OptTEST
OPTIMISING TESTING AND LINKAGE TO CARE FOR HIV ACROSS EUROPE

OptTEST: Literature review of legal and regulatory barriers to HIV testing and access to treatment & care in Europe

April 2017

Author: Lisa Power for OptTEST by HIV in Europe

This literature review was commissioned by the OptTEST by HiE project, coordinated by CHIP, RegionH, and produced by consultant Lisa Power.

Acknowledgments
Thanks to the OptTEST project partners and steering committee, in particular Sara Croxford, PHE, for help with the literature searches and the CHIP-team for edits and layout.

OptTEST is co-funded by the 2nd Health Programme of the European Union.

Disclaimer
The content of this report represents the views of the author and it is his/her sole responsibility; it can in no way be taken to reflect the views of the European Commission and/or the Executive Agency for Health and Consumers or any other body of the European Union. The European Commission and/or the Executive Agency do(es) not accept responsibility for any use that may be made of the information it contains.

Suggested citation:
Lisa Power for OptTEST by HIV in Europe, OptTEST: Literature review of legal and regulatory barriers to HIV testing and access to treatment & care in Europe, UK, 2017.

UK, April 2017

Contents

OptTEST: Literature review of legal and regulatory barriers to HIV testing and access to treatment & care in Europe

1. Background

This literature review was commissioned within the project OptTEST by HiE (Optimising testing and linkage to care for HIV across Europe) co-funded by the EU Commission. OptTEST ran from 2014 -2017 and aimed to help reduce the number of undiagnosed people with HIV infection in the European region and to promote timely treatment and care. It has resulted in a series of tools and assessment methods to analyse and effectively respond to late presentation for HIV care and treatment, with a particular emphasis on priority regions and groups throughout Europe. The tools are available at the project website: http://www.opttest.eu/Tools/

The literature review forms part of the OptTEST work stream focused on legal and regulatory barriers to HIV testing and access to care. The specific aim of this work has been to demonstrate the role of legal and regulatory barriers in hindering access to HIV testing, treatment and care across Europe and to produce tools to help dismantle them.

The literature review has informed a series of tip sheets and ten case studies intended to support and inspire the HIV community to address and overcome existing barrier (available here: http://www.opttest.eu/Tools/Addressing-Legal-And-Regulatory-Barriers-To-Testing). In addition a survey was conducted to assess country-specific data on legal and regulatory barriers. Based on this data the updatable, searchable and cross-comparable database "Barring The Way To Health" was produced (legalbarriers.peoplewithhiveurope.org), which contains country-specific data on some of the key issues raised in this review.

Given recent increases in the understanding of the role that early diagnosis and treatment play in preventing onward transmission of HIV as well as decreasing mortality and morbidity in people with HIV, there is a stronger impetus than ever to understand how countries can try to reach the 90-90-90 target. This UNAIDS target requires that by 2020, 90% of all people living with HIV will know their HIV status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90% of all people receiving antiretroviral therapy will have viral suppression. A vital component of understanding how to reach the targets is to understand where and why failures occur along the continuum of care.

Continuum of care data from the European Centre for Disease Protection and Control (ECDC) gathered while monitoring European countries for the Dublin Declaration (1) shows that 78% of responding countries had breakpoints

relating to diagnosis, 41% in linkage to care and 48% in getting people in care onto treatment. Most break points (other than initial diagnosis) were far greater in non-EEA countries; three times greater in linkage to care (78% vs 22%) and in Antiretroviral therapy (ART) to viral load (VL) suppression (60% vs 21%) and more than double from entry into care to accessing ART (75% vs 35%). Although differing ways of measuring the care continuum points in different countries make comparisons complex, this gives some indication of where barriers are occurring but not whether they may be due to legal and regulatory impediments.

Two thirds of responding countries, however, identified legal or policy issues which had an adverse impact on access to prevention, testing and/or care. The ECDC Evidence Brief on HIV and Leadership states the goal "that laws and policies are not barriers to the delivery of vital HIV services" as one of its main leadership issues in Europe.

The primary objective of this paper was to identify and review research which identifies legal and regulatory barriers to HIV testing and care, where it exists.

2. Methodology

The initial literature review, undertaken to inform the development of a toolkit, was carried out between January and October 2015 in the English language. A further search was made in November 2015 using the Russian language. A review of this was undertaken in April 2017 to produce a final document for publication.

A large number of papers were found on PubMed and Google Scholar using combined search terms; "HIV" and terms such as "barriers to testing" and "barriers to care". However, on review most of these did not address legal or regulatory barriers but social and financial ones, most commonly stigma, educational and prevention issues and funding concerns. Therefore a wider grey literature search was undertaken online to identify relevant reports and conference proceedings using "HIV", "barriers to testing (or) treatment (or) care" and key population identifiers. Where possible the search was restricted to the 53 countries of the Council of Europe; other papers were included only where they illustrated barriers otherwise given in anecdotal settings or where European studies were scarce (e.g. on self testing). Unpublished data on regulatory barriers from EATG and GNP+, gathered in the last two years, was included as it gave country-specific examples of current barriers. Material communicated to the researcher during the course of OptTEST work was also included in the 2017 revision, including data contained in the "Barring The Way To Health" survey.

