seen as a quarantine disease within many jurisdictions.
KI3, 245-251

Perceived stigma regarding origins, ethnicity, and sexual orientation emerged in almost all the interviews. Given the disparities in terms of educational level and professional background, such a homogeneity seems related to the familiarity with people living with HIV and sexual health knowledge. KIs tended to remain focused on the topic and did not digress that much, even though analogies were present. Even when pro-criminalisation views were sustained, there was little to no blame or shame in the discourse, however, two main features arose.

The first was the consequentialist view that living with HIV can be difficult and, therefore, can stand for a harm or prejudice. However, in the discourse of KIs, it was disconnected from any judgement on the route of acquisition. Secondly, when the deliberate and intentional transmission was discussed, six of nine of the KIs insisted that it was a residual phenomenon, and two of them highlighted the underlying “mental health issues” ([section 7.2.3.2](#)). This was the only form of possible stigma found in KIs.

6.3 Research Question 3: Effects of Participation on Participants?

6.3.1 Pre-assessment data

Questions

Half of the participants (50%) reported that people are responsible for their own health (Q1 'yes'); the other half (50%) shared the same view but mentioned other aspects such as educational level and social inequalities likely to affect their health (Q1 'other'). The majority of the participants (78%) reported that people living with a long-term condition should be protected by society (Q2 'yes'); remaining responses specified conditions or provisions (Q2 'other').

Standardised scales scores

The control group (n = 14) was used to characterise participants who agreed to take part in the focus group. Descriptively, KIs showed lower global stigma scores, lower social desirability scores and higher knowledge scores than other participants (FG and control group). Scrutinising the subscales' scores, KIs had higher perceived stigma scores and Participants of the FGs showed lower scores on all but the social desirability score.

Given the small sample size, establishing the normal distribution of each group was not possible. Therefore, the Kruskal-Wallis test was used to assess the intergroup differences (KIs, FG participants and controls). Results appear in [Table 8](#). There was a significant difference between the scores of the three groups:

- in the Blame Stigma subscale ($H(2) = 8.478$, $p = .014$) with a mean rank of 10.06 for KIs, 22.43 for FGs participants and 21.32 for the control group.
- in the Perceived Stigma subscale ($H(2) = 7.473$, $p = .024$) with a mean rank of 27.39 for KIs, 15.25 for FGs participants and 17.36 for the control group.
- in the Knowledge scores ($H(2) = 8.710$, $p = .013$) with a mean rank of 25.94 for KIs, 12.96 for FGs participants and 20.57 for the control group.

Table 8 Mean scores and standard deviation (SD) for pre-assessment variables and intergroup difference

Group	Stigma score				SDS-17 total score	Knowledge score (/1)
	Blame scale	Perceived stigma scale	Equity	Total		
Key Informants (n = 9)	11 (2)	24.22 (3.53)	4.22 (.67)	39.44 (.78)	6.89 (3.48)	.56 (.17)
FG participants (n = 14)	13.07 (1.54)	20.21 (3.7)	5.36 (1.45)	38.64 (3.08)	8.50 (2.57)	.143 (.17)
Control (n = 13)	14.23 (3.9)	21.46 (3.28)	5.69 (2.14)	41.38 (5.4)	7.31 (3.1)	.33 (.2)
Total (n = 36)	12.97* (2.9)	21.67* (3.76)	5.19 (1.67)	39.8 (4.1)	7.86 (2.81)	.31* (.3)
<p>Note. ^a Kruskal Wallis test * p<.05</p>						

Exploring the intergroup differences, a pairwise comparison was performed using Scheffé's posthoc test (equal variance assumed and small sample size⁸⁵). The Blame scale scores were significantly different ($p = .034$; CI 95%) between the KIs ($M = 11$, $SD = 2$) and the control group ($M = 14.93$, $SD = 2.9$) only. Perceived stigma scale scores were significantly different ($p = .04$; CI 95%) between the KIs ($M = 24.22$, $SD = 3.53$) and the FGs' participants ($M = 20.21$, $SD = 3.7$). Knowledge scores were significantly different between the KIs and the FGs participants ($p = .003$; CI 95%). The control group showed a higher blame subscale score and a higher knowledge score than participants in the FGs. This allows describing the participants from the public who took part in the FGs as less knowledgeable and less blaming than the control group. This will be discussed in terms of recruitment and sampling biases ([section 7.6](#)).

Screening experiences

In terms of screening experiences (see [Table 9](#)), the three groups were similar; only the age at first and last screening differed substantially. Six participants disclosed they had never been tested for an STI or HIV; five reported not knowing where to be tested in the area they lived. For the majority of the participants, the first screening experience was reported as a positive experience even though shyness or anxiety were noted. Six participants reported negative experiences from staff when being tested, such as feeling judged or moralised (Screening Question 10),

⁸⁵ As a precautionary measure, Tamhane T^2 posthoc test (unequal variance and small sample size) and Bonferroni test (non-parametric post hoc analysis by adjusting the p-value) were performed. The same significant results were found. Scheffé's test was deemed the most appropriate (Shingala and Rajyaguru, 2015; Shingala and Rajyaguru, 2017).

Homophobic doctor with little awareness of how to approach my experiences.
K14

Regarding the last screening, five participants reported a negative experience, for instance
(Screening Question 12):

Incredibly unprofessional and showed racial bias. They talked about how black men were promiscuous, tended to be the ones to have unprotected sex but had the highest statistics of STIs. Control Participant 4, Screening Question 12

Judgemental, arrogant, complacent and unprofessional, plus irresponsible.
FG2P1

Table 9 Distribution of participants' answers to screening questions

	KIs / interviews (n = 9)	Public / FG (n = 14)	Control (n = 14)	Total (n = 37)
Age range at first screening	17-41	15-34	15-24	15-41
Felt like professionals were judgemental at first screening	40%	21%	7%	17%
Age range at last screening	29-57	22-51	20-35	20-57
Felt like professionals were judgemental at last screening	10%	7%	8%	8%
STI and/or HIV screening test as part of yearly check-up	66%	29%	15%	33%
Ever been to a Sexual Health Clinic	77%	85%	62%	74%
Know you can get tested for free in NHS clinics and Trusts	100%	79%	85%	86%
Know where to get tested in living area	89%	93%	69%	83%
Ever diagnosed with an STI	22%	14%	15%	17%
Diagnosis changed the frequency of STI or HIV screening	0%	14%	15%	11%

6.3.2 Responsive evaluation

Participants' feedbacks after the FG/Interview

Overall, the debate was considered sensitive or difficult. Six participants (FG3 and FG4) reported that the debate changed their initial opinion. During the direct feedback after the FGs, participants expressed either how they adjusted their views on people living with HIV,

I thought people living with HIV is their fault and their responsibility to tell. (...)I feel sorry for them and the stigma that comes with it.
FG3P5

Or how they experienced the FG,

It involves personal opinion. It can be a sensitive topic depending on people's background and personal experience. Not a sensitive topic for me, however, it is difficult as it does involve moral matters and one's expectation about society.

FG1P2

I feel frustrated when other people think something different that I think is unfair, but I cannot change them...

FG4P1

I feel like I learnt a lot about it. It is a tricky subject, with blurred lines that are context dependent. FG3P4

Two of the KIs declared a change in opinion or in their arguments. The discussion was said to be important and/or sensitive. All of them developed their opinion in the comments, summarising their views or feelings:

I feel it is difficult to balance questions of individual justice with greater public good and individual's well-being with the virus.

KI3

Still feel the same, but maybe with more questions.

KI7

Fear of generalising a very complex issue.

KI9

Restitution session

The restitution session occurred within 3 to 18 months after the FG/interview. All the FGs' participants who completed the restitution form expressed an unchanged opinion on the topic, except one:

I went into the group discussion with a view based on what I believed was right but listening to other people's opinions and viewpoint made me think about how the situation could be different. I was able to put myself in somebody else's shoes. This gave me an alternative viewpoint and helped me to appreciate how complex some instances of transmission can be.

FG4P2

Nevertheless, for those who did not change their views, the conversation and diverse arguments were described as an opportunity to reflect more or to further their argument.

Not sure if they evolved, however, they were analysed deeply, and I would not have done this analysis if I was not taking part in this research. However, I do not think I changed my opinion either. FG4P1

Post-assessment and restitution feedback showed agreement in terms of participants' perception of themselves. However, if the opinion on the topic discussed did not change, standardised scores showed different trajectories.

6.3.3 Exploratory statistical analysis

Given the small sample size, correlation and regression were not relevant. Nevertheless, Kruskal Wallis test was used to assess the potential effect of specific factors on standardised measures during the pre-assessment. This is not a parametric analysis but an exploration for further hypotheses.

Familiarity with people living with HIV:

Based on the contact hypothesis data from the pre-assessment were analysed ([Table 10](#) and [Table 13](#)). After dichotomising the sample ($n = 37$) according to their familiarity with people living with HIV: familiar ($n = 17$) and non-familiar ($n = 20$) (knowing or not knowing someone living with HIV, respectively), a significant difference between the two groups was found:

- in the Blame Stigma subscale scores ($H(1) = 4.982, p = .026$) with a mean rank of 14.76 for familiar participants and 22. for unfamiliar participants.
- in the Equity Stigma subscale scores ($H(1) = 4.106, p = .043$) with a mean rank of 15.53 for familiar participants and 21.25 for unfamiliar participants.
- in the Knowledge scores ($H(1) = 5.742, p = .017$) with a mean rank of 23.53 for familiar participants and 15.15 for unfamiliar participants.

Views on criminalisation: stigma scores and knowledge

Further to the qualitative analysis participants ($n = 23$) were categorised into three groups regarding their views on criminalisation: pro ($n = 10$), anti ($n = 11$) and uncertain ($n = 2$). There was a significant difference between the scores of the three groups:

- in the Blame Stigma subscale ($H(2) = 6.553, p = .038$) with a mean rank of 14.35 for participants holding pro-criminalisation views, 8.55 for those with anti-criminalisation views and 19.25 for uncertain participants. Blaming tendency is associated with pro-criminalisation views.

- in the Knowledge scores ($H(2) = 7.056, p = .029$) with a mean rank of 8.10 for participants holding pro-criminalisation views, 15.73 for those with anti-criminalisation views and 11 for uncertain participants. A lower level of knowledge is associated with pro-criminalisation views.

6.3.4 Analyses of repeated measures

Descriptively (Table 10), two tendencies can be observed. The first one is the increase of the perceived stigma score (57%), and the decrease of the blame scale score (50%) in FGs between the pre- and post-assessment. Overall, long-term consistency was not found between pre- and post-assessment and/or restitution. Participants who described themselves as more empathetic showed decreased perceived stigma scores; two participants who showed decreased blame scores during the post-assessment had an even higher score for the restitution session.

To explore the difference within participants who completed the full study (Table 11), a repeated measures ANOVA with a Greenhouse-Geisser correction determined that Knowledge scores differed statistically significantly between time points within subjects ($F(1.946, 13.619) = 3.259 = 21.032, P < 0.0005$). Post hoc tests using the Bonferroni correction revealed that the difference between pre- and post- assessment scores ($.38 \pm 0.28$ vs $.44 \pm 0.36$, respectively) was significantly increased ($p = .0005$). The difference between post-assessment and restitution session ($.44 \pm 0.36$ vs $.12 \pm 0.18$, respectively) was significantly decreased ($p = .0005$) while the difference between pre- and restitution assessment was not statistically significant ($p = .115$). This might indicate that the discussions operated as a familiarisation intervention, and making participants more sensitive to the challenges faced by people living with HIV.

Table 10 Participants' scores of repeated measures (stigma, social desirability, and knowledge) and intergroup differences

Assessment	Sample	N	Stigma scores				SDS 17	Knowledge scores
			Blame subscale	Perceived stigma subscale	Equality subscale*	Total		
Pre-assessment	KIs	N = 9	11 (2)	24.22 (3.53)	4.22 (0.67)	39.44 (0.78)	6.89 (3.48)	0.56 (1)
	FGs	N = 14	13.07 (1.54)	20.21 (3.7)	5.36 (1.45)	38.64 (3.08)	8.5 (2.57)	0.143 (0.4)
	Total	N = 37	12.97* (2.9)	21.67 (3.76)	5.19* (1.67)	39 (4.03)	7.86 (2.81)	0.38 * (0.28)
Post-assessment	KIs	N = 9	10 (0)	24.44 (0.87)	4 (0)	38.44 (0.87)	Not applicable	0.67 (0.3)
	FGs	N = 14	12.57 (2.21)	21.93 (4.78)	4.86 (1.17)	39.64 (3.08)		0.27 (0.28)
	Total	N = 23	11.57** (2.92)	22.91 (4.19)	4.52 (0.99)	39 (4.95)		0.44* (0.36)
Restitution assessment	KIs	N = 1	10 (0)	26 (0)	4 (0)	40 (0)	1 (0)	0.2 (0)
	FGs	N = 7	13 (2.31)	20.43 (3.65)	6.14 (1.07)	38.57 (5.2)	7.5 (1.87)	0.32 (0.15)
	Total	N = 8	12.63 (2.38)	22.03 (3.9)	5.88 (1.25)	39.63 (4.8)	6.57 (2.99)	0.12 (0.18)

Note.
a Kruskal Wallis test
 * $p < .05$
 ** $p < .005$

Table 11 Participants' individual scores for repeated measures: increase/decrease from pre-assessment baseline

Participant	Pre-assessment							Post-assessment					Restitution					
	Blame scale	Perceived stigma scale	Equity scale	Stigma TOTAL	SDS17	K Score (/1)	Blame scale	Perceived stigma scale	Equity scale	Stigma TOTAL	K Score (/1)	Blame scale	Perceived stigma scale	Equity scale	Stigma TOTAL	SDS17	K Score (/1)	
fg1p1	12	22	5	39	7	0.4	10	21	7	38	0.6	12	24	5	41	5	0.2	
fg1p2	14	17	8	39	11	0	14	21	7	42	0.5	16	22	8	46	6	0.4	
fg1p3	13	14	6	33	12	0	12	18	6	36	0.5	13	14	6	33	8	0.2	
fg2p1	12	25	4	41	10	0.4	12	22	4	38	0.4							
fg2p2	11	14	7	32	8	0.2	10	8	4	22	0.4							
fg3p1	15	21	5	41	13	0	14	26	5	45	0.25	16	24	6	46	10	0.4	
fg3p2	13	23	4	40	10	0	13	23	4	40	0							
fg3p3	12	25	4	41	5	0	14	25	4	43	0							
fg3p4	12	24	4	40	5	0.4	11	23	5	39	0.75	11	22	7	40	7	0.4	
fg3p5	13	22	4	39	9	0	14	27	4	45	0							
fg4p1	15	17	7	39	8	0	15	21	4	40	0	13	18	5	36	9	0.2	
fg4p2	14	21	7	42	7	0.4	10	27	4	41	0.4	10	19	6	35	4	0.6	
fg4p3	16	18	6	40	5	0.4	17	24	6	47	0.4							
fg4p4	11	20	4	35	9	0.4	10	21	4	35	0.4							
I1	12	25	4	41	13	0.8	10	24	4	38	0.8							
I2	11	23	4	38	8	0	10	23	4	37	0							
I3	10	26	4	40	2	0.4	10	27	4	41	0.4							
I4	10	23	4	37	7	0.4	10	22	4	36	0.4	10	26	4	40	1	0.2	
I5	16	16	4	36	7	0	10	21	4	35	0.8							
I6	10	27	6	43	4	0.6	10	26	4	40	0.6							
I7	10	26	4	40	6	1	10	27	4	41	1							
I8	10	24	4	38	11	0.6	10	22	4	36	0.6							
I9	10	28	4	42	4	1	10	28	4	42	1							

Increase Decrease

6.5 Limitations and Biases

Limitations regarding this study are related to the recruitment, the sampling biases, the small sample size, and the lack of generalisability.