In all, 52 papers and reports were identified in 2015 and a further 36 incorporated in 2017 (for full list see Appendix 1). The substantial and growing interest in this area of research means that further useful documents will continue to emerge post-publication; despite delaying as long as possible,

several research papers identified as likely to make a contribution were still in pre-publication and unable to be accessed at time of final edit.

2.1 Definition of legal and regulatory barriers to access

For the purposes of this paper, legal barriers are defined as legal statutes or instruments passed by the Parliament or ruling body of a country and subject to its legal processes. These have been broken down into two categories:

- Direct legal barriers such as laws which prohibit and punish certain sexual behaviours by people with HIV or laws which criminalise certain sexual or social behaviours by key affected populations and thus discourage or debar them from accessing HIV testing and/or care, and
- Indirect legal barriers which are defined as lack of legal protections for people with HIV which may deter them from any act which could identify them as such, including seeking testing and/or care and fail to give them legal redress against discriminatory acts. However, stigma as such is not included because it is a societal rather than legal or regulatory barrier.

Regulatory barriers are defined as regulations, which may be national or local, which guide how, where and when HIV-related testing and care services may be provided. These may be laid down by governmental instrument or healthcare bodies but they are administrative and do not require legislative action to change them. Again, these are considered in two categories:

- Direct regulatory barriers such as those covering types of test that can be used, who can test and who can provide care (and where this may be done). It also includes prison regulations which hinder access to e.g. ART and financial barriers to testing and/or care (particularly for migrants).
- Indirect regulatory barriers are defined as the lack of evidence-based good practice guidelines or national guidance on best practice in provision of HIV testing and/or care.

2.2 Definition of key populations

For the purposes of this project, key populations were defined as: men who have sex with men (MSM); people who inject drugs (PWID); sex workers, transgender people, prisoners and migrants.

3. Identification of legal and regulatory barriers to HIV testing and care (the care continuum) in Europe

Legal Barriers (Direct)

The impact of laws criminalising HIV transmission/exposure or key populations are mostly relatively well documented areas of research in human rights literature, but the link to HIV and access to the continuum of care has often been restricted to the stigmatising impact of the law, with less regard paid to the practical barriers that it may throw up.

3.1 Criminalisation of perceived exposure & transmission of HIV

Seventeen papers identified barriers relating to criminal prosecutions or police investigations for perceived exposure or actual transmission of HIV. These ranged from the general to the specific:

- Punitive laws fuel the HIV epidemic (12, 84)
- Criminalisation deters testing for HIV (13, 18, 25, 34, 37, 88)
- Criminalisation impedes access to treatment & care (13, 34, 38, 71, 84) including deterring PLHIV disclosure of risk behaviours which might otherwise trigger ART treatment as treatment as prevention (TasP)
- Prosecutions disproportionately affect migrants (6, 24, 25, 39, 50) and sex workers (39) and do not reflect the epidemic (25, 50)
- Prosecutions do not reflect HIV science or social complexities (6, 25, 49, 50,79)
- Stress of lengthy criminal cases (38, 49) contributes to treatment disruption (38)
- Prejudicial media coverage of HIV criminal cases demonises people with HIV (38, 49) and deters testing (38), specifically in at-risk individuals (83)

There is a wealth of literature on criminalisation of HIV but few published studies provide concrete evidence of the harms caused and barriers raised. A recent IAPAC policy paper (34) recommended “Laws that criminalize the conduct of people living with HIV (PLHIV) based on perceived exposure to HIV, and without any evidence of intent to do harm, are not recommended and should be repealed where they have been enacted”. However, while giving the recommendation its highest rating of importance (a), it simultaneously gave it its lowest rating of evidence quality (iv).

Of greatest use in examining barriers were papers which documented actual cases and systems (6, 49, 50) and those which reported service provider reactions (38) and statements by formal country representatives that criminal prosecution of HIV exposure or transmission creates a problem (71).

3.2 Criminalisation of activities of key populations: sex workers

Sixteen papers identified specific barriers relating to criminalisation of sex work (SW) and sex workers (SWs):

- Detention or arrest of SWs as a barrier to using HIV services generally (9, 10, 13, 85)
- Countries where aspects of SW are legalised have significantly lower HIV prevalence among SWs than those who fully criminalise it (73)
- Criminalising of SW deters women from accessing HIV testing (88) and care (34, 37, 42, 71)
- Arrest and forcible testing of SWs creating a moral panic (15)
- Mandatory testing in state licensed brothels drives majority of SWs underground (and thus away from testing and care) (40, 75)
- Reluctance to disclose SW even in partially decriminalised setting deters majority of female SWs from disclosure to GP (41) or where there is no option of anonymity (74)
- Use of centralised administrative records across a range of social institutions makes many SWs reluctant to disclose (74)
- Migrant SWs unable to access free treatment in some countries (42, 75) and health insurance regulations may be a barrier, especially for migrant SWs (74, 75)
- Prosecutions for HIV perceived exposure and transmission disproportionately affect SWs (39)
- Fear of deportation or prohibition of residence deters migrant SWs from services (74)

Papers relating to sex workers, although often academically more rigorous, tended to cover the stigma of sex work more often than legal or regulatory barriers. Where these were shown, they were often intersectional with other identities (e.g. undocumented migrant sex workers). However, one major European comparative study (73) clearly demonstrated a correlation between criminalisation and higher rates of HIV in SWs and the ECDC Special Report (85) identified six countries where even the government respondents identified their current SW laws as a barrier to HIV testing and treatment.
It was notable that sex workers, along with migrants (and often simultaneously both) were identified as a group disproportionately affected by prosecutions for HIV exposure, perceived exposure and transmission.

3.3 Criminalisation of activities of key populations: sex between men

Eight papers dealt with the small number of countries with continuing anti-gay legislation, primarily what are known as “gay propaganda” laws which prevent “promotion” of homosexuality by association or information provision. Most European countries now have equalised ages of consent, with a small caveat for age-discordant relationships in Greece where it is 17 for MSM but 15 for all others. Social regulation of homosexuality increases in the East (14) and this is where what European-specific data was available emerged:

- legal and regulatory barriers to MSM activities are harmful in an HIV context (86), particularly those relating to forming gay community organisations (13)
- Anti-gay legislation triggers violence and deters access to gay community and HIV services (45)

- Anti-gay propaganda laws deter men from disclosing sexual identity to service providers (46)
- Repeal of anti-gay laws would optimise the care continuum (34)
- Alternative testing facilities and linkage to care needed for MSM in Russia (26)
- Bureaucratic obstacles to registering NGOs and to receiving external funding may particularly affect MSM services (72)
- Service characteristics such as opening hours and location may deter some MSM (72)
- 6/41 European countries surveyed had no legal protection for MSM against discrimination in service provision (72)
- Lack of trust in confidentiality affects access for MSM (72, 86)
-

Given that moves towards more repressive anti-gay laws in a small number of Eastern European countries were recent, relatively few papers so far have done more than condemn these moves based on assumptions. There is a considerably larger body of evidence for the direct impact of anti-gay laws in Africa and Asia, not included here as much of it relates to direct criminalisation of gay sex rather than "propaganda" laws. There is also a substantial body of research about the impact of stigma on MSM (and most other key populations) access to HIV services, notably the lack of any targeted testing programmes for them in most non-EU/EEA countries, but this was not within the scope of the current search. ECDC Thematic Reports on MSM for both 2015 and 2017 were included in this section as they contained some different topics.

3.4 Criminalisation of activities of key populations: transgender people

While seven papers were identified as explicitly relating to transgender legal or administrative issues in Europe, many more covered stigma as a barrier. There were many other papers relating to trans people and general healthcare but not specifically HIV services and these were thus excluded from the current review.

- 11/47 European states have no provision for legally changing gender identity while, of those who do, many mandate sterilisation or divorce as a condition (48, 54)
- Lack of, or complexity of legal protocol to obtain new ID documents (54, 80)
- Transgender people included in "gay propaganda" laws (48, 53)
- Provider refusals to test or treat transgender people (52) as their documentation may not match their presenting identity (82)
- Intersectionality of trans women as sex workers enhances barriers (53)
- Lack of recognition of transwomen means sex interpreted as "with another man" and thus shunned (53)
- Erasure of trans identities from recorded data by being reported as MSM sexual transmission (80, 81) means issues and needs not recognised

Many of the papers identified for MSM also referred to transgender people. However, transgender people also face a different set of legal issues to other lesbian, gay, bisexual, transgender (LGBT) people in that they are as often, if not more, negatively impacted by lack of supportive laws rather than directly punitive laws. There is also, as the Open Society Foundation noted (54), "an incomplete and inaccurate picture of HIV in transgender communities" through lack of data which distorts service provision and deters access.

3.5 Criminalisation of activities of key populations: people who inject drugs (PWID)

Ten papers referenced laws covering illegal drugs and those who use them. In some cases it was difficult to divide legal and regulatory barriers and some of the below may refer to the latter.

- Imprisonment or detention of PWID is a barrier to ART treatment (2, 9, 10, 69, 70)
- Detention of PWID hinders access to HIV care in general (9, 10, 71)
- Reporting to police registers of PWID seeking treatment (69)
- Repeal of legal measures against PWID would optimise the care continuum (34)
- Limited or no access to opiate substitution therapy (OST) in many countries deters adherence to HIV care (13, 17) The same applies to heroin-assisted therapy which the International Narcotics Control Board (a UN-sponsored body) has obstructed the use of (17)
- Decriminalisation of drug use is linked to a drop in new HIV diagnoses and mortality (13)
- Police presence at medical centres deter access by PWID (79)

Injection drug use is one of the areas where there is excellent evidence of how differing governmental attitudes to using the law can impact on public health. The contrast between studies of Portugal and Switzerland, where decriminalisation or provision of harm reduction turned an epidemic around, and Russia where incarceration and abstinence are official policy and HIV is soaring, is stark. However, this is one area where a parallel literature review in Russian would have been helpful since there must be more papers on the Eastern European experience which were not accessed due to the language barrier.