Recruitment and sampling

Regarding the sampling biases, the control group contained mostly people who refused or could not take part in the FGs and showed higher Blame scale scores and lower social desirability scores. This could indicate that people who declined to attend a FG might have been more prejudicial to people living with HIV. This might be an artefact of self-selection bias. The second is the voluntary sampling bias. Finally, FGs' participants showed higher social desirability scores than the control group (pre-assessment), this could also indicate that FGs' participants have a tendency to positively self-present (higher social desirability) might mitigate their initial scores.

Response rate (acceptance, attendance and completion)

While standards are common practice in quantitative studies (Fincham, 2008), consensual standards regarding acceptance and completion rates do not exist in qualitative or mixed studies. Furthermore, the sensitivity of the topic hardened the recruitment of participants, whether KIs or from the public. Only (57%) of the participants (KIs and FGs) completed the study.

Sample size and generalisability

In qualitative studies, recommended sample size ranges from 5 to 50 (Dworkin, 2012; Baker and Edwards, 2012) according to the topic, the design, the need for representation, the aims and objectives. The sample size is determined intuitively, based on experience (Sandelowski, 1995), or when reaching data saturation (Mason, 2010; Marshall et al., 2013). In the present study, the data saturation was reached at the third focus group and the seventh interview. While a small sample size is not considered as a bias in qualitative studies depending on the aims of such studies, it becomes an issue when using mixed methods. Therefore, the statistical analyses performed were non-parametric tests and only allowed for the description of individual trajectories regarding the variables repeatedly assessed. Despite providing an empirical ground to consider the potential impact of research, the generalisability is low if not null.

6.6 Summary of the Findings

Research Question 1: Views on the Criminalisation of HIV Transmission

Among the participants from the public (FGs), pro-criminalisation views were dominant. Pro-criminalisation views on the exposure to HIV also emerged. Poor knowledge regarding HIV was highlighted by both the standardised measures and the discussions, and participants enacted what could be a form of stigma during the FGs. Among KIs, anti-criminalisation views were the majority, knowledge regarding HIV and perceived stigma were higher, both qualitatively and quantitatively. With regards to the moral rationales, it is interesting to note that the same line of reasoning might lead to different conclusions, and conversely, the same conclusion is reached by apparently contradictory arguments. Therefore, it appeared difficult to map or associate an opinion with a certain type of reasoning or moral argument. This will be discussed in the light of the background chapters ([section 8.1](#)).

Research Question 2: Social Representations of HIV

FGs' participants enacted typical misconceptions and SR of HIV. Lack of knowledge was addressed when related to basic facts and participants seemed responsive, however, unable to recall the information during the post-assessment or the restitution session. The precedence of shame over other emotions and "stigmatising" moments from participants holding pro-criminalisation views seemed to argue for HIV prejudice as a ground for criminalisation. Globally, FGs' participants were concerned with STIs or HIV not being transmitted to them, insisting on the duty to protect the others for people living with HIV (e.g. one another to protect them); while key-informants tended to emphasise the individual's responsibility to protect themselves and not to acquire HIV. This framed different expectations in terms of disclosure and can be associated with the different perceived stigma subscale scores between KIs and FGs' participants. These findings will be furthered by a theme-oriented discussion on [knowledge](#), [disclosure](#) and [stigma-reducing interventions](#).

Research question 3: Effect of the research process

The tailored design allowed for the self-reported, responsive and standardised assessment of the effects of participating in the research. Three main features were observed. The first relates to the significant short-term increase of knowledge and the potential informative effect of the research on participants. The second refers to the descriptive increase of perceived-stigma subscale scores, indicating that participants might be more empathetic towards the challenges faced by people living with HIV. The third concerns the increase of the blame

subscale score, indicating a possibility to be more blaming towards people living with HIV after taking part in the study. The two first elements plead in favour of familiarisation effect of the research; the latter could reflect a possible negative impact. Given the small sample size, no conclusion can be drawn upon this analysis; nevertheless, this will be discussed in terms of [further research and methodological recommendation](#).

CHAPTER 7 - DISCUSSION

This study is the first qualitative study to examine the views of participants from the general public on the topic of the criminalisation of HIV transmission. This study is also the first mixed method study to assess the impact of stigma research on participants. The results have important implications for clinical practice and the understanding of the lived experiences of people living with HIV, for interventions and policies in terms of health and equality promotion, and for research in terms of ethical and methodological concerns.

This chapter first discusses the results in the light of findings of the review ([Chapter 2](#)). It continues with a discussion on the interaction of knowledge and stigma from an out-group perspective. It then explores the issues and challenges of concealed identities, and the link between knowledge, stigma and disclosure. The last develops the implications of the primacy of morality; further research and methodological recommendations are suggested.

7.1 Synthesis of the Findings

KIs' interviews provided comprehensive insights into pro- and anti-criminalisation rationales from knowledgeable participants. The three key populations (i.e. MSM, people living with HIV and professionals working with people living with HIV) found in the empirical review were represented ([section 2.3.3](#)). Globally, the same rationales (e.g. anti-criminalisation except in the context of deliberate transmission) and connected themes (i.e. disclosure, educational needs) were identified. Among the KIs (KI2 and KI5) who maintained a pro-criminalisation view, one was a person living with HIV; the other was a criminal justice professional. KIs also provided further insights regarding the reason to file or not file against, alluding, among others, to community identity, possible biases in the judicial system, and stigma.

By contrast, views from the public were mostly pro-criminalisation. Four argued an anti-criminalisation view based on principle (FG2P1), consequences (FG2P2) and mistake or possible miscarriage of justice (FG4P1). Only three participants developed substantiated views and showed awareness of the related moral aspects (FG2P1, FG2P2, and FG3P4). Only one participant demonstrated a high knowledge related to HIV (FG2P2)

In terms of common feature, both KIs' and public's views revolved around the idea of health as a standard and its the counterpart of illness and disease being a prejudice ([section 4.2.2](#)). The main difference was based on the social and legal responses to this new moral standard. KIs tended to promote other types of regulations (e.g. Civil Law) or reparations (KI6's proposition of restorative justice), except in the context of deliberate transmission. Alternatively, some participants from the public maintained a pro-criminalisation view on the criminalisation of HIV and STIs (FG3P4, FG4P3) arguing that any condition is deleterious and should be considered a harm. This seemed embedded in a more generic view on health and healthy living in general (Spoel et al., 2012). If health and a healthy lifestyle are posited as moral standards, the unhealthy behaviour and/or the external cause of the acquisition of a condition are likely to be blamed (e.g. Behaviourally Driven Health Conditions). This blame can be expressed as stigma (Corrigan, 2010), but it can also appear as a ground for a legal complaint and a legal liability.

In the present study, the problem of knowledge was discussed relative to the concept of responsibility. When participants differed concerning the criminal liability, all participants considered that a person who knows they are HIV-positive should be held responsible for the potential consequences of what they know. Such a stance highlighted a sort of double standard regarding who knows what, as to what one knows about oneself and what one knows in general; namely a person living with HIV knowing how onward transmission could occur, and a person not living with HIV knowing how HIV could be acquired.

Three main contexts are to be developed to identify the role of stigma in the impediment of knowledge. The first explores the public's knowledge of HIV, the public understanding of science and the public legal knowledge ([section 8.2](#)). The second unfolds the disclosure debate on two aspects mentioned by participants ([section 8.3](#)): disclosure of one's status (KI1, KI3, KI5, KI7) and disclosure of one's sexual behaviours (FG2P1, KI4).

With respect to the emotions involved, fear and shame were dominant. Fear seemed related to a lack of information and the uncertainty of certain situations. Stances on deliberate transmission were drawn upon assumptions on the personality of the one who would deliberately transmit HIV. This unveiled a strong underlying statement: human nature is good, and bad actions result from a mental health issue (i.e. the *sick mind* equates to the nasty one). This can be put in perspective with mental health stigma and the fear of people suffering a mental health condition (see sections 3. 4.3.3). This also pleads for the cumulative and intersectional nature of stigma.

Among FGs' participants, shame was by far the most frequent emotion, whether internally (feeling ashamed) or externally (shaming) attributed, whether related to acquiring HIV or judgments on one's behaviour. HIV-related shame, stigma and their relationships being already robustly documented⁸⁶, and shame being a moral emotion; this will be discussed from the perspective of the primacy of morality ([section 8.4](#)).

7.2 Knowledge, HIV and the Public Understanding of Science

The problem of knowledge is threefold: the knowledge of the law, the knowledge on HIV and more generally sexual health and the knowledge of or contact with people living with HIV.

(Lack of) Knowledge and the law

While KIs showed a good knowledge of the law and demonstrated their knowledge of criminal cases, FGs participants showed basic knowledge and little interest in the legal aspects.

Furthermore, it was highlighted in chapter that people living with HIV had a poor knowledge of the law.

Recent legal surveys in the UK highlighted that professed knowledge of one's rights might not always correspond to the actual knowledge (Denvir et al., 2013). While these studies on public legal education are large-scale surveys (Plesence et al., 2011), they provide constructive insights on how the law and the justice system are perceived (Plesence et al., 2015).

However, criminal law and aspects of the law that would be relevant with the topic of this study are not developed in the surveys aforementioned.

While specific legal training for both people living with HIV and professionals (Satriano et al., 1999; Beletsky et al, 2011) are documented, little is known regarding large-scale legal education actions or programme for the public. In relation to sexual health and the criminalisation of HIV transmission, Human Rights education might appear a promising area (Tinnits, 2002), at the intersection of human rights, sexual/reproductive health and relationships (Cook et al., 2003).

⁸⁶ See for instance Weston, 2003; Christensen et al., 2013; Skinta et al., 2014; Gordensky et al., 2015; Hutchinson and Dhairyawan, 2017; Walker, 2017.

(Lack of) Knowledge and sexual health

The majority of studies investigating sexual health knowledge in the UK are surveys in the general population or qualitative studies in vulnerable populations. The Third British National Survey of Sexual Attitudes and Lifestyles (NATSAL-3) found that lack of sexual competence and receiving sex education from a non-school based source were both factors associated with unplanned pregnancy (Wellings et al., 2013). Furthermore, people reporting being sexually active and deemed at risk of STIs did not perceive themselves as 'at-risk' (Mercer et al., 2017); finally, at-risk adults sometimes exhibit a lack of basic sexual knowledge (Dalrymple et al., 2016a, 2016b). These discrepancies highlight the challenges in the British population for whom knowledge on STIs and HIV appears basic in various sections of society⁸⁷.

The problem of knowledge related to HIV in the population can be understood from different viewpoints, at the individual and global level. In the context of the present-day in the UK, if knowledge and information are accessible to the majority of the population, the integration of this knowledge and modification of behaviours and/or attitudes is not granted and can be examined through the public's perception and understanding of HIV and more generally of science.

Public knowledge and understanding of disciplinary knowledge

While treatments have been available and efficient for over a decade, some participants (FG1P2, FG3P2, FG3P5, and FG4P2) thought a pregnant woman would inevitably transmit HIV to the foetus. This medical advance follows from ART and vertical transmission, in the UK, has been reduced significantly (Raffe et al., 2017; Peters et al., 2017). Whether not advertised or not integrated, this lack of knowledge can be worrying⁸⁸. Relatively new (Wynne, 1992, 2008), the study of the public understanding of scientific or academic knowledge has been linked with political issues and in the context of health with acute crisis or pandemic (see a recent study on Ebola risks, Fischhoff et al., 2017) and health policies such as vaccines.

⁸⁷ For instance, studies on HPV and cervical cancer highlighted women's poor knowledge (Waller et al., 2004; Marlow et al., 2013), however, an increase, partly attributable to vaccine campaigns, was found in an online survey (Sherman et al., 2016). Young religious people show poorer sexual health knowledge than nonreligious youth (Coleman and Testa, 2008).

⁸⁸ Public health problems and priorities are defined by epidemiological criteria (e.g. prevalence and incidence), social impact, individual impact and altered quality of life, and the availability of preventive and/or curative means (Brownson et al., 2003). Hence, other conditions such as, for instance, cancers and cardiovascular diseases, or health areas often take hold over sexual health. The politics of sexual health will not be developed.

The public's understanding of specific fields of expertise has been reliant on social sciences theories and methods, highlighting how the soft sciences serve a social purpose (Macnaghten et al., 2005) and how interventions are framed using a social science approach. Mainly, the two approaches identified were the Deficit Model of public attitudes and the Contextualist Approach (Sturgis and Allum, 2004). The first is focused on the acquisition of the expected information and/or behaviours while the second is based on smaller objectives required to perform a specific task or reach a specific goal. The hidden (optimistic) assumption in the public's understanding of science is that knowledge acquisition will modify attitudes and behaviours.

The public's understanding of scientific or specialised disciplinary knowledge faces several challenges, at different levels (Miller, 2001). At the epistemological level, the status of scientific facts or knowledge will depend upon consensual views in the field. In the absence of such a consensus, the contradictory information provided to the public might be more deleterious than beneficial. In practical terms, the public understanding of any field of expertise is based on a combination of factors: the access to the information, the readability of the information, and the necessity of the information. These were the reason why some authors recommend the involvement of the public and of patients during any scientific process and subsequent guidelines (Schicktanz et al., 2012).

At the structural and global level, ensuring the education and acquisition of knowledge of a whole population is hardly ever reached. The general challenges of health promotion and education-based interventions are well known in general, but in the context of sexual health, there are further difficulties related to sub-norms or standards. The Identity-Protective Cognition Theory provides an individual and structural account explaining why people are resistant to scientific facts or evidence (Sherman and Cohen, 2002; Kahan, 2017).

Drawing upon Social Identity theories, Identity-Protective Cognition gathers a series of concepts based on the idea that people reject knowledge to maintain their belief systems and/or a sense of integrity. Several labels refer to this, such as the backfire effect (Nyhan and Reifler, 2010; Wood and Porter, 2016) or motivated reasoning (Sinatra et al., 2014). The majority of these studies were framed under the Self-Threat Theory and the Self-Affirmation Theory (Sherman and Cohen, 2006). Such theories have been applied to the public's political opinions and to public understanding of health policies. These theories assume that a knowledge-based approach is limited, as people tend to seek-out a confirmation bias and

avoid contradictory information. Identity-Protective Cognition is a bridge between social identity and epistemic communities. This approach seems congruent with the position adopted previously on the primacy of morality (social perception as a moral experience) on epistemology (knowledge). Further directions are proposed in [section 7.4.2](#).