3.6 Criminalisation of activities of key populations: migrants

In all 19 papers were identified which referred specifically to legal barriers and related regulatory restrictions for migrants. Most of these related to undocumented or illegal migrants but some covered other restrictive legal barriers or the knock-on effect on legal migrants through confusion and/or fear. Multiple European countries report generalised barriers to healthcare for migrants (5, 13, 22, 87).

- Restrictions on entry, stay or residence for PLHIV migrants in 8 EECA countries (63)

- No access to anything but emergency care without correct papers (4, 13, 55, 57, 58, 60)
- Other restrictions on access to treatment for undocumented migrants (32, 55, 56, 57, 58, 71, 87)
- Complexity of regulations and system deters access (32, 36, 55, 56, 57,58, 60)
- Mandatory HIV testing as a visa/residence permit requirement (16, 24)
- Only “unofficial” access to healthcare (4)
- Seeking HIV support triggers reporting to other authorities/deportation (4, 32, 55, 58, 60)
- Restrictive immigration policies and laws deter migrants from testing, particularly Black Africans (24), undocumented migrants or people from high prevalence areas for HIV (87)
- Disproportionate prosecutions of migrants for HIV transmission/exposure offences (6, 24, 25, 39)
- Denial of ART while in detention centres (13)
- Failure to comply with legal rights to access by some hospitals (32, 55, 58)
- Restricted access to specific centres for undocumented migrants (58)
- Healthcare access restrictions used to deter migrants (59)
- Inability to register for healthcare/link to care after testing without a permanent address (60)

Most barriers in this section were the result of a lack of legal immigration status but it was also clear in some papers that the barriers were blurred due to individual health care staff refusing to implement them on humanitarian or public health grounds. In some countries, asylum seekers were also restricted in what they could access (60). The devolution of healthcare in some countries also helps create a mass of bureaucratic requirements which can vary, e.g. 18 different sets of regulations in Spain (60) each of which can take months to negotiate. This creates a “word of mouth” culture for accessing healthcare which can also act as a deterrent, promulgating rumours of reporting to immigration authorities which are sometimes justified e.g. in Germany (4). Failure to abide by laws or regulations can operate in both directions, with five out of 24 European countries reporting routine testing of migrants for HIV despite no mandatory testing requirement (24). Please note that both the 2015 and 2017 ECDC Thematic Reports on Migrants are included, due to some variations in topics covered.

3.7 Legal barriers relating explicitly to prisoners

Five papers relating to each of the key populations above also covered incarceration, since this is a potential result of punitive laws. In particular, there was a strong crossover for people who inject drugs (PWID), with 28 of 29 respondent countries to an ECDC survey (12) reporting intersectional risk between prisoners and PWID. Links were also demonstrated between prisoners, sex workers and undocumented migrants. Again, many documents examined concentrated more on prevention problems in prison than barriers to testing and treatment.

- No HIV testing in all (2 countries) or some (12 countries) prisons (12)
- In 3 countries (Bosnia & Herzegovina, Kyrgyzstan, Ukraine) governments reported that there was mandatory HIV testing in prisons but civil society respondents reported this was not being done (12)
- HIV treatment is not always available to prisoners (12, 69)
- Legal & regulatory barriers to harm reduction measures such as OST and needle exchange are widespread (12)
- alternatives to detention can be as crucial to HIV treatment as ARVs (2)
- ARVs not always accessible in detention centres for undocumented migrants (13)
- lack of coordinated referral between prison and civil authorities (7)

3.8 Other Legal Barriers for PLHIV

A small number of other forms of legal barriers affecting PLHIV were found which did not fit into the above. In the case of Turkey, it is illegal for PLHIV to marry; those wishing to marry must provide blood test results for HIV, HCV, BHV and syphilis which show that they have "no contagious diseases" (79). In Sweden, it is illegal to provide anyone under the age of 20 with needles and syringes (62). In Russia, migrants diagnosed with HIV will be deported (79).
The other legal barrier reported was the age of consent below which parental consent is required for an HIV test (61). This will be covered in 3.13 but is noted here because in many countries it is a legal, rather than a regulatory requirement.

3.9 Legal Barriers (Indirect): lack of protective laws

Six papers referred to the role of protective laws and the lack of them as a barrier, though this was not closely examined by either.

- Only half of EU/EEA countries prohibit HIV screening as a prerequisite for general employment (5)
- Four countries report systematic HIV testing for employment (16, 79)
- The majority of European countries do not include gender identity in their anti-discrimination laws (48, 54)
- As noted above in 3.3, 6/41 European countries surveyed had no legal protection for MSM against discrimination in service provision (72)

Regulatory barriers (Direct)

Although a surprisingly high number of papers referred to some form of regulatory barrier, the descriptions were vague. The majority of practical examples of barriers were given in non-governmental organisation (NGO) discussion papers rather than academic journals or policy papers. There were also relatively few evidence-based examples of impact. Many papers examined focused on stigma and the impact of health carer attitudes, or impact of these upon prevention and regulatory barriers were sometimes hard to disentangle from this.