7.3 Concealed Identities, Risk of Transmission and Disclosure

As highlighted in the results, the disclosure debate was twofold. On the one hand, FGs' participants expected people living with HIV to disclose their status (one of them even thought it was a legal obligation). On the other hand, if disclosure was encouraged by professionals, the notion of shared responsibility and the use of protective measures took into considerations the potential impediments to disclosure.

7.3.1 Factors associated with (non) disclosure in people living with HIV

The relationship between the different types of stigma experienced (undergone, perceived and self-stigma) and disclosure to sexual partners have been documented for at least two decades (Li et al., 2013; Overstreet et al., 2013). The greater the stigma experienced, the less likely a person living with HIV is to disclose their status. Moreover, the deleterious impact of negative reactions to HIV disclosure can lead to increased loneliness or risk-taking behaviours (Cama et al., 2017). While this is a complex process in interpersonal relationships (Chaudoir et al., 2011), different factors have been identified as facilitating or impeding disclosure, such as socio-demographic, relational and personal factors regarding the person disclosing (Bird et al., 2017; Li, Zang and Chow, 2016; Smith et al., 2017) but also the person to whom the disclosure is to be made (e.g. a lower socioeconomic status associated with more stigmatising attitudes, see Mateveke et al., 2016). A recent systematic review concluded the perception of interpersonal risks was associated with HIV-status disclosure and experiencing anxiety and fear (Evangeli and Wroe, 2017).

An older age, being non-white, recently diagnosed and not having a stable relationship were identified as the main factors determining non-disclosure by people living with HIV in the UK (Daskalopoulou et al., 2017). The fear of stigma and a prior small number of disclosures within social circles were identified as barriers to disclosure to sexual partners. Bird et al. (2017) also suggested a model on the likelihood of disclosure based on three main aspects, the degree of sexual risk (under ART, sexual behaviours), the type (casual vs steady) and perceived trustworthiness of the partner(s), (anticipated rejection or stigma).

The sexuality and sexual health of people living with HIV are mostly studied through the lens of the risk of an onward transmission. Disclosure is thought to be a right standard in how people living with HIV can enact their sexuality. While UK-based studies focus on personal, relational and context-dependant factors, it is interesting to note that international and multi-cultural studies tend to highlight structural stigma.

The disclosure debate is rhetorically ambiguous. People viewed as risk takers can be seen either as victims of cumulative factors or as people deliberately endangering others (German and Latkin, 2012; Gourlay et al., 2017). Similarly, in the present study, KIs tended to see risk takers as vulnerable people (KI4, KI6, KI7, KI8, KI9) while some FG's participants focused on the threat to their own health (FG1P1, FG3P3, FG3P4, FG4P2, FG4P3). This section highlighted how people, from whom disclosure is expected, are caught in the middle of dilemma or potential paradoxical injunctions. The non-disclosure can be due to stigma or the fear of thereof, whereas disclosure could lead to stigma.

While interventions trying to address combined or cumulative stigma (e.g. ethnicity, homophobia and HIV stigma, see Frye et al., 2017; Arnold et al., 2014) are implemented, the expectation or recommendation of disclosure stands for the responsible standard practice (Andersen et al., 2013), leading to a responsible/irresponsible dichotomy among people living with HIV. It is tempting to consider that disclosure would both prevent new HIV transmission/acquisition; however, North American studies did not find any impact of disclosure laws on the prevalence and incidence of HIV (Patterson et al., 2015). Therefore, disclosure appears more of a moral and relational standard than a public and sexual health one (Rangel and Adam, 2014). While disclosure and informed consent can be looked upon as practical solutions, they are impeded by stigma. The situation of non-gay identified MSM is similar but highlights the intersectional nature of stigma even more so, and how stigma is also a cause of health inequalities (e.g. as hidden populations access services, see Hatzenbuehler et al., 2008 and Hatzenbuehler et al., 2013).

7.3.2 (Non) Disclosure of sexual orientation and/or sexual behaviours: the situation of non-gay identified MSM

It seems important to note that some of the gay-identified participants (FG2P1, KI3, KI4 and KI9) associated HIV-stigma with homophobia. They related their anti-criminalisation views to the history of their community and while accepting the possible prejudice in terms of health of acquiring a condition, they tended to exclude the possibility of a criminal liability. This leads to

question the differences in terms of perception and experiences of HIV between older and younger MSM. Participants' inputs (KI3, KI4, and FG2P1) were in agreement with published works ([section 2.3.3](#)). Younger people, who were not present during the early days of the pandemic and the decimation of the gay community, are likely to be more at-risk of acquiring HIV (Weatherburn et al., 2008; Dodds, 2009; Millett et al., 2012; Beyrer et al., 2013; Pachankis et al., 2015a) but also tend to be more stigmatising towards people living with HIV (Smit et al., 2012). As one participant (FG2P1) pointed emphatically, the potential contribution of non-gay identified MSM to the global burden of HIV, the challenges faced by this subpopulation and more generally the social perception and lived experiences of non-heteronormative sexual orientation and behaviours are briefly developed below.

Since Kinsey's studies (1948, 1950) sexual behaviours have been studied based on participants' self-report. Kinsey estimated that only 5 to 10% of the population would be exclusively homosexual or heterosexual. As sexual orientation and behaviour studies show sampling and self-report biases (Catania et al., 1990), self-reported data on sexual orientation and on sexual behaviours are rarely congruent (Chandra et al., 2011). According to Pathela et al. (2006), the number of people having same-sex intercourse is tenfold higher than the number of people identifying as gay and bisexual.

More recently in the UK, the NATSAL-3 survey (Mercer et al., 2013) highlighted an increase in self-reported same-sex sexual experiences with 8.4% of men and 9.7% of women, while 8.1% of men and 11.7% of women reported an exclusive attraction to the opposite sex. Since the depsychiatrisation of homosexuality, studies investigated self-acceptance and related difficulties in sexual minorities (Kus, 1988). Where studies were found addressing the sexual health and risk-taking behaviours of MSM, they rarely made any explicit mention to the inclusion of men that did not identify as gay in their sample, study design or intervention considerations.

Since the 1970s, sociological, anthropological and journalistic works have documented sexual behaviours in non-traditional places, as non-gay identified MSM are more likely to frequent non-gay identified places and/or cruising sites (Humphreys, 1975; Aveline, 1995; Lichtenstein, 2000). The absence of the gay social identity has been explained by different constructs of masculinity and sexuality (Ford et al., 2007; Reback et al., 2010; Tomori et al., 2017). It can also refer to a performative and fluid conceptualisation of sexual orientation (Katz-Wise, 2015; Katz-Wise and Hyde, 2015) and gender identity (Klein, 1990; Diamond, 2008; Butler, 2011).

Qualitative studies focusing on life trajectories elicited the importance of normative expectations; social isolation and ambivalence towards homosexuality and self-perception (see Bond et al., 2009, Wheeler, 2006; Schwitters and Sondage, 2016). A form of homophobia, or internalised homonegativity (self-stigma related to sexual orientation), has been identified in non-gay identified MSM (Allen and Oleson, 1999).

In the absence of negative social experiences, non-gay identified MSM seem to exhibit less anxious and depressive disorders (Pachankis et al., 2015b); other studies attributed a higher risk of somatic conditions and psychological difficulties to issues concerning secrecy and concealment of their sexual behaviours (Cole et al., 1996). Recent studies on the sexual health of non-gay identified MSM highlighted that this population is not targeted by prevention and testing interventions (Rapid Response Service, 2014; Harawa et al., 2013) despite the presence of risk-taking behaviours (Schrimshaw et al., 2010) and potential onward transmission (Siegel et al., 2008). Other studies focused on internalised homonegativity and risk-taking sexual behaviours (Ross et al., 2001; Ross et al., 2008).

Non-gay identified MSM are a heterogeneous population, and some subgroups have been identified as particularly vulnerable. People living in rural areas are more likely to undergo a normative social pressure preventing them from coming-out, and leading to risk-taking behaviours including sexual risk behaviours (Preston et al., 2004; Schwitters et al., 2016). Pathela et al., (2006) reported that 43% of non-gay identified MSM were not born in the country (i.e. USA). Structurally, this relates to the social treatment of homosexuality within a migration context and potential conflicting norms (Cherabi and Fanget, 1997; Sandfort et al., 2007); in terms of personal experience, it relates to cumulative stigma or even repeated victimisation of minorities (Crenshaw, 1991). The association between enacted stigma and risk behaviours has been robustly documented (Balaji et al., 2016) and the challenges to reach this population (Benoit et al., 2012; Forenza and Benoit, 2016) still require tailored conceptual and practical means (Dyer et al., 2012; Strömdahl et al., 2015)

7.4 The Primacy of Morality and its Implications

What has been developed so far is a generic constructivist stance, according to which reality is a consensus (Vygotsky op. cit., Moscovici, 2003), truth is possible within the application of a methodological or systematic axiomatic (Vuillemin op. cit), and both are constraints on or frames of subjective realities and experiences (Foucault, op. cit). In social life, this leads to the existence of, non-exclusive, moral and epistemic communities erecting norms and standards.

Subsequently, assuming the primacy of one kind of aspects (i.e. epistemological, ontological or moral) in social perception has practical and theoretical implications.

7.4.1 Implications of the precedence of morality over ontology

[Chapter 4](#) featured the hidden morality at work in medical, stigma and HIV-related fields while stated that social perception is a moral experience. This leads to consider that, regardless of one's ontological premises (what is a human being, what is a patient) morality comes first. If this leads to dilemmas in daily life, this can also inform potential interventions.

[Moral dilemma and challenges in clinical practice](#)

In terms of clinical practice, the numerous studies on stigma, experienced in healthcare settings and within the community (Kay et al., 2017; Penner et al., 2017), force us to confront the fact that the neutrality is an ideal. Indeed, the moralisation of treatment adherence for young people living with HIV (Bernays et al., 2017) or the individual opinion on PrEP (Calabrese et al., 2017) highlights the moral aspects of medical interventions, decision-making and attitudes of health professionals (Pickles et al., 2017). The debate on PrEP gathers various arguments, from the renunciation to safe sex, to the practicalities of risk-reduction. Both arguments are valid, as operating from different stances, but also promoting certain values (Loughlin, 2002) and a certain idea of the body that is intrinsically moral (Waldby, 2003; Weait, 2016).

Dilemmas in clinical practice are also concerned with how people living with HIV and patients in general experience the medical aspects of HIV, and how professionals are able to take into consideration the psychosocial aspects. Recent studies showed the paradoxical stigmatising effect related to pharmacological preventative drugs (PrEP) (Golub et al., 2017; Franks et al., 2017; Grace et al., 2017). Hence, clinicians and patients might benefit from works on the public understanding of preventive treatments and medication, whether related to communicable or non-communicable diseases (Falade et al., 2005).

Finally, while health and quality of life of people living with HIV are investigated (WHOQOL-HIV Group, 2004; Cooper et al., 2017) and guidelines regarding sexual and reproductive health for people living with HIV are promoted (Fakoya et al., 2008), the sexual well-being and sexual quality of life of people living with HIV remain under-investigated. When studied, sexual behaviours of people living with HIV are mostly framed under public health priorities and the identification of risk-taking sexual behaviours likely to lead to an onward transmission. The

question here is a genuine one. Is the scarcity of sexological studies⁸⁹ in people living with HIV related to the prominence of public health priorities, or to moral aspects of practice and research? Drawing a parallel with the comments from FGs' participants (e.g. FG4, "people living with HIV should only have sex with people living with HIV), what would be, among professionals, the SR of the sexuality of people living with HIV? Which sexuality do we (professionals, public) allow and support? If safe sex is enough in terms of public health priorities, is it sufficient when considering individuals' sexual health and well-being?

Implications in terms of stigma-reducing interventions

If the hypothesis of the primacy of moral experience on knowledge and theoretical considerations is followed, it leads to a minimising of the potential impact of informative and educational approaches. This also leads to the consideration that trying to convince people not to criminalise HIV transmission or exposure may be not worth the efforts (Woody, 2015). Nevertheless, it opens a new field in health and equality promotion under the, otherwise known, concepts and practices of experiential learning (Kolb et al., 2001) and experiential cognitive restructuring (Vincelli et al., 2000; Riva et al., 2001). If health and equality promotion are often framed under behaviour change theories, new technologies might be a tool able to conciliate positive or wanted experiences with knowledge and behaviour acquisition (Lohrmann, 2011). One type of interventions is discussed here, following an experiential gaming model (Kiili, 2005) applied to health and equality promotion: game-changers⁹⁰ and serious games (McAdams, 2014).

Game changers and serious games are playful activities using virtual reality and immersive technologies (Wortley, 2014). They are designed to lead the gamer(s)/participant(s) to acquire expected skills. Game changers can be an individual or a team activity (e.g. a small group of participants immersed in a virtual environment) while serious games are a more digital individual one (e.g. online platform). Based on virtual environments and scenarios developed with experts in the field of the skills to be acquired, these games immerse the participants in a given situation requiring a decision-making process, without the participants noticing. Game

⁸⁹ In studies on sexual dysfunctions, sexual health or difficulties in people living with HIV, most of the publications found are focusing on risk-taking behaviours and medication (Scanavino, 2011; Sandfort et al., 2013; Hart et al., 2015). Only a few studies on sexual satisfaction exclusively were retrieved, in relation to legal repressive context and abstinence (Kaida et al., 2015) and in the context of serodiscordant couples (Gamarel et al., 2014).

⁹⁰ The new information and communication technologies (NICT) have been shown great potential and used in various ways: health apps, Big Data and Data healthcare, online consultation, health (Bashshur et al., 2011; WHO, 2007) and sexual health interventions (Bowen et al., 2008; Carpenter et al., 2015; Chen and Mangone, 2016).

changers are usually targeting the public while serious games tend to target experts or professionals. Serious games are becoming more prevalent as pedagogical tools among health professionals (Arnab, 2012) or as digital health promotion interfaces (DeSmet et al., 2015).

The potential of a game-changer remains unknown. Indeed, the possibility to provide a safe environment to create new experiences (and, therefore, moral experiences) remains unexplored. The scarcity of game changers on sexual health or equality promotion (due to the cost of such an apparatus) leads to the absence of study regarding participants' experiences and potential effects. As people seem to engage and be responsive to such initiatives (Küng, 2017), serious games and game changers appear as a promising new type of experiential interventions that may benefit interdisciplinary translational research (Sheridan et al., 2016)⁹¹.

7.4.2 Implications of the precedence of morality over epistemology

In philosophy, the primacy of morality has been developed following diverse stances and systems. Kant's categorical imperative can be read as a form of moral primacy (Gardner, 2006). Nevertheless, it is a rational and top-down form of primacy, while this study emphasised an experiential primacy of morality. The position taken, if needed, would be Schopenhauer's Critique of the Kantian philosophy (1819) and the assumption that morality stems from compassion, hence from experience and relationships more than from principles (1840)⁹². This stance is adopted as it is compatible and relevant with clinical and research practices (Baker and McCullough, 2007). At an individual and interpersonal level, this means that perceiving one another is experiencing one another, and this experience is foremost moral; this also relates to the continental philosophy of otherness (Levinas, 1989, 1998; Dussel, 1999).