3.10 Testing regulations and practices

The literature was relatively robust in this area with 27 papers, many of them covering multiple potential barriers. Some papers covering novel topics such as self testing were of necessity from outside Europe due to laws on this form of testing only recently or currently undergoing change. Issues addressed included a variety of ingenious barriers:

- Prohibitions on community (CBVCT) and/or rapid testing (3, 16, 30, 61, 68) including rapid testing only in clinic (30) which particularly deters key populations at risk (88), including MSM (86) and which would increase testing (3, 16, 19)
- Legal barriers to provision of HIV self testing (88) which would increase testing (19, 21, 23, 28, 29)
- Legal barriers to use of HIV self-sampling tests (88)
- Prohibitions on where testing can take place and who can test varying by target group (but often not enforced) (79)
- Prohibitions on who can perform HIV tests (15, 23, 27, 30, 33, 34, 61, 77, 88) which covered
  - Only specialist doctors (30,33)
  - Only doctors and nurses (30, 61, 77, 79)
  - Only doctor/healthcare personnel allowed to interpret result (30, 61)
  - NGOs requiring health board permission or certification (30,33)
  - Dried blood spot tests only to be done by laboratory assistants (30)
  - Testing only to be done by authorised laboratories (30)
  - Only medical personnel to take blood (inc. dried blood spot) (30)
  - Others can do the test but doctor must be physically present in the facility (30, 79)
- Prohibitions on who can perform pre/post test counselling (61)
- Prohibitions on where testing can take place (15, 30, 33)
- Prohibitions on disposal of waste (33)
- Lengthy waits for results deter from testing (23, 51, 72)
- Testing clinic opening hours inconvenient (42, 51, 64, 68)
- Lack of HIV testing in drugs services (13)
- Requirement to show identity documents to get confirmation of initial diagnosis (63, 77, 79)
- “Free” testing requiring proof of social insurance (32)
- Testing in prisons only available to those with health insurance (79)
- Intensive pretest counselling as a barrier (19, 21)
- Requirement for written informed consent (65)
- Long distances to small number of licensed testing centres (21, 64, 68, 79)
- Testing limited to specific hospitals only (23)
- Greater difficulty of changing testing regulations where they are enshrined in law (23, 27)
- Failure to update testing regulations or guidance, in some cases for a decade or more (27, 65, 77, 88)
- Lack of national guidelines (88)

- Failure to target key populations (63, 68, 77) including gaps in services (88)
- Free testing actively targeted at wrong populations (77)
- Alternative testing facilities and linkage to care needed for key populations (26, 68)
- Clinician opposition to community based testing (CBT) (77) unless it employs them to be present (33)
- Large variations in cost of CBVCT due to varying wholesale prices of self-tests and varying requirements for staffing facilities (67)
- Lack of confidentiality in primary care settings serving the entire family (64)

It would appear from the above that Europe would benefit from greater harmonisation of testing guidance, as suggested by Deblonde, ECDC and other papers. The majority of respondents to a WHO Europe survey in 2007 (16) said that their country's testing and counselling policies needed change and that the services were not easily accessible, and little appears to have changed on this. One paper from Scotland (51) illustrated this by a comparative survey of barriers to testing amongst gay men in 2000 and in 2010 which showed that while some other barriers had significantly reduced, those related to clinic structures had not. A 2013 review of testing guidelines across Europe (65) found “guideline gaps” on community based and self-testing and on testing for migrants and those under 18.
One paper exploring the acceptability of self-testing (64) found that the level of complexity in instructions for administration of self-testing which was required to obtain EU licensing was felt to over-complicate the process by some potential users.

Deblonde et al (9) posited the need for better evidence of barriers but work done by EATG and GNP+ (30, 33, 79) give strong country-specific examples as a basis for this. However, regulatory barriers to testing are often either an accustomed feature of the wider healthcare system, particularly in ex-Soviet countries, or are supported by specialist clinicians who do not accept task shifting as a necessary change or oppose the loss of control over what they perceive as part of their speciality. Given the recent changes in understanding of the importance of testing to prevention as well as care, this is obviously a priority area alongside wider regulatory barriers to the care continuum (see below).

3.11 Regulations which impact on the continuum of care beyond testing

Twenty two papers, almost as many as for testing barriers, outlined regulations or working practices which deterred people from accessing HIV care of various kinds including treatment.