From an epistemological point of view, it elicits the implicit moral stances operating within moral and social psychology research and in HIV research (Gaist and Stirrat, 2017). Focusing on the psychological facts (i.e. judgement) removes the diversity of moral views, but also the primacy debate. Nevertheless, the primacy of morality in social perception studies can be found either as a result of experimental studies (Martijn et al., 1992; Brambilla et al., 2011) or as an epistemological stance. Some authors affirm that psychology is intrinsically moral (Canguilhem, 1958; Prilleltensky, 1994; Brinkmann, 2011). Conversely, morality tends to be psychologised and or evidence-based to appear neutral and acceptable in secular and/or

⁹¹ On-going research on Virus War, the first game-changer on STIs/HIV, <http://www.hf-prevention.com/index.php/hf-prevention/virus-wars>; this laser game is a team escape game.

⁹² The reference to Schopenhauer is also made on the basis of previous works in relation to Wittgenstein (Glock, 1999; Engel, 1969; McDonough, 1993; Griffiths, 1973)

multi-faiths societies (Brandt and Rozin, 1997). As pointed out by Cushman and Young (2009), moral philosophy and the resolution of psychological dilemmas are not congruent. More precisely, moral judgements are the product of diverse rationales philosophical stances, and psychological systems. In addition, this leads to the possibility of a moral phenomenology, as the experiences are what psychological systems and subsequent judgements are built on (Sinnot-Armstrong, 2008).

Theoretical ground for the non-integration of knowledge and the Contact Hypothesis

A recent cross-sectional analysis of surveys from 26 countries confirmed that personal contact with people living with HIV was associated with less avoidance and stigma (Chan and Tsai, 2017). Conversely, less contact with the community is associated with more prejudice against it from both non-professionals (Norcini Pala, 2016) and professionals (Aggarwal et al., 2017). Congruent with the findings of this study, globally, the lack of knowledge regarding HIV and the lack of familiarity with people living with HIV are both associated with higher stigma and negative stereotypes towards people living with HIV.

The precedence of morality on epistemology can be put in perspective with the relative failure of knowledge-based approach and the resistance to evidence. It also provides a philosophical or transtheoretical explanation of the Contact Hypothesis. The explicit beliefs or scientific facts even though assimilated or recalled may not modify the actual moral experience of one other and subsequent judgements. On the other hand, the positive experience of an out-group member confirms the experiential embedding of social perception and ensuing cognitions.

Further research and methodological recommendations

In parallel to possible stigma-reducing interventions advocated for, further research may develop. Three directions shall be taken further to this study. A theoretical investigation of connected topics, such as the perception of health and diseases, the social construction of health and body in our current societies. This can be related to philosophical, theoretical, retrospective works, and conceptual analyses. Interdisciplinary empirical research could be directed to the neuroscience of prejudice, social sciences and philosophy (Dovidio et al., 2008; Decety et al., 2010; Reynolds and Kilk, 2016; Schmidt and Amodio, 2017). However, following the assumption of the present study, this would be valid if and only if framed under a monist psychological stance and a clarification of ontological and moral premises (Bhaskar, 1997). A second beneficial direction for further research could be bridging moral phenomenology and stigma research.

Research design and evaluation might benefit a careful re-examination. Primarily, a methodological framework enabling the systematic assessment (responsive, qualitative and/or quantitative assessment) of stigma research would achieve two main goals. Firstly, this would inform researchers on their nature and quality of the impact of their study; this is intrinsically related to ethical, and thereby moral, concerns in interdisciplinary and stigma research. Secondly, this would allow comparability between the studies and would contribute to a better understanding of the phenomenon and to the improvement of interventions.

This field of research can be put in perspective with current studies assessing the effect of pre-assessment or baseline assessment on clinical trials and other interventions; this is called assessment reactivity (Moos, 2008) or reactivity to measurement (French and Sutton, 2010). For the last decade, research was developed on the effect of assessment in clinical practice (Donovan et al., 2012), mostly in the field of addictions' treatment and interventions (Fazzino et al., 2016; Schrimsher and Filz, 2011; Maisto et al., 2007). Variables or reasons considered are stress and emotional responses, but also the probing and self-monitoring effect of the assessment (Kypri et al., 2007). Recently, assessment reactivity was translated into the field of sexual health and proven promising (Carey et al., 2015). From a clinical and health psychology perspective, it also allows bridging, what most of the clinicians or practitioners intuit within an experimental design or a research setting; it might also contribute to understanding what makes a treatment or an intervention work. Developing the "effect-approach" of any aspect of a study, including the non-interventional aspects (e.g. assessment and context) would lead to the renewal of behaviour change theories, or at least contribute to a greater dialogue between sub-disciplines by initiating a reflection on the contribution of contingent elements to the success of an intervention. For instance, a self-reported baseline assessment may operate as a behaviour change technique (e.g. self-monitoring of behavioural outcomes) and, therefore, contribute to the intervention efficacy without being one of its components. This field of research remains in a relative state of infancy but appears promising, stigma research might definitely benefit from advances, conceptual and methodological innovations in the behaviour change theories and techniques field. Applied in the context of stigma research, studying assessment reactivity would provide further information on the impact of the research process on participants, leading to both more ethical research and tailored stigma-reducing interventions.

Eventually, longitudinal studies may bring further insight when applied to the general population. While mostly concerned with clinical populations and stigmatised groups, longitudinal studies are rarely conducted or funded in the general population. A longitudinal design could be used in studies investigating the course of moral views or to assess the long-term impact of interventions (e.g. educational, diversity promotion) in both the general population and health practitioners. Stigma research and stigma-reducing interventions primarily and legitimately focus on stigmatised groups and their direct interlocutors. If the purpose of equality had to be explicitly recognised and promoted, it would require the explicit integration of moral and subsequent views in the dialogue with the general population, beyond the social challenges raised by HIV.

CONCLUSION AND PERSPECTIVE

This study examined for the first time how HIV-stigma and pro-criminalisation views on the criminalisation of HIV sexual transmission were intricate, mostly in participants from the general public. The identification of varied stances and rationales on the criminalisation of transmission of, exposure to, and non-disclosure of HIV in both KIs and FGs' participants accounts for the variety of personal experiences, here explained by (a transtheoretical account of) the primacy of morality. This study also raised unprecedented concerns regarding the impact of stigma research; when participants from the public who completed the study seemed responsive and familiarised with HIV and challenges faced by people living with HIV, the increase of the blaming for a few participants suggests a possible deleterious effect that cannot be ignored any longer.

To summarise, in participants from the public, the lack of knowledge and familiarity with HIV are likely to lead to stigmatising attitudes. Further, stigmatising or prejudicial views of people living with HIV are likely to lead to pro-criminalisation views. People who are self-stigmatising are likely to be more vulnerable but also to take more risks. HIV stigma is embedded within other sets of prejudice related to ethnicity, class, gender, sexual orientation or a combination of these. The debate and views on the criminalisation of HIV transmission are based upon underlying assumptions of what justice and health are, in theory, and in practice. They are also based upon a generic view on what a reasonable, or responsible, person is thought to be, from both a legal and interpersonal perspective. When people are not familiar with HIV or people living with HIV, they tend to consider that one another (e.g. the one living with HIV) should protect them. Finally, if social perception is a moral experience, it has to lead us to reconsider educational interventions and how they are framed.

This study developed how intricate all these aspects are in daily life and how they silently operate and frame our appraisal of reality and one another. To terminate this interdisciplinary journey, a personal opinion needs to be developed, and interrogations related to the recent case ruled in Brighton need to be expressed and shared. There is no questioning or challenging of the legal ground of criminalisation, rather an interpretation of what it, socially, proceeds from and leads to.

The Criminalisation of HIV Transmission: From Double Bind to Institutionalised Stigma

The different themes connected to the criminalisation of HIV transmission (i.e. health, justice, and sexuality) and participants' views sketched the contours of what a reasonable person is or should be. While some participants conceded the failure of reason, the expected behaviours (not to acquire a condition, not to transmit a condition, and how to disclose a condition) emphasised the normative and moralistic attitudes towards sexuality and health in general.

The possibility to prosecute for HIV transmission does not exist *per se*. It relies on a specific use of the criminal law; suggesting a bottom-up rather than a top-down process. Indeed, in the absence of a specific offence, grievous bodily harm as a generic offense was deemed relevant as to include the reckless or intentional transmission of HIV. The criminalisation of HIV transmission then seems to appear at the intersection of the legal conception of bodily harm and the public's sense of harm and prejudice rooted in two main structural elements, health as a standard of living and social representations of HIV.

As such, it confirms, even makes official within a certain frame, the innocent/guilty dichotomy among people living with HIV: the innocent characterised as the responsible and the guilty as the irresponsible. If people living with HIV were to embrace this dichotomy or position themselves somewhere on the innocent-guilty continuum, this would lead to criminal proceedings by the 'innocent' (at the expense of being the victim of an irresponsible other) and potential self-stigma by the 'guilty'. Such a view, even though extrapolated, cannot be satisfactory as it is grounded in prior HIV stigma. Therefore, it is here affirmed that stigma leads to criminalisation, and criminalisation is a form of institutionalised stigma.

If stigma is based on the interpersonal moral experience that leads to negative judgements and attitudes, the criminalisation of HIV transmission can be interpreted as the structural expression of this experience. In this sense, this institutionalised stigma (Kalichman, 2007) is:

- i) Framed under the premises of health as a moral value (and its stereotypical counterpart, disease as a prejudice) and the reasonable person as trustworthy and healthy (and its stereotypical counterpart the sick, unworthy, unreasonable person),
- ii) Enacted through criminal and health policies (see for instance Peckham, 2013; Francis and Francis, 2012).

Institutionalised stigma or institutional stigma has been previously mentioned but not precisely defined in the literature (Renesto et al., 2014; Guo et al., 2012; Kalichman, 2007). It vaguely refers to stigma enacted within specific institutions, mostly those charged with taking care of stigmatised people. The institutionalised stigma here is defined as a legal grey area allowing social stigma to emerge at the structural and legal level without involving other legal areas such as anti-discrimination laws.

The criminalisation of HIV transmission is a marginal total social fact that condenses moral, ontological and epistemological challenges, to which any response will be foremost moral and prejudicial. In the case of criminalisation, it is prejudicial to people living with HIV as a new or increased stigma is attached to the community. In the context of non-criminalisation, it could be prejudicial to people considering themselves as the victim of one another's action and in contradiction with the current implicit social standards. In brief, the criminalisation of HIV transmission exemplifies the contradiction, if not the aporia, of our modern and liberal society congested with morality despite its daily enactment.

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Given the recent criminal cases, convictions and debates, this dissertation is likely to be outdated relatively soon. Nonetheless, given the small number of empirical studies, this will at least contribute to the ongoing discussion and a British socio-historical understanding of the criminalisation of HIV transmission. It is hoped that the investigation of the public's and key informants' views will provide a provisional ground, obviously to be furthered, to understand the social roots and inform further directions regarding the criminalisation of HIV transmission in the UK and upcoming debates.

Following the findings of this study and the likely imminent debates, one path of action seems to stand above all others: the consultation of people living with HIV on the topics of the criminalisation of the transmission of HIV, the exposure to HIV and non-disclosure of one's status. While challenges can already be anticipated, both the people living with HIV and the civil society will certainly benefit from a public consultation and concertation on this topic. The forms that such a project would take could also be the result of a consultation process involving the different stakeholders to ensure participation, limit biases (e.g. access to the internet in the case of online consultation) and tailor the most appropriate research (e.g. in

person and/or online), using participative methods, such as deliberative fora or a Delphi method study.

This dissertation investigated explicit views on the criminalisation of HIV transmission and their latent cognitive, conative and moral content. The sensitivity of the topic, diversity of opinions, breadth of rationales, and epistemological differences led to the assumption of the primacy of morality in social perception, social interactions, social action and social sciences. Such a stance has consequences in research and clinical settings, in which moral aspects are often dismissed, ignored, seen as unprofessional, to the benefits of a science- or evidence-based approach. The aspiration to professional neutrality and benevolence is entangled with the moral aspects and judgements inherent to social interactions.

This study confirmed the social exceptionalism of HIV, oscillating between empathy and anger or shame, support and sentence, harm associated with a death sentence and the manageability of a chronic condition associated with a life sentence. It is, therefore, as health and social work professionals, our responsibility to reflect and more deeply understand our representations and how this social exceptionalism is enacted, in daily life and daily practice, to provide, if not the ideal and good one, the best education and the best care we can offer.

67,657 words

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Chiropractor Act 1994

Disability Discrimination Act 1995

Education Act 1993

Equality Act 2010

Government of Wales Act 2006

Health and Social Care (Community Health and Standards) Act 2003

Health and Social Care Act 2012

Health and Medicines Act 1988

Health Authorities Act 1995

Human Tissue Act 2004 for England, Wales and Northern Ireland

Human Tissue Act 2006 for Scotland

Local Government Act 1986

Local Government Finance Act 1992

Medicines Act 1968

National Health Service and Community Care Act 1990

Offences Against the Persons Act, 2003, London, HMSO.

Parliamentary Commissioner Act 1967

Social Security Act 1997

Supply and Appropriation Act 2015

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APPENDICES

Appendix A – Participant information Sheet

Participant Information Sheet

An interdisciplinary study on the criminalisation of STIs and HIV transmission in UK.

Thank you for considering to take part in this research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. If anything you read is not clear or if you would like more information do not hesitate to ask. Take time to decide whether or not to take part.

What is the purpose of the study?

This study collects people's views on the sensitive topic of STIs/HIV transmission criminalisation. This study tries to understand what are the components and determinants of people's views related to this topic.

More generally, this project investigates how emotion and morals can influence our behaviours and our thoughts.

The results of this study will find applications in public health policy, outreach programs, patients follow up and professional training.

Why have I been invited?

Anyone over 18 year-old.

Do I have to take part?

It is up to you to decide. We will describe the study and go through the information sheet, which we will give to you. We will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If I decide to take part:

- I will meet a PhD student/clinical psychologist and will take part in a focus group (group discussion on one specific topic) or an interview.
- The interview will last at least 30 minutes and consists in open questions and/or a questionnaire. The focus group will last at least 50 minutes and consists in a group discussion or debate on one specific topic.
- There will be one encounter (Group interview or individual interview). Following this encounter, the researcher can meet again the participant to share the result/analysis and discuss the result/analysis. This second encounter is offered as a possibility for the participant to criticise the research and raise his/her voice, and a possibility for the researcher to confront his findings to the participant's experience and improve the research project. The investigator can be contacted for any further inquiry.
- My contact and civil details are not required and the sensible personal data that I may provide are protected by the Data Protection Act (1998)
- I have no obligation to answer and if I am too uncomfortable I can refuse to answer or even withdraw at any time

Expenses and payments?

There is no payment to take part in this study.

What are the possible disadvantages and risks of taking part?

This research study may discuss or explore sensitive issues (personal life, sexuality, feelings and so on). If at any point of the interview or questionnaire, you think or feel discomfort you can speak to the interviewer and stop the study. You have also the entire disposal of the data collected and can prevent anyone from using them.

The interviewer can provide any referral or address of appropriate support services to your questions or discomfort.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from the study will help:

- to give a freedom of speech to people living with HIV and help to raise their voices
- to inform and improve health professionals' practice
- to improve the understanding and to address social stigma.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact details at the end of the document and on the coupon of the consent form).

If you have any legal concern or enquiry, you can contact the Manchester Metropolitan University Legal Department:

All Saints Building
Manchester, M15 6BH
foi@mmu.ac.uk

If you remain unhappy and wish to complain formally, the Manchester Metropolitan University Information Commissioner can be contacted at:

Wycliffe House, Water Lane
Wilmslow, Cheshire SK9 5AF
Telephone +44 (0)1625 545700

Will my taking part in the study be kept confidential?

This research study follows the Cadicot principles and/or Data Protection Act (1998). This means that:

- The interviewer, after signing the consent form, will give me a code and this code will be related to my interview/answers
- The research supervisor and I (interviewer/PhD student) are the only person able to identify the data that I provided as mine.
- All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the university will have your name and address removed so that you cannot be recognised (authorised persons such as researchers within the team, supervisors, sponsors and for monitoring the quality, regulatory authorities /R&D audit).

What will happen to the results of the research study?

The results of the research study will be published, but individual report will not.

If you wish to read the results or have information you can contact your interviewer.

Who is organising or sponsoring the research?

This research is supported by the Manchester Metropolitan University, Interdisciplinary Studies Department.

Further information and contact details:

Marie Chollier - Department of Interdisciplinary Studies MMU Cheshire Campus
Crewe Green Road CW1 5DU
07907748014 / marie.chollier@stu.mmu.ac.uk

Appendix B – Consent Form

Centre Number:
 Study Number:
 Participant Identification Code:

Participant’s coupon

Centre / City :
 Study number:
 My identification code:
 Interviewer’s contact:
 Marie Chollier
 07907748014
 marie.chollier@stu.mmu.ac.uk

CONSENT FORM

Title of Project: **Criminalisation of STIs/HIV transmission in UK**

Name of Researcher: **Marie Chollier**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections and data collected during the study, may be looked at by individuals from **the Interdisciplinary Studies Department** and partner’s project from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. I understand my anonymity is guaranteed.

4. I agree to take part in the above study.

Name of Participant	Date	Signature

Name of Person taking consent	Date	Signature

Appendix C – Pre-assessment form

Thank you for taking part in this research. None of the following questions are mandatory, however, if you could take the time to fill this in, this would be helpful and should not take more than 15 minutes. Please, rate the following statement, you can provide explanation to sustain your choice in the blank space.

Do you think people are responsible for their own health?

- Yes
- No
- Other

Comments:

Do you think people living with a medical condition should be protected by society (Law, policies, community...)?

- Yes
- No
- Other

Comments:

Please, read the following statement and choose the corresponding box/item. You can write comments in the blank space after each statement.

Statement	Strongly disagree	Disagree	Agree	Strongly agree
1. People living with HIV/AIDS should be ashamed.				
2. People with AIDS should be isolated from other people				
3. People who have HIV/AIDS are cursed.				
4. A person with HIV/AIDS should be allowed to work with other people.				
5. People living with HIV/AIDS deserve to be punished.				
6. Families of people living with HIV/AIDS should be ashamed				
7. It is reasonable for an employer to fire people who have HIV/AIDS.				
8. People with HIV/AIDS are disgusting.				
9. People who have HIV/AIDS deserve compassion.				
10. People with HIV should be allowed to participate fully in the social events in this community.				
11. People living with HIV/AIDS face neglect from their family.				
12. People living with HIV/AIDS face physical abuse.				
13. People want to be friends with someone who has HIV/AIDS				
14. People living with HIV/AIDS face ejection from their homes by their families				
15. Most people would not buy vegetables from a shopkeeper or food seller that they knew had AIDS.				
16. People who are suspected of having HIV/AIDS lose respect in the community.				
17. People who have HIV/AIDS face verbal abuse				
18. People living with HIV/AIDS face rejection from their peers.				
19. People who have HIV/AIDS should be treated the same as everyone else.				
20. People with HIV/AIDS do not deserve any support.				
21. People with HIV/AIDS should not have the same freedoms as other people				
22. People living with HIV/AIDS should be treated similarly by health care professionals as people with other illnesses.				

Please, read the following statement and choose the corresponding box/item. You can write comments in the blank space after each statement.

<p>Below you will find a list of statements. Please read each statement carefully and decide if that statement describes you or not. If it describes you, check the word "true"; if not, check the word "false".</p>		
1. I sometimes litter	True	False
2. I always admit my mistakes openly and face the potential negative consequences.	True	False
3. In traffic I am always polite and considerate of others.	True	False
4. I always accept others' opinions, even when they do not agree with my own.	True	False
5. I take out my bad moods on others now and then.	True	False
6. There has been an occasion when I took advantage of someone else.	True	False
7. In conversations I always listen attentively and let others finish their sentences.	True	False
8. I never hesitate to help someone in case of emergency.	True	False
9. When I have made a promise, I keep it--no ifs, ands or buts.	True	False
10. I occasionally speak badly of others behind their back.	True	False
11. I would never live off other people.	True	False
12. I always stay friendly and courteous with other people, even when I am stressed out.	True	False
13. During arguments I always stay objective and matter-of-fact.	True	False
14. There has been at least one occasion when I failed to return an item that I borrowed.	True	False
15. I always eat a healthy diet.	True	False
16. Sometimes I only help because I expect something in return.	True	False

1. When (age) did you have your first STI and/or HIV screening test?	
2. When (age) did you have your last STI and/or HIV screening test?	
3. Is STI and/or HIV screening test part of your yearly check-up?	<input type="checkbox"/> yes <input type="checkbox"/> no
4. Have you ever been to a Sexual Health Clinic?	<input type="checkbox"/> yes <input type="checkbox"/> no
5. If yes, how did you feel (before calling or dropping in and/or in the waiting room...)?	
6. Do you know you can get tested for free in NHS clinics and Trusts?	<input type="checkbox"/> yes <input type="checkbox"/> no
7. Do you know where to get tested in your area?	<input type="checkbox"/> yes <input type="checkbox"/> no
8. Have you ever been diagnosed with any STI?	<input type="checkbox"/> yes <input type="checkbox"/> no
9. If yes, Did it change the frequency of your STI or HIV screening test?	<input type="checkbox"/> yes <input type="checkbox"/> no
10. What did you think of professional(s) attitude when you went for an STI and/or HIV screening test for the first time?	
11. Did you feel like professionals were judgemental?	<input type="checkbox"/> yes <input type="checkbox"/> no
12. What did you think of professional(s) attitude when you went for an STI and/or HIV screening test for the last time?	
13. Did you feel like professionals were judgemental?	<input type="checkbox"/> yes <input type="checkbox"/> no

1. According to you what is the difference between HIV and AIDS?
2. In your opinion, how many persons are currently living with HIV diagnosis in UK?
3. In your opinion, how many persons are currently estimated to live with undiagnosed HIV in UK?
4. In your opinion, how many persons are diagnosed with HIV each year?
5. New diagnoses concern mostly ...

Appendix D – Post-assessment form

Thank you for this contribution.

Below a few questions about your experience and your impressions.

1. Did you have any opinion regarding this topic (criminalization of HIV transmission) before the discussion?

Yes

No

Comments:

2. How do you feel about this discussion on a sensitive topic?

Comments:

3. Do you think your opinion, or arguments might have changed after this discussion?

Yes

No

Comments:

4. Do you think people are responsible for their own health?

Yes

No

Comments:

5. Do you think people living with a medical condition should be protected by society (Law, policies, community...)?

Yes

No

Comments:

Please, read the following statement and choose the corresponding box/item. You can write comments in the blank space after each statement.

Statement	Strongly disagree	Disagree	Agree	Strongly agree
1. People living with HIV/AIDS should be ashamed.				
2. People with AIDS should be isolated from other people				
3. People who have HIV/AIDS are cursed.				
4. A person with HIV/AIDS should be allowed to work with other people.				
5. People living with HIV/AIDS deserve to be punished.				
6. Families of people living with HIV/AIDS should be ashamed				
7. It is reasonable for an employer to fire people who have HIV/AIDS.				
8. People with HIV/AIDS are disgusting.				
9. People who have HIV/AIDS deserve compassion.				
10. People with HIV should be allowed to participate fully in the social events in this community.				
11. People living with HIV/AIDS face neglect from their family.				
12. People living with HIV/AIDS face physical abuse.				
13. People want to be friends with someone who has HIV/AIDS				
14. People living with HIV/AIDS face ejection from their homes by their families				
15. Most people would not buy vegetables from a shopkeeper or food seller that they knew had AIDS.				
16. People who are suspected of having HIV/AIDS lose respect in the community.				
17. People who have HIV/AIDS face verbal abuse				
18. People living with HIV/AIDS face rejection from their peers.				
19. People who have HIV/AIDS should be treated the same as everyone else.				
20. People with HIV/AIDS do not deserve any support.				
21. People with HIV/AIDS should not have the same freedoms as other people				
22. People living with HIV/AIDS should be treated similarly by health care professionals as people with other illnesses.				

1. According to you what is the difference between HIV and AIDS? 2.	
3. In your opinion, how many persons are currently living with HIV diagnosis in UK?	
4. In your opinion, how many persons are currently estimated to live with undiagnosed HIV in UK?	
5. In your opinion, how many persons are diagnosed with HIV each year?	
6. New diagnosis concern mostly...	
Regarding the following questions, you can tick the box or choose to write directly	
1. Age (year of birth) : <input type="checkbox"/> <input type="checkbox"/> Prefer not to say	2. Gender : <input type="checkbox"/> female <input type="checkbox"/> male <input type="checkbox"/> other <input type="checkbox"/> prefer not to say
	3. Level of Education : <input type="checkbox"/> EMD <input type="checkbox"/> GCSE <input type="checkbox"/> Bachelor Degree <input type="checkbox"/> Master (MA, Msc) and over <input type="checkbox"/> Other: ... <input type="checkbox"/> prefer not to say
6. Living area	<input type="checkbox"/> Urban: Conurbation <input type="checkbox"/> Urban: City and Town <input type="checkbox"/> Rural: Town and Fringe <input type="checkbox"/> Rural: Village and Hamlets <input type="checkbox"/> Prefer not to say
7. Ethnicity:	
8. Professional activity domain (profession and/or your domain of activity):	
9. Do you know any person living with HIV?	<input type="checkbox"/> Yes, myself <input type="checkbox"/> Yes, my partner <input type="checkbox"/> Yes, first degree relative(s) <input type="checkbox"/> Yes, relative(s) <input type="checkbox"/> Yes, friend(s) <input type="checkbox"/> Yes, colleague(s) <input type="checkbox"/> Yes, acquaintance(s) <input type="checkbox"/> Yes, other(s), specify (if you wish) <input type="checkbox"/> No

Thank you very much for your contribution.

Appendix E – Restitution session form

Restitution Session

Thank you for accepting this last part of the research. You have been sent or given orally the preliminary analysis of your interview, and this analysis is now to be discussed with you. The conversation is to be recorded, if you agree with this. This page is to write down your comments criticisms and/or insights regarding your contribution.

1. Do you think your opinion, or arguments have changed or evolved since we last met?

Yes No

Please, briefly explain.

2. Do you think or feel like the analysis corresponds to your opinion at the moment of the interview?

Yes No

Please explain.

3. Do you think people are responsible for their own health?

Yes No

Comments:

4. Do you think people living with a medical condition should be protected by society (Law, policies, community...)?

Yes No

Comments:

Please, read the following statement and choose the corresponding box/item. You can write comments in the blank space after each statement.

Statement	Strongly disagree	Disagree	Agree	Strongly agree
1. People living with HIV/AIDS should be ashamed.				
2. People with AIDS should be isolated from other people				
3. People who have HIV/AIDS are cursed.				
4. A person with HIV/AIDS should be allowed to work with other people.				
5. People living with HIV/AIDS deserve to be punished.				
6. Families of people living with HIV/AIDS should be ashamed				
7. It is reasonable for an employer to fire people who have HIV/AIDS.				
8. People with HIV/AIDS are disgusting.				
9. People who have HIV/AIDS deserve compassion.				
10. People with HIV should be allowed to participate fully in the social events in this community.				
11. People living with HIV/AIDS face neglect from their family.				
12. People living with HIV/AIDS face physical abuse.				
13. People want to be friends with someone who has HIV/AIDS				
14. People living with HIV/AIDS face ejection from their homes by their families				
15. Most people would not buy vegetables from a shopkeeper or food seller that they knew had AIDS.				
16. People who are suspected of having HIV/AIDS lose respect in the community.				
17. People who have HIV/AIDS face verbal abuse				
18. People living with HIV/AIDS face rejection from their peers.				
19. People who have HIV/AIDS should be treated the same as everyone else.				
20. People with HIV/AIDS do not deserve any support.				
21. People with HIV/AIDS should not have the same freedoms as other people				
22. People living with HIV/AIDS should be treated similarly by health care professionals as people with other illnesses.				

Below you will find a list of statements. Please read each statement carefully and decide if that statement describes you or not. If it describes you, check the word "true"; if not, check the word "false".		
1. I sometimes litter	True	False
2. I always admit my mistakes openly and face the potential negative consequences.	True	False
3. In traffic I am always polite and considerate of others.	True	False
4. I always accept others' opinions, even when they do not agree with my own.	True	False
5. I take out my bad moods on others now and then.	True	False
6. There has been an occasion when I took advantage of someone else.	True	False
7. In conversations I always listen attentively and let others finish their sentences.	True	False
8. I never hesitate to help someone in case of emergency.	True	False
9. When I have made a promise, I keep it--no ifs, ands or buts.	True	False
10. I occasionally speak badly of others behind their back.	True	False
11. I would never live off other people.	True	False
12. I always stay friendly and courteous with other people, even when I am stressed out.	True	False
13. During arguments I always stay objective and matter-of-fact.	True	False
14. There has been at least one occasion when I failed to return an item that I borrowed.	True	False
15. I always eat a healthy diet.	True	False
16. Sometimes I only help because I expect something in return.	True	False

1. According to you what is the difference between HIV and AIDS?
2. In your opinion, how many persons are currently living with HIV diagnosis in UK?
3. In your opinion, how many persons are currently estimated to live with undiagnosed HIV in UK?
4. In your opinion, how many persons are diagnosed with HIV each year?
5. New diagnoses concern mostly ...

Thank you very much for taking part into this research.

SUPPLEMENTARY MATERIALS

Desk Research 1: References to HIV in UK Law and legal decisions

Informed by qualitative legal research (Dobinson and Johns, 2007), this desk research was a preliminary work that aimed at answering two main questions: what are the current legal practices related to HIV and is the population involved in the criminal cases representative of the population of people living with HIV. To understand the theoretical and practical legal treatment of HIV-related issues, two sets of legal documents were consulted and synthesised: the primary and secondary legislation, and a set of legal decisions where HIV was mentioned.