- Separation of healthcare into vertical specialities (e.g. HIV, drugs, TB) which hinders successful linkage and referral (1,2,7,8,35, 69, 71)
- Significantly lower levels of integrated care with HCV, HBV, TB or cardiovascular services (71) particularly in EECA countries (76)

- Lower level of access to resistance testing in EECA countries (76)
- Appointment systems and lengthy waits for referral (2, 33, 35, 43, 44)
- Inflexibility in clinic hours can deter sex workers from treatment access (42)
- Poor communications between HIV and drugs services (7)
- Lack of case management systems (35)
- Failure to provide OST destabilises patients in care (1, 2, 8, 70)
- Current illegal drug use a barrier to HIV treatment access (69) in 63% of EECA countries (77)
- Regulations preventing/interrupting ART in prison settings (1)
- Lack of referral systems between prison and civil authorities (7)
- Decentralised healthcare systems lead to localised non-evidence based policies (7), practices (78) and confusion about rights to access (66)
- Failure to follow EACS guidelines on treatment initiation (76)
- Complex administrative requirements to initiate or change treatment (69)
- Limited range of ART access points (8)
- Referral systems more complex for NGOs (33) with 1 in 5 CBVCTs having no formal referral agreements (61)
- Ineffective linkage to care (72)
- Clinic refusal to accept NGO referrals, insisting on re-testing via primary care (33)
- Fragmentation of healthcare system requiring multiple appointments while needing to maintain employment (35)
- Failure to integrate healthcare with social support organisations (43)

These barriers fell into the categories of barriers caused by healthcare system structural failures; inadequate HIV specialist provision; inadequate linkage and case management systems; and added barriers to NGO participation. While there were particular barriers for some groups (PWID, prisoners) some of those found in studies of a single group may impact more widely (e.g. restricted clinic hours). It was notable that many of these barriers have been removed or reduced in some healthcare systems but not others (e.g. lengthy waiting times, opening hours, integrated services) and that an emphasis on sharing relevant good practice across countries in Europe might be helpful. There were many more reports of systemic barriers and poor or outdated organisational practices reported from EECA countries, but barriers to treatment and care exist across Europe.

3.12 Regulations which create financial barriers:

These seven papers included the impact of direct financial regulations on both testing and treatment and the indirect impact of healthcare systems where bribery is acceptable and even expected.

- Anonymous testing charged for (30, 47)
- Lack of, or insufficient insurance to cover HIV treatments (35) (see also migrants section)

- Lack of affordable care may particularly deter migrants from testing (24)
- Complex entitlement regulations deter access (24)
- “Out of pocket” payments common for medical services in Russia (7)
- Hidden or “collateral” fees where patient is a PWID (69)
- Bribes requested for treating people with HIV (33)
- Laboratories charge NGOs more than state systems for processing their HIV test results (33)

While only one paper (30) explicitly identified health insurance systems as a general barrier, it is suspected that this is an under-scrutinised area. There were a substantial number of reports of it as a specific barrier to undocumented migrants, which have been included in the section on migrants above. There is also a complex relationship between health insurance systems and confidentiality; for example, in Switzerland (47) you can get tested anonymously, provided that you pay for it, but if you are tested under your health insurance, your insurer will be notified of the result. While the issue of bribes, or out of pocket payments, is not strictly one of regulations, it was included as an essential barrier within the healthcare system which is not necessarily stigma-related.

3.13 Regulations which hinder confidentiality or anonymity

Only seven papers directly laid out barriers caused by loss of anonymity, though many more stated it as a fact without giving details. This was enhanced by personal communications about testing in Switzerland.

- Anonymous testing is chargeable (30) but free testing can cause disclosure to insurer (47)
- Testing is anonymous but referral requires disclosure of personal details (33)
- Testing is officially anonymous, but you must show your passport or identity card to access it (33, 79)
- No anonymous testing in Turkey (5)
- Treatment & care access is hindered by poor confidentiality (71)
- Many sites refuse to test minors without parental consent (15, 61)

A small number of papers described testing practices which, while nominally anonymised, were in practice nothing of the kind. The other barrier, raised in only two papers but repeatedly in conversation with the author by people from Eastern and South-Eastern Europe, is that of refusal to test minors (actual age dependent on country-specific laws) without parental consent, even where that minor is clearly sexually active. A survey of the age of consent to test issue (61) suggests that there is also substantial confusion between testing sites and authorities as to the in-country law in this area.

3.14 Regulatory barriers (Indirect): lack of guidelines for best practice in testing and care

Nine papers covered barriers caused by a lack of recognised or official best practice guidelines, or by the failure to actively promote such guidelines.

- Decentralisation of healthcare policy decisions leads to local guidelines that are not evidence based (7)
- Lack of guidelines leads to inconsistent provision of key services (9)
- Inconsistency in testing guidelines across Europe is problematic (15, 24)
- Failure to update testing guidance (27)
- Lack of redress where guidelines not adhered to (15)
- Rollout and implementation of directive on universal offer of antenatal screening results in significant increases in uptake (9)
- Lack of awareness of existing guidance hinders implementation (9)
- Laws or guidelines preventing HIV discrimination often ignored (13)
- Practice often differs from policy (15, 27, 33, 79) sometimes due to financial constraints (27)

While a number of calls for European testing guidelines - particularly for key populations - were made, it was notable that as many references concerned failure to follow or use guidelines as to their absence or inadequacy. The example of English antenatal screening rollout (9) was cited as an excellent evidence-based example of how guidelines must not only be written, but also need training and leadership in implementation to be successful.

3.15 Other regulatory barriers:

Four papers made useful observations which did not fit into the categories above.