HIV in Primary and Secondary Legislation

Legal appearances of HIV in Law are found in primary legislation (the Acts of Parliament) and secondary legislation (statutory instruments, which enforce, update or amend primary legislation). Primary legislation is usually applied across the UK while statutory instruments can be local. Thirteen and forty-eight references to HIV have been found⁹³ respectively in primary (Table 12) and secondary legislation (Table 13)⁹⁴.

HIV reference in primary legislation

The first Act is the AIDS (Control) Act, 1987, repealed by the Health and Social Care Act 2012. This Act provided the criteria for public health and epidemiological reporting, the type of data to be collected and shared (1, 2, 3). The National Health Service and Community Care Act 1990, and the Health Authorities Act 1995 (8, 13, 15) led to minor amendments regarding competent health authorities.

The Health and Medicines Act 1988 section 23, provided regulations regarding HIV testing and screening, mostly prescribing the selling and supplying of components, and regulation of non-registered professionals to test people (6 and 7). With the advent of community involvement in testing campaigns and technological advances (e.g. HIV self-testing and rapid testing), this legislation was no longer appropriate to the current health promotion and screening practices. These regulations were revoked by local orders in 2014 in England, Wales and Scotland and in 2015 in Northern Ireland (42, 43, 44, and 45).

⁹³ Retrieved from <https://www.legislation.gov.uk/browse>, using the keywords “HIV” and “AIDS”. Irrelevant sources referred to synonymous and truncated words (e.g. food aids, archives).

⁹⁴ When statutory instruments were directly related to the act, they were presented together; numbers in brackets refer to the number of the statutory instrument in table xx.

To the explicit references to HIV introduced above, one indirect reference must be added. In 1988, the Chapter 10, section 28, of the 1986 Local Government Act, which defined the regulation of local authority publicity (including publicity in educational settings and schools), was amended. This modification specified the prohibition of promoting homosexuality by teaching or by publishing material, in relation to schools and educational activities. Section 28(2), further stated, *“Nothing in subsection (1) above shall be taken to prohibit the doing of anything for the purpose of treating or preventing the spread of the disease.”* This indirect reference (ineffability of HIV referred to as “the disease”) exemplifies a particular socio-legal treatment of HIV/AIDS in the early days of the epidemic: firstly, the ineffability of HIV/AIDS and its association with homosexuality, reflecting possible taboos or stigmatising social views at the time; secondly, the necessity to find a compromise between public health priorities (treating and preventing) and socio-moral standards (prohibition of homosexuality promotion).

In 1995, the Disability Discrimination Act considered that people living with HIV (from the point of diagnosis) were entitled to ‘disability status’. The Equality Act 2010 specified the medical conditions eligible to the disability status: cancer, HIV and multiple sclerosis. These Acts and local orders (20) ensure the legal protection of people living with HIV in general (Equality) and in relation to potential discrimination because of their medical condition.

While the independent advisory group on sexual health and HIV was launched by the public health minister in 2003, it was officially added to the 1967 Parliamentary Commissioner Act by in 2005 (17, 18) and maintained by subsequent orders (21, 22, 25, 26, 30, 31, and 39).

The Health and Social Care (Community Health and Standards) Act 2003, and later the Supply and Appropriation Act 2015 (and subsequent versions) added to health expenditures the financial support for people who were infected with HIV and Hepatitis C through treatment administered by the NHS (i.e. victims of the tainted blood scandal and subsequent coverage of health expenses related to the conditions acquired through blood products).

References to HIV in the UK General Public Acts in force to date are generic legal frameworks regulating health services and health products, and ensuring the civil rights and protection of people living with HIV. Nevertheless, secondary legislation is more prolific and develops other legal aspects of HIV.

Table 12 Summary Table of UK Public General Acts mentioning HIV by chronological order

	Name	Year Reference	Content
1	AIDS (Control) Act 1987 (repealed)	1987 c. 33	Periodical reports on matters relating to AIDS and HIV - Act repealed (1.7.2012) by Health and Social Care Act 2012 (c. 7), ss. 59(1), 306(4); S.I. 2012/1319, art. 2(3)
2	Health and Medicines Act 1988	1988 c. 49	Health and Medicines Act 1988 1988 CHAPTER 49, section 23 HIV testing kits
3	National Health Service and Community Care Act 1990	1990 c. 19	Minor amendment to The AIDS (Control) Act 1987 32.(1) NHS
4	Health Authorities Act 1995	1995 c. 17	minor amendment to The AIDS (Control) Act 1987. Special Health Authority
5	Disability Discrimination Act 1995	1995 c. 50	SCHEDULE 1 - Provisions Supplementing Section 1 / Persons deemed to be disabled / Progressive conditions / Interpretation
6	Health and Social Care (Community Health and Standards) Act 2003	2003 c. 43	minor * Expenditure to charitable trusts and companies providing financial support and other relief to persons who contracted HIV and Hepatitis C through receiving NHS treatment.
7	Parliamentary Commissioner Act 1967	1967 c. 13	The Parliamentary Commissioner Order 2008 (S.I. 2008/3115), art. 2, Sch. Independent Advisory Group on Sexual Health and HIV.
8	Equality Act 2010	2010 c. 15	SCHEDULE 1 - Disability: supplementary provision. Part 1 Determination of disability / Certain medical conditions, 6.(1) Cancer, HIV infection and multiple sclerosis are each...
9	Supply and Appropriation (Anticipation and Adjustments) Act 2015	2015 c. 10	Added to health expenditure: Expenditure to charitable trusts and companies providing financial support and other relief to persons who contracted HIV and Hepatitis C through receiving NHS treatment.
10	Supply and Appropriation (Main Estimates) Act 2015	2015 c. 31	Expenditure to charitable trusts and companies providing financial support and other relief to persons who contracted HIV and Hepatitis C through receiving NHS treatment.
11	Supply and Appropriation (Main Estimates) Act 2016	2016 c. 23	
12	Supply and Appropriation (Anticipation and Adjustments) Act 2016	2016 c. 3	
13	Supply and Appropriation (Anticipation and Adjustments) Act 2017	2017 c. 8	

HIV reference in secondary legislation

Among the forty-eight references to HIV found in secondary legislation, twenty-two have already been mentioned above. The remaining twenty-six statutory instruments are detailed by chronological order and related Act.

Seven orders amended the National Health Service and Community Care Act 1990, regulating health authorities and health provisions (8, 14, 15, and 34), free access to HIV testing and/or treatment for overseas visitors (4, 5, 46).

Twelve orders were amendments to the Local Government Finance Act 1992 (29, 32, 33, 35-41, 47, 48) ensuring that victims of the tainted blood scandal (acquisition of HIV through NHS blood products) are not taxed on their perceived indemnities. This was later secured by four orders (11, 24, 27, and 28) ensuring special provisions of the 1997 Social Security Act, regarding the special status and indemnities for people who acquired HIV through NHS treatment and blood products.

One order (9) amended the 1993 Education Act, stating explicitly that HIV was excluded from the national science curriculum, as it is part of sex education⁹⁵.

One order (23) amended the Government of Wales Act 2006. It ensured education and training for people living with “(ii) a progressive health condition (such as cancer, multiple sclerosis or HIV infection) where it is at a stage involving no physical or mental impairment”.

Two orders (10 and 16) related to the Medicines Act 1968, specifying that public advertisement is prohibited regarding “*serious infectious diseases including HIV-related diseases and tuberculosis*”. While advertising medicinal products to prevent conditions such as cardiovascular diseases are allowed, advertising HIV preventative drugs (i.e. pre-exposure prophylaxis - PrEP) remained prohibited.

One reference was found in the General Chiropractic Council (Professional Indemnity Insurance) Rules Order 1999 (12) regarding insurance policies and professional risks excluding liability related to AIDS or HIV.

The Blood Safety and Quality Regulations 2005 (19) updated the blood testing requirements and procedures in accordance with the European Parliament directive. This also relates to the Human Tissue Act 2004 for England, Wales and Northern Ireland, and the Human Tissue Act 2006 for Scotland.

Globally, except the abstruse appearance in the Chiropractor Act 1994 (12), secondary legislation on HIV is diverse and covers two main areas: individuals’ rights (e.g. data protection, anti-discrimination) and public health regulation (e.g. health provisions, sex education). Legal responses to HIV are not public health Law, but laws framing public health interventions and

⁹⁵ For a comprehensive review of sex education, HIV and Law in Britain, see Monk, 1998 and 2002, and Blair and Monk, 2012.

people's protection. This leads to a relatively low legal presence of HIV and legal grey areas⁹⁶, as HIV-related aspects are ruled and defined through a small number of texts (Chalmers, 2008). The next section reviews the legal decisions and judgements referencing HIV; the nature of their content in relation to HIV is summarised.

Table 13 Summary table of UK Statutory instruments mentioning HIV by chronological order

#	Statutory Instrument	Reference to Public General Act	Legislation Year Reference	Summary of content / Explanatory note (verbatim)
1	The AIDS (Control) (Northern Ireland) Order 1987	AIDS (Control) Act 1987	Northern Ireland Orders in Council 1987 No. 1832 (N.I. 18)	Art. 2(2): definition of "Board" repealed (1.4.2009) by Health and Social Care (Reform) Act (Northern Ireland) 2009 (c. 1), ss. 32, 33, 34(3), Sch. 6 para. 9(1)(a), Sch. 7; S.R. 2009/114, art. 2 F2Art. 2(2): definition of "HSS trust" repealed (1.4.2009) by Health and Social Care (Reform) Act (Northern Ireland) 2009 (c. 1), ss. 32, 33, 34(3), Sch. 6 para. 9(1)(a), Sch. 7; S.R. 2009/114, art. 2 F3Art. 2(2): definition of "relevant body" added (1.4.2009) by Health and Social Care (Reform) Act (Northern Ireland) 2009 (c. 1), ss. 32, 34(3), Sch. 6 para. 9(1)(b); S.R. 2009/114, art. 2
2	The AIDS (Control) (Contents of Reports) Order 1988		UK Statutory Instruments 1988 No. 117	This Order amends the Schedule to the AIDS (Control) Act 1987 by specifying additional information to be contained in the reports made by a District Health Authority and a Health Board in pursuance of section 1(2) of the said Act. The additional information concerns the number of positive results obtained in the reporting period from blood samples tested for HIV antibodies.
3	The AIDS (Control) (Contents of Reports) (No. 2) Order 1988		UK Statutory Instruments 1988 No. 1047	This Order further amends the Schedule to the AIDS (Control) Act 1987 so as to secure that reports of the number of positive results of HIV antibody tests are covered by the confidentiality provisions in paragraph 3. The previous Order of 1988, which required this number to be reported without that safeguard, is revoked.
4	The National Health Service (Charges to Overseas Visitors) (Scotland) Amendment Regulations 1988	National Health Service and Community Care Act 1990	UK Statutory Instruments 1988 No. 13 (S. 2)	These Regulations amend the National Health Service (Charges to Overseas Visitors) (No. 2) Regulations 1982 which prescribe charges for some overseas visitors for services forming part of the national health service. Regulation 2(2) replaces an exemption from charges relating to clinics for sexually transmitted diseases; in particular, the new exemption extends, in the case of treatment relating to a Human Immunodeficiency Virus (HIV), only to testing and associated counselling. Regulation 2(3) introduces a charge for hospital out-patients for the supply of a drug or medicine designed to treat HIV.
5	The National Health Service (Charges to Overseas Visitors) Amendment Regulations 1988	National Health Service and Community Care Act 1990	UK Statutory Instruments 1988 No. 8	
6	The Health and Medicines (Northern Ireland) Order 1988	Health and Medicines Act 1988	Northern Ireland Orders in Council 1988 No. 2249 (N.I. 24)	HIV testing kits and services

⁹⁶ For instance, the Public Health (Control of Disease) Act 1984 does not mention HIV. Nevertheless, procedures and/or regulations in the context of other conditions or categories (e.g. such as serious illnesses, infectious diseases) remain in force and are likely to be applied in the case of HIV and people living with HIV.

7	The HIV Testing Kits and Services Regulations 1992		UK Statutory Instruments 1992 No. 460	These Regulations make it an offence, subject to various exceptions, to sell or supply an HIV testing kit or component to a member of the public (regulation 2), to sell or supply an HIV testing kit without an accompanying warning notice (regulation 3), to provide HIV testing services which are not directed by a registered medical practitioner (regulation 4). In addition, regulation 5 places restrictions on advertisements for such kits, components and services.
8	The National Health Service Functions (Administration Arrangements and Amendment of Directions) Regulations 1992	National Health Service and Community Care Act 1990	UK Statutory Instruments 1992 No. 659	SCHEDULE, ENACTMENTS CONFERRING FUNCTIONS EXERCISABLE BY ANOTHER HEALTH AUTHORITY
9	The Education (National Curriculum) (Attainment Targets and Programmes of Study in Science) (Amendment) Order 1994	-	UK Statutory Instruments 1994 No. 1520	2. The Education (National Curriculum) (Attainment Targets and Programmes of Study in Science) Order 1991(1) is hereby amended— (a) by the substitution in article 7 for the words “articles 8 to 10” of the words “articles 7A to 10”; (b) by the insertion after article 7 of the following article— “7A.—(1) The programme of study set out in the Document and specified by article 9 and Schedule 2 in relation to the third key stage and which relates to attainment target 2 (life and living processes)(2) is hereby amended— (a) by the deletion of the words “(including Human Immunodeficiency Virus (HIV))” and “and understand the need to have a responsible attitude to sexual behaviour”, and (b) by the insertion after the word “adolescence” of the word “and”. (2) No programme of study in the Document shall include— (a) Acquired Immune Deficiency Syndrome and Human Immunodeficiency Virus, (b) any other sexually transmitted disease, or (c) aspects of human sexual behaviour, other than biological aspects.” The matters set out in paragraph (2) of new article 7A inserted by this Order, which are concerned with sex education, are excluded from the programmes of study in the Document, and amendments are made to the programme of study relating to attainment target 2 (life and living processes) for the third key stage.
10	The Medicines (Advertising) Regulations 1994	<i>Medicines Act</i> 1968	UK Statutory Instruments 1994 No. 1932	SCHEDULE 1 Diseases in Respect of which Advertisements to the Public are Prohibited - Serious infectious diseases including HIV-related diseases and tuberculosis
11	The Social Security (Recovery of Benefits) Regulations 1997	Social Security Act 1997	UK Statutory Instruments 1997 No. 2205	Social Security (Miscellaneous Amendments) (No.2) Regulations 2004 (S.I. 2004/1141), regs. 1(1), 7(a) / any payment made by MFET Limited, a company limited by guarantee (number 7121661) of that name, established for the purpose in particular of making payments in accordance with arrangements made with the Secretary of State to persons who have acquired HIV as a result of treatment by the NHS with blood or blood products

12	The General Chiropractic Council (Professional Indemnity Insurance) Rules Order 1999	Chiropractors Act 1994	UK Statutory Instruments 1999 No. 3071	Prescribed risks - (2) The policy of insurance in respect of the prescribed risks may exclude liability in connection with acquired immune deficiency syndrome (AIDS) or human immunodeficiency virus (HIV), or any similar syndrome or condition, and in connection with ionising radiation or radioactivity (but not in connection with the use of X-ray equipment in the course of the chiropractor's practice).
13	The Health Act 1999 (Supplementary, Consequential etc. Provisions) Order 2000	AIDS (Control) Act 1987 (repealed)	UK Statutory Instruments 2000 No. 90	Minor amendment to the AIDS (Control) Act 1987
14	The National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) Regulations 2002	National Health Service and Community Care Act 1990	UK Statutory Instruments 2002 No. 2375	8. Limitations and restrictions on the exercise of functions relevant to Primary Care Trusts only / (5) In exercising the functions specified in Schedule 1 to the extent that they consist of— (a)providing or securing the provision of facilities and services for— (i)testing for, and preventing the spread of, AIDS, HIV and genito-urinary infections and diseases
15	The National Health Service Reform and Health Care Professions Act 2002 (Supplementary, Consequential etc. Provisions) Regulations 2002	National Health Service and Community Care Act 1990	UK Statutory Instruments 2002 No. 2469	Consequential amendments to AIDS (Control) Act 1987, section 1.
16	The Medicines (Advertising) Amendment Regulations 2004	Medicines Act 1968. section 92	UK Statutory Instruments 2004 No. 1480	SCHEDULE 1 - DISEASES IN RESPECT OF WHICH ADVERTISEMENTS TO THE PUBLIC ARE PROHIBITED Serious infectious diseases including HIV-related diseases and tuberculosis / Sexually transmitted infections (..) remove the prohibition on advertising to the public medicinal products for the treatment, prevention or diagnosis of bone, cardiovascular, endocrine, psychiatric and joint, rheumatic and collagen diseases, genetic disorders, diseases of the liver, biliary system and pancreas, serious disorders of the eye and ear, serious gastrointestinal, neurological and muscular, renal and respiratory diseases, and serious skin disorders. The prohibition on advertising medicinal products for chronic insomnia, diabetes and other metabolic diseases, malignant diseases, serious infectious diseases and sexually transmitted diseases remains.
17	The Parliamentary Commissioner Order 2005	Parliamentary Commissioner Act 1967	UK Statutory Instruments 2005 No. 249	Schedule substituted for Schedule 2 to the Parliamentary Commissioner Act 1967 - Section 4 - SCHEDULE 2 Departments Etc Subject to Investigation - Independent Advisory Group on Sexual Health and HIV.
18	The Parliamentary Commissioner (No. 2) Order 2005	Parliamentary Commissioner Act 1967	UK Statutory Instruments 2005 No. 3430	Schedule substituted for Schedule 2 to the Parliamentary Commissioner Act 1967 - Section 4 - SCHEDULE 2 Departments Etc Subject to Investigation - Independent Advisory Group on Sexual Health and HIV.
19	The Blood Safety and Quality Regulations 2005	The Human Tissue Act 2004 - (2005) 68(5) MLR 798-821	UK Statutory Instruments 2005 No. 50	7.Blood establishment requirements - 7 basic testing requirements, 12.Information that test results detecting markers for viruses, 2.1.Deferral criteria for donors of whole blood and blood components

20	The Disability Discrimination (Northern Ireland) Order 2006	Disability Discrimination Act 1995	Northern Ireland Orders in Council 2006 No. 312 (N.I. 1)	18. Meaning of "disability" / In Schedule 1 (provisions supplementing section 1), in paragraph 8 (progressive conditions), in sub-paragraph (1)(a), for "infection by the human immunodeficiency virus" substitute " HIV infection ".
21	The Parliamentary Commissioner Order 2007	Parliamentary Commissioner Act 1967	UK Statutory Instruments 2007 No. 3470	Schedule substituted for Schedule 2 to the Parliamentary Commissioner Act 1967 - Section 4 - SCHEDULE 2 Departments Etc Subject to Investigation - Independent Advisory Group on Sexual Health and HIV.
22	The References to Health Authorities Order 2007	AIDS (Control) Act 1987 32.(1)	Wales Statutory Instruments 2007 No. 961 (W. 85)	minor amendment to The AIDS (Control) Act 1987 32.(1)
23	The National Assembly for Wales (Legislative Competence) (Education and Training) Order 2008	Government of Wales Act 2006	UK Statutory Instruments 2008 No. 1036	.Amendments to Schedule 5 to the Government of Wales Act 2006 - Education and training for (...) (ii) a progressive health condition (such as cancer, multiple sclerosis or HIV infection) where it is at a stage involving no physical or mental impairment.
24	The Social Security (Recovery of Benefits) (Lump Sum Payments) Regulations 2008	Social Security (Recovery of Benefits) Act 1997	UK Statutory Instruments 2008 No. 1596	These Regulations make provision for the recovery of lump sum payments being payments to which section 1A(2) of the Social Security (Recovery of Benefits) Act 1997 (c. 27) ("the 1997 Act") applies. Section 1A was inserted into the 1997 Act by section 54 of the Child Maintenance and Other Payments Act 2008 (c. 6) ("the 2008 Act").
25	The Parliamentary Commissioner Order 2008	Parliamentary Commissioner Act 1967	UK Statutory Instruments 2008 No. 3115	Schedule substituted for Schedule 2 to the Parliamentary Commissioner Act 1967 - Section 4 - SCHEDULE 2 Departments Etc Subject to Investigation - Independent Advisory Group on Sexual Health and HIV.
26	The Parliamentary Commissioner Order 2010	Parliamentary Commissioner Act 1967	UK Statutory Instruments 2010 No. 239	Schedule substituted for Schedule 2 to the Parliamentary Commissioner Act 1967 - Section 4 - SCHEDULE 2 Departments Etc Subject to Investigation - Independent Advisory Group on Sexual Health and HIV.
27	The Social Security (Miscellaneous Amendments) (No. 2) Regulations 2010	Social Security (Recovery of Benefits) Act 1997	UK Statutory Instruments 2010 No. 641	to introduce disregards or exemptions in respect of payments by "MFET Limited". MFET Limited is a company limited by guarantee (number 7121661), established and funded by the Secretary of State, for the benefit of persons who have acquired HIV as a result of treatment by the NHS with blood or blood products.
28	The Social Security (Miscellaneous Amendments (No. 2) Regulations (Northern Ireland) 2010		Northern Ireland Statutory Rules 2010 No. 69	
29	The MFET Limited (Application of Sections 731, 733 and 734 of the Income Tax (Trading and Other Income) Act 2005) Order 2010	Income Tax (Trading and Other Income) Act 2005	UK Statutory Instruments 2010 No. 673	This Order applies sections 731, 733 and 734 of the Income Tax (Trading and Other Income) Act 2005 (c. 5) (periodical payments of personal injury damages etc.) to certain periodical payments to persons infected by HIV through contaminated blood or blood products used by the NHS. The effect of the Order is that no liability to income tax will arise for the recipients of these payments
30	The Parliamentary Commissioner Order 2011	Parliamentary Commissioner Act 1967	UK Statutory Instruments 2011 No. 751	Schedule substituted for Schedule 2 to the Parliamentary Commissioner Act 1967 - Section 4 - SCHEDULE 2 Departments Etc Subject to Investigation - Independent Advisory Group on Sexual Health and HIV.
31	The Parliamentary Commissioner (No. 2) Order 2011		UK Statutory Instruments 2011 No. 2986	

32	The Council Tax Reduction Schemes (Prescribed Requirements) (England) Regulations 2012	Local Government Finance Act 1992	UK Statutory Instruments 2012 No. 2885	"MFET Limited" means the company limited by guarantee (number 7121661) of that name, established for the purpose in particular of making payments in accordance with arrangements made with the Secretary of State to persons who have acquired HIV as a result of treatment by the NHS with blood or blood products;
33	The Council Tax Reduction Schemes (Default Scheme) (England) Regulations 2012		UK Statutory Instruments 2012 No. 2886	
34	The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012	National Health Service and Community Care Act 1990	UK Statutory Instruments 2012 No. 2996	11. The Board must arrange, to such extent as it considers necessary to meet all reasonable requirements, for the provision as part of the health service of the services specified in Schedule 4. SCHEDULE 4 Services for rare and very rare conditions / 17. Adult specialist services for patients infected with HIV.
35	The Council Tax Reduction (Scotland) Regulations 2012	Local Government Finance Act 1992	Scottish Statutory Instruments 2012 No. 303	"MFET Limited" means the company limited by guarantee (number 7121661) of that name, established for the purpose in particular of making payments in accordance with arrangements made with the Secretary of State to persons who have acquired HIV as a result of treatment by the NHS with blood or blood products;
36	The Council Tax Reduction (State Pension Credit) (Scotland) Regulations 2012		Scottish Statutory Instruments 2012 No. 319	
37	The Council Tax Reduction Schemes and Prescribed Requirements (Wales) Regulations 2012		Wales Statutory Instruments 2012 No. 3144 (W. 316)	
38	The Council Tax Reduction Schemes (Default Scheme) (Wales) Regulations 2012		Wales Statutory Instruments 2012 No. 3145 (W. 317)	
39	The Parliamentary Commissioner Order 2013	Parliamentary Commissioner Act 1967	UK Statutory Instruments 2013 No. 238	Amendment to schedule 2 - "Independent Advisory Group on Sexual Health and HIV"
40	The Council Tax Reduction Schemes and Prescribed Requirements (Wales) Regulations 2013	Local Government Finance Act 1992	Wales Statutory Instruments 2013 No. 3029 (W. 301)	"MFET Limited" means the company limited by guarantee (number 7121661) of that name, established for the purpose in particular of making payments in accordance with arrangements made with the Secretary of State to persons who have acquired HIV as a result of treatment by the NHS with blood or blood products;
41	The Council Tax Reduction Schemes (Default Scheme) (Wales) Regulations 2013		Wales Statutory Instruments 2013 No. 3035 (W. 303)	
42	The HIV Testing Kits and Services Regulations 1992 (Revocation) (Wales) Regulations 2014	Health and Medicines Act 1990	Wales Statutory Instruments 2014 No. 256 (W. 34)	These Regulations revoke the HIV Testing Kits and Services Regulations 1992 (the "1992 Regulations") in relation to England only. The 1992 Regulations provide that it is an offence, subject to various exceptions: - to sell or supply an HIV testing kit or component to a member of the public; - to sell or supply an HIV testing kit without an accompanying warning notice; - and to provide HIV testing services which are not directed by a registered medical practitioner.
43	The HIV Testing Kits and Services Revocation (Scotland) Regulations 2014		Scottish Statutory Instruments 2014 No. 42	
44	The HIV Testing Kits and Services (Revocation) (England) Regulations 2014		UK Statutory Instruments 2014 No. 451	

45	The HIV Testing Kits and Services (Revocation) Regulations (Northern Ireland) 2015		Northern Ireland Statutory Rules 2015 No. 412	
46	The National Health Service (Charges to Overseas Visitors) Regulations 2015	National Health Service and Community Care Act 1990	UK Statutory Instruments 2015 No. 238	Schedule 1 Diseases for which no charge is to be made for treatment (HIV)
47	The Council Tax Reduction (Scotland) Amendment Regulations 2017	Local Government Finance Act 1992	Scottish Statutory Instruments 2017 No. 41	Amendment of regulation 2 3. In regulation 2 (interpretation), in paragraph (1) after the definition of “independent hospital” insert— “infected blood payment scheme” means a scheme established by, or under arrangements made with, the Scottish Ministers, the Secretary of State, the Welsh Ministers or the Department of Health in Northern Ireland for making ex gratia payments to or in respect of persons who have acquired HIV or hepatitis C as a result of treatment with blood or blood products within the national health service;”.
48	The Scottish Infected Blood Support Scheme (Application of Sections 731, 733 and 734 of the Income Tax (Trading and Other Income) Act 2005) Order 2017	Income Tax (Trading and Other Income) Act 2005	UK Statutory Instruments 2017 No. 446	MFET Application of sections 731, 733 and 734 of the Income Tax (Trading and Other Income) Act 2005 / This Order applies sections 731, 733 and 734 of the Income Tax (Trading and Other Income) Act 2005 (periodical payments of personal injury damages) to certain periodical payments under a scheme established by the Scottish Ministers to persons infected by hepatitis C or HIV, or both, through contaminated blood or blood products used by the NHS. The effect of the Order is that no liability to income tax will arise for the recipients of these payments.

An overview of the legal decisions related to HIV in the UK

Sources and search

To understand the type of legal decisions in relation to HIV, a review of legal decisions in the UK was performed. A full review was not possible as criminal proceedings in the UK are not systematically available online, with non-publicity and anonymity in certain cases making them hard to retrieve. To provide an overview of the legal treatment of HIV, sources were retrieved from the Lexis Library website⁹⁷. Search criterion was “HIV” in the complete database, last updated on Aug 8, 2017. In total, 1673 legal sources were found. A sample of 408 documents from civil and criminal courts was retrieved and full texts were read: for England and Wales, 330 judgments; for Northern Ireland (17): Northern Ireland Law Reports (3), Northern Ireland Unreported Judgments (14); for Scotland (61): Scottish Case Digests (9), Scottish Civil Law Reports (8), Scottish Court Opinions (35), Scottish Criminal Case Reports (7), and Scottish Transcripts Archive (2). After eliminating judgements from the European Court (n = 8) and

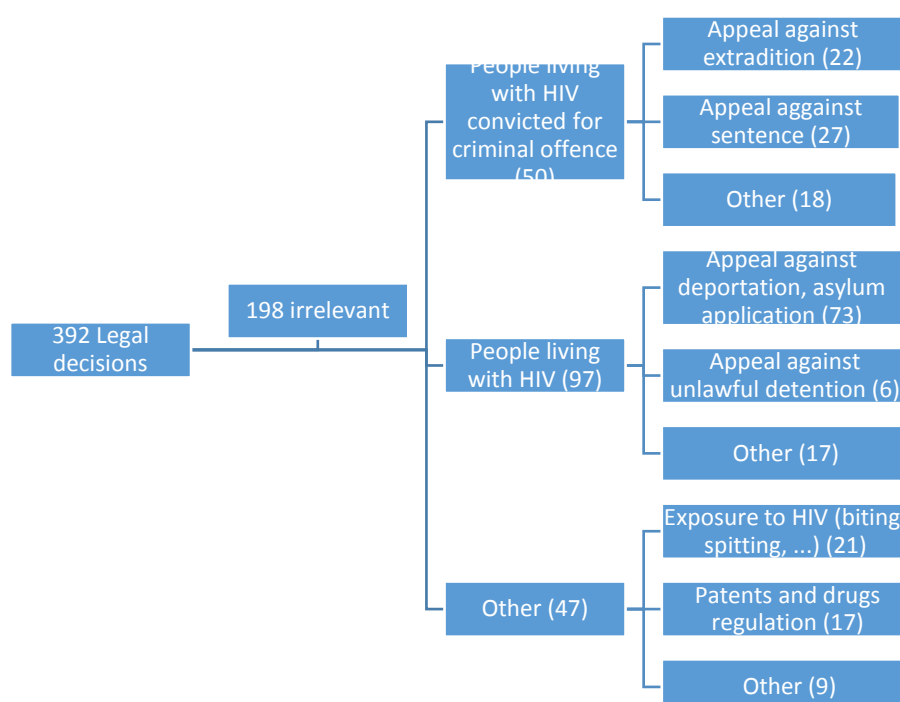
⁹⁷<https://www.lexisnexis.com/uk/legal/search/flap.do?flapID = home&random = 0.8267436056398819>.

duplicates (n = 14), 392 judgements referencing HIV were identified. The types of judgements retrieved were applications for judicial reviews and appeals. The judgement itself was not the focus here; rather the focus was on the daily legal practice related to HIV.