- A systematic overview found a lack of structured information addressing legal, administrative and financial barriers (9)
- Lack of harm reduction due to medical regulations fuels HIV transmission (17)
- At least three governments had legal barriers to rapid testing and outreach testing, yet allow (and in one case supervises and funds) such services through NGOs (33 , 79)

The last two reports cited here provide an excellent example of the triumph of pragmatism and public health concerns over legal or regulatory red tape. The same could be said for the many health services across Europe which ignore legal or regulatory barriers, in particular those hindering treatment for undocumented migrants, in order to protect public health as well as individual.

4. Conclusions and Next Steps

Many of the papers and reports identified were primarily about wider issues, often with one paragraph within them referring to legal and regulatory (the latter often called “policy” or “systemic”) barriers. In particular, relatively few papers were found which gave specific examples of regulatory barriers within European countries and evaluated their impact. Where these existed they were often in the grey literature. It would be extremely useful to create a more complex map of country-specific barriers in order to make useful comparisons and to target reform.

Linked to this, it was also apparent (particularly from the Dublin Declaration reports and EATG/GNP+ data) that civil society reports of barriers could be both more concrete but also more critical than governmental sources. In determining legal and regulatory barriers it is important not just to rely on official reports of what should be happening but also to ask for the experiences of the people things are happening to (or not happening when they should be, in some cases).

While some of the barriers identified may require major changes to wider health systems, or long term legal reform, many are open to a simple change in regulations or custom and practice. It would be helpful if a body such as ECDC were to further highlight good practice in removing regulatory barriers and to encourage clinicians and healthcare policy makers in particular to review ways of working which may no longer be appropriate in light of new knowledge about the importance of rapid testing and early treatment alongside more holistic care, and in dialogue with the people whose care is (or is not) being provided.

Appendix 1: Reference list

(1) Thematic Report on Continuum of Care, Monitoring Implementation of the Dublin Declaration, ECDC 2015
(2) Beyrer et al, Time To Act: a call for comprehensive responses to HIV in people who use drugs, Lancet 2010; 376:551-63
(3) Yang et al, The acceptability of different HIV testing approaches: cross sectional study among GMSM in Australia, Sex Trans Infect 2014; 90:592-595
(4) Synthesis of National Country Reports on HIV and migrants in EU, Euro HIV EDAT, 2014 eurohivedat.eu
(5) Evidence brief: HIV and Leadership. Monitoring implementation of the Dublin Declaration, ECDC 2015
(6) Bolumar-Monteroa et al, Time trends, characteristics and evidence of scientific advances within the legal complaints for alleged sexual HIV transmission in Spain 1996-2012, AIDS Care 2015;27(4):529-35
(7) Tkatchenko et al, Why do health systems matter? Exploring links between health systems and HIV response: a case study from Russia, Health Policy Plan. 2010 25(4):283-291
(8) Bobrova et al, Obstacles in provision of anti-retroviral treatment to drug users in Central & Eastern Europe and Central Asia: a regional overview, Int Journal Drug Policy 2007 18(4) 313-318
(9) Deblonde et al, Barriers to HIV testing in Europe: a systematic review, Eur J Public Health 2010 Aug;20(4):422-32
(10) Bollini et al, HIV prevention in prisons – do international guidelines matter? Eur J Public Health 2002; 12:83-9
(11) Aral et al, Commercial sex work, drug use and sexually transmitted infections in St Petersburg, Russia. Soc Sci Med 2005; 60:2181-90
(12) Thematic report: HIV and Prisoners, Monitoring implementation of the Dublin Declaration. ECDC; 2015
(13) HIV and the Law: Risks, Rights & Health, Global Commission on HIV & the Law, UNDP 2012
(14) Platt et al, HIV in the European Region: using evidence to strengthen policy and programmes, World Bank & WHO 2013 report #78187
(15) Overcoming Obstacles to Testing, report from NeLP's prevention & testing project, Sarajevo 2014
(16) Khotenashvili et al, HIV testing and counselling policies and practices in Europe: lessons learned, ways forward HIV Medicine 2008: 9 (Suppl 2) 30-33
(17) Csete & Grob, Switzerland, HIV and the power of pragmatism: Lessons for drug policy development, Int J Drug Policy 23(2012)82-86
(18) Weait, Intimacy & Responsibility: The Criminalization of HIV Transmission, Routledge-Cavendish (2007)
(19) Mavedzenge et al, A Review of Self-Testing for HIV: research & policy priorities in a new era of HIV prevention CID 2013:57
(20) Flavell et al, Dried blood spot testing: an alternative to point of care testing in public venues, Sex Transm Inf Online First 10.1136/sextrans-2014-051684