1.1.2.2 Description of the 392 legal decisions

Among the 392 legal decisions retrieved, the majority was unrelated to HIV. Legal decisions related to HIV were concerned with offenders living with HIV, non-criminal ruling regarding a complainant or an applicant living with HIV, and a heterogeneous subset of varied decisions.

Figure 3 Summary of the legal decisions related to HIV



Legal decisions unrelated to HIV (n = 198)

These cases cited legal provisions mentioning HIV and/or other condition (n = 121), related to appeals against deportation and extradition orders based on medical conditions and the lack of health provisions and/or potential danger to the appellant in the country of destination. Other frequent cases mentioned a third party (e.g. witness) living with HIV (n = 28). In the context of sex offences, HIV testing and waiting-times for results were mentioned as a factor of distress for the complainants (n = 14). Remaining judgements (n = 35) mentioned HIV in reference to the workplace or professional domain (e.g. HIV clinics) of people involved in the case, or in reference to risks incurred to both sexual and gender minorities in certain countries. One judgement, *R v Golding*, mentioning HIV was an appeal against the sentence after the appellant was convicted for the reckless transmission of herpes.

Legal decisions regarding people living with HIV convicted for criminal offences (n = 50)

Almost half of the cases (n = 22) regarding offenders living with HIV were appeals against extradition orders based on a medical condition (HIV or HIV and other conditions). Other cases were appeals against the sentencing (n = 27), the majority unrelated to living with HIV (n = 17). One of these judgements, *HM Advocate v Mola*, was an appeal against the sentence for the criminal conviction for the transmission of HIV in Scotland. The last one was an application for anonymity in the case of an offence against the person unrelated to HIV.

Legal decisions regarding people living with HIV (n = 97)

The majority of the cases retrieved (n = 73) were asylum application cases and appeals against deportation orders because of medical conditions (HIV or HIV and other medical conditions, mostly mental health issues). Six appeals or applications for judicial reviews were of people living with HIV claiming for unlawful detention (deportation) based on a medical condition and insufficient health provisions (n = 6). Other judgements (n = 13) were mostly discrimination and social housing claims, ruled in accordance with the Equality Act 2010, the Housing Act 1996, and the National Health Service and Community Care Act 1990 (or previous legislation in force at the time of the ruling). Three (3) judgements were unrelated to HIV but the appellants were living with HIV (e.g. property, inheritance). One case reported an insurance liability in the acquisition of HIV through blood products. Finally, the last mention was a person living with HIV claiming to have acquired HIV after sexual assault.

Other (47)

Other judgements were heterogeneous. Two were court orders for HIV testing (n = 1) and treatment (n = 1) of a child against parental authority. Seventeen (17) were related to HIV Drugs and Patent's British and European legislation. Five (5) judgements were concerned with UK regulations and public health policy. Two (2) judgements ruled against health professional malpractice (e.g. breach of confidentiality) likely to affect patients living with HIV. Remaining judgements (n = 21) referenced potential exposure to HIV, thirteen were held in Scotland, six in England, and one in Northern Ireland; the first set of judgements (n = 8) referred to biting and spitting offences, with the threat of transmitting HIV⁹⁸; the second (n = 13) referred to potential exposure to HIV in the context of professional duty, and the possible employer's responsibility and liability (e.g. breach of duty of care, health and safety procedures).

⁹⁸ E.g. in *R v Crouch*, the defendant was charged with several counts of assault, of which one was actual bodily harm for attacking someone with a syringe said to be infected with HIV, later revealed false. The defendant was acquitted for this latter count but convicted regarding other assault offences.

Among the 194 judgements retrieved, the types of legal enforcement found are more varied . Half of the judgements (n = 102) were concerned with Human Rights (asylum-seekers), twenty-one with Regulatory Law, eleven with Criminal Law, and six with Civil Law. Mixed cases between Human Rights and Criminal Law are found in extradition cases (n = 26), between Human Rights and Civil Law in discrimination cases (n = 13), and between Regulatory and Civil Law (n = 15) in potential exposure to HIV in the context of professional duty.

Summary

To summarise, the Law tends to be protective of people living with HIV and takes steps to ensure that the public is given the tools and means to be tested, screened and treated. Globally, the overview of judgements emphasised that legal practices are concerned with vulnerable people, and, in some instances, cumulative vulnerabilities of sub-populations such as migrants and asylum-seekers living with HIV, people living with HIV in precarious situations, and offenders living with HIV. Nevertheless, through the sex offences and the exposure cases, also transpires the idea that being exposed to and potentially acquiring HIV is a prejudice and a cause of distress. In regards to this legal history, the criminalisation of HIV transmission appears as an epiphenomenon. Finally, the number of biting and spitting cases with the explicit threat (real or otherwise) to transmit HIV raises another issue regarding intention. Indeed, the likelihood of an actual transmission is low to null. Exposure cases in professional settings and distress induced by HIV testing for the victims of sex offences highlighted the perceived prejudice a person may experience after possibly being exposed to or acquiring HIV.

Desk Research 2: A review of discrimination, prejudice and stigma-related topics.

Background

Since the 1960s, the course and development of stigma studies have been focusing on specific features. Phelan et al. (2008) asked if stigma and prejudice were the same *animal*. They reviewed and compared main theories and concluded that differences in the formal object (e.g. gender, ethnicity) were historical and both corpuses of research were complementary. The authors provided in their article a complex model of stigma theories in a meta-approach, a theory of stigma theories. Our interest lies in an appendix in which they counted the human characteristics associated with stigma and prejudice. Given the increase of publications in the last decade, the question of a clear line between stigma and prejudice remains. To understand the evolution of this field of research, a review of stigma, prejudice and discrimination publications' main topics was performed.

Method

Search and inclusion criteria

To compare Phelan et al. (2008) counts, three reviews were performed with the following title keyword search: *prejudic**, *stigma** and *discriminati** in the NCBI database in January 2015. Respectively 376, 1049 and 3769 articles have been found. There was no date criterion. Regarding the type of publications, book reviews were excluded, all other types of publications (e.g. commentaries, editorial, original paper, prospective research, scales validation studies) were included and topics were collected.

Data collection and analysis

Abstracts of 5104 articles were read. When key-words referred to other uses of the terms, the article was excluded. Regarding stigma, excluded articles referred to biological stigma. Regarding discrimination, the majority of the articles retrieved actually used the term in its first meaning (i.e. the capacity to differentiate elements). The characteristics of the articles retrieved were collected and organised in a database. Characteristics included the year of publication, the country of origin, the target population and the characteristics related to stigma, prejudice, or discrimination. Descriptive statistics were used to analyse the topic distribution.

Limitations

This review focused on one database (NCBI) voluntarily different from the authors and did not include grey literature. Sample bias then relates to publication and source biases. NCBI is an evidence-based database and is not entirely representative of stigma research.

Findings

Articles retrieved

After verifying the content of 5104 abstracts, 1540 articles remained. 111, 836 and 550 articles were included for respectively prejudic*, stigma* and discriminati* search and 43 articles showed mixed terminology.

General characteristics of the studies

Year of publication ranged from 1919 to 2015. Research participants and/or authors affiliation come from more than 50 different countries including Australia, Belarus, Belgium, Bangladesh, Botswana, Brazil, Cambodia, Canada, Chile, China, Ethiopia, Finland, Ghana, Haiti, Iran, Italy, Jamaica, Japan, Kenya, Mexico, Mozambique, Namibia, Nepal, Nicaragua, Peru, Puerto Rico, Romania, Russia, South Africa, Tanzania, Thailand, Uganda, UK, Ukraine, USA, Vietnam, Zambia and Zimbabwe. Articles included were empirical studies, reviews, meta-analyses and editorials. Regarding the disciplinary background, it was impossible to identify one dominant discipline, as the professions of the authors, the journal or the content of the articles were mostly non-congruent (e.g. discrimination of people living with a condition published in a psychology review).

Themes distribution in prejudice, discrimination and stigma publications

The first topic distribution is shown in Table 14 and the main topic of each stigma and prejudice bibliography is compared to Phelan et al. (2008) in Table 15. The category “other” gathers all the topics with under five occurrences. Topics found in this category were: abortion, sexual practices, literacy, homelessness, violence, suicide, war soldiers and sexual violence. Among “ethnicity and other” are found combined characteristics (i.e ethnicity and gender, ethnicity and sexual orientation) and discrimination is related to both characteristics. A different distribution than the authors is observed. This can be explained by different databases and the narrowed research to keywords in titles only. Since 2008, publications on theoretical and assessment tools (e.g. validation study) increase for stigma only.

Table 14 Distribution of articles' main topic according to keywords

Topic	Keyword				Total
	Discrimination	Mixed keywords	Prejudice	Stigma	
Age	15	0	0	4	19
Assessment tool	4	0	0	40	44
Education	3	0	0	0	3
Ethics	3	0	0	0	3
Ethnicity	199	4	23	5	231
Ethnicity and other	61	1	0	0	62
Gender	22	0	4	0	26
Gender identity	0	0	0	4	4
Genetics	12	0	0	0	12
Health system	56	2	32	35	125
Illness / disability	52	29	21	662	764
Law and/or cases	16	0	0	0	16
Migrants	10	0	1	2	13
Not specified	42	2	3	1	48
Offender	2	0	0	2	4
Other	8	0	4	13	25
Positive discrimination	4	0	0	0	4
Sex work	0	1	0	7	8
Sexual orientation	13	1	8	20	42
Social class	1	0	1	1	3
Theory	4	3	13	36	56
Weight	7	0	1	4	12
Work	16	0	0	0	16
TOTAL	550	43	111	836	1540

A topic-related tendency is observed: discrimination with ethnicity, stigma with illness/disability, prejudice, to a lesser extent, with ethnicity and illness/disability. A geographical variation is noticed. The majority of discrimination studies are Northern American while more than 50 countries are represented for stigma studies. Finally, while prejudice studies seem to decrease, medically related stigma research and assessment tools (scales, questionnaires) increase.

Stigma and medical conditions

More than 50 different medical conditions have been identified (mental illness category includes schizophrenia, addiction, mood disorders, anxiety disorders). Among the 719 articles retrieved, 648 have a specific focus on medical conditions (theoretical and assessment tools have been included when condition-related).

The most frequent conditions are HIV/AIDS (42%), mental illnesses (37%), cancer, tuberculosis, epilepsy and obesity, STIs (2% each). Table 16 shows the distribution number of studies per medical condition. The seventy-one remaining articles do not focus on one condition (e.g. theoretical or generic reviews).

Table 15 Number of occurrences per conditions in stigma review

Condition	N (per condition)	%
BDHC, Bereaved adults Chagas disease, Child disorder of sex development, Cirrhosis, Colostomy, Cystic fibrosis, Down Syndrome, Fournier's gangrene, Genetic conditions, HIV and TB, Huntington disease, Infectious disease, Inflammatory bowel disease, Leishmaniosis, Malaria, Narcolepsy, Parkinson disease, Primary ciliary dyskinesia, Primary ovarian insufficiency, Psychotrauma, Rheumatology, SARS, Urinary symptoms.	1	0%
Congenital handicap, Ebola, H1N1, Migraine, Sickle cell disease (drepanocytosis), Terminally ill	2	0%
Deafness, dementia	3	0%
Podoconiosis	4	1%
Diabetes	5	1%
Eating disorder, Leprosy	7	1%
Public health	8	1%
STIs	13	2%
Epilepsy, Obesity, Tuberculosis	14	2%
Cancer	18	3%
Mental illness	267	37%
HIV/AIDS	306	43%
Not specific to one condition	71	10%
Total	719	100

Table 16 Distribution of the main topic compared to Phelan et al. (2008).

CHARACTERISTICS	PHELAN ET AL., 2008		PREJUDICE		STIGMA		DISCRIMINATION	
	Prejudice	Stigma	All	Since 2008	All	Since 2008	All	Since 2008
	N = 139 %	N = 162 %	N = 111 %	N = 61 %	N = 836 %	N = 697 %	N = 550 %	N = 349 %
Age				-	0.5%	0.4%	3%	3%
Education							1%	0%
Gender	7%	2%	3.6%				4%	5%
Gender identity					0.5%	0.6%		
Migration			0.9%		0.2%	0.3%	2%	3%
Race / ethnicity	62%	4%	20.7%	21.3%	0.6%	0.7%	47%	56%
Sexual orientation	3%	4%	7.2%	9.8%	2.4%	2.9%	2%	3%
Social class			0.9%	1.6%		0.1%	0.1%	
Illness/disability - Total		70%	12.6%	18.0%	79.2%	78.2%	9%	9%0
Illness/disability - mental health/illness	0%	38%	8.1%	6.6%	31.8%	30.6%		
Illness/disability - HIV AIDS	1%	16%	4.5%	4.9%	36.5%	38.5%	5%	5%
Illness/disability - Cancer					2.2%	1.9%		
Illness/disability - Other	6%	22%	6.3%	1.6%	8.7%	7.3%	4%	4%
Other - Health			28.8%	26.2%	4.2%	3.7%	10%	5%
Other -Unspecified characteristics	11%	2%	2.7%		0.1%	0.1%	8%	8%
Other - Other characteristics	6%	0%	4.5%	3.3%	3.2%	3.0%	7%	7%
Stigma - Theory			11.7%	19.7%	4.3%	4.4%	0.1%	0.1%
Stigma - Assessment tool/scale			0.0%		4.8%	5.5%	0.1%	0.1%

The degree of perceivability varies: obvious deformity (podoconiosis, gangrene), physical sign of a condition or state (Down syndrome, obesity, Parkinson), secondary or treatment signs (cancer), or socially unperceivable (child sex disorder). The blemishes of character or personal weakness attributions are reported according to two main aspects. The first one is the attribution of dispositional traits (narcolepsy with laziness, obesity, diabetes and eating disorder with lack of controllability with food). The second one is the condemnation of behaviours likely to lead to the condition (lung cancer, STIs). Discrimination, stigma and prejudice studies tend to focus on different objects. Prejudice seems to be less used and/or in conjunction with stigma. Prejudice, as the cognitive content underpinning stigma, is also more difficult to study or observe, than reported experiences of stigma.

Summary

This desk research aimed at identifying how discrimination, prejudice and stigma relate to similar or different topics. It highlighted that stigma studies are mostly focussing on health and/or specific conditions among which HIV. This desk research is a preliminary work to the rationale and argument focusing on the medicalisation of stigma studies and its corollary, the evidence-based morality in health research developed in Chapter 4.