(21) Bavinton et al, Which Gay Men Would Increase Their Frequency of HIV Testing with Home Self-Testing?, Aids Behav (2013) 17:2084-2092
(22) Pharris et al, From Assessment to Action: HIV in migrant populations in Europe, ECDC 2012
(23) Mattioli et al, HIV test: which is your best? A national survey on testing preferences among MSM in Italy, JIAS 2014, 17(suppl 3):19598
(24) Fakoya et al, Barriers to HIV testing for migrant black Africans in Western Europe, HIV Medicine (2008) 9 (suppl 2) 23-25
(25) Criminalisation of HIV Transmission in Europe, a rapid scan GNP+/Terrence Higgins Trust 2005 (online paper)
(26) Wirtz et al, The HIV care continuum among men who have sex with me in Moscow, Russia, Sex Transm Infect doi:10.1136/sextrans-2015-052076
(27) Mounier et al, HIV testing strategies across European countries, HIV Medicine (2008) 9(suppl 2), 13-19
(28) Greacen et al, Internet using men who have sex with men would be interested in accessing authorised HIV self-tests, AIDS Care 2013; 25(1): 49-54
(29) Greacen et al, Access to and use of unauthorised online HIV self tests by internet-using French-speaking MSM, Sex Trns, Infect 2012 Aug; 88(5):368-74
(30) HIV community based voluntary testing in Europe and Central Asia, 2014, EATG internal paper (unpublished)
(31) Raymond et al, Large disparities in HIV treatment cascades between eight European and high income countries: analysis of break points. AIDS 2014, Melbourne (poster)
(32) European HIV Legal Forum Report (2016)
(33) Notes of Shell Project and WP7 OptTEST meeting (unpublished, personal communication) Tallinn 2015
(34) Guidelines for Optimizing the HIV Care Continuum, IAPAC 2015
(35) Williams et al, Qualitative Assessment of Barriers and Facilitators to HIV Treatment, J Assoc Nurses AIDS Care 2011 Jul-Aug; 22(4): 307-312
(36) Perez-Molina et al, How is the implementation of the new legal framework for healthcare affecting HIV-infected immigrants in an irregular situation in Spain? Enferm Infecc Microbiol Clin 2014
(37) Sexual Health, Human Rights and the Law, WHO report, 2015
(38) Dodds et al, Keeping Confidence, Sigma Research 2013
(39) EATG/IPPF/DAH Berlin Criminalisation Seminar report, EATG 2012
(40) Odabasi et al, The Experience of Violence and Occupational Health Risks of Sex Workers Working in Brothels in Ankara, Balkan Med Journal 2012 Jun; 29(2)153-159
(41) Jeal, Salisbury, Self reported experiences of health services amongst female street based prostitutes, Brit Journ Gen Practice54.504 (2004)515-519
(42) WHO, UNFPA, UNAIDS, NSWP, World Bank, Implementing comprehensive HIV/STI programmes with sex workers (2013)

(43) Burns et al, Why the(y) wait? AIDS Care 2007 Jan;19(1):102-8
(44) Burns, Fenton, Access to HIV care amongst migrant Africans in Britain, Psychol Health Med 2006 Feb; 11(1):117-125
(45) Beyrer, Pushback: the current wave of anti-homosexuality laws and impacts on health PLOS Med 2014 11(6):e1001658
(46) Efremov et al, Success of evidence-based combined HIV prevention amongst Siberian gay men, poster, AIDS 2014 Melbourne MOAE0204
(47) personal correspondence with Swiss residents, 2015
(48) TGEU, Transrespect versus Transphobia Worldwide report 2012
(49) Policing Transmission, Terrence Higgins Trust, 2009
(50) Power et al, Understanding Criminal Prosecutions for Sexual Transmission of Disease, Terrence Higgins Trust, 2015
(51) Flowers et al, Has testing been normalised? HIV Medicine 2013 14:92-98
(52) Sperber et al, Access to healthcare for transgender persons, Int Journ Trans Vol 8 Issue 2-3
(53) Baral et al, Human Rights, the Law and HIV amongst Transgender People, working paper, Global Commission on HIV & the Law
(54) Transforming Health, Open Society Foundation (2012)
(55) Thematic report: HIV and Migrants, Monitoring implementation of the Dublin Declaration. ECDC (2015)
(56) Migrant Health Working Group of COHERE (EuroCoord), Timing of cART initiation in male and female migrants living with HIV in Western Europe; JAIDS 2017 (pre-publication online)
(57) PICUM, Undocumented migrants with HIV/AIDS in Europe; 2010 (online update report)
(58) Medecins du Monde European Observatory, Access to Healthcare for Undocumented Migrants in 11 European countries (2009)
(59) HUMA Network Report, Access to Healthcare for Undocumented Migrants and Asylum Seekers in 10 European Countries (2009)
(60) EuroHIV EDAT, Access to HIV testing & linkage to care for migrants in the European Union; undated report online (est. 2016)
(61) COBATEST, Qualitative Study Report on Implementation of CBVCT Testing Programmes; undated report online (est. 2016)
(62) Personal communication via EATG member
(63) Tsereteli (ECOM), HIV Testing in EECA; presentation to HepHIV Conference, Malta (2017)
(64) Witzel TC et al, HIV self testing among MSM in the UK; Plos One 11(9)eo162713
(65) HIV in Europe, HIV Testing Services: analysis of guidelines and perceptions of practice across WHO European Region; Mar 2016 (online report)
(66) Lepir, B., Community engagement in ensuring access to HIV services (EATG Policy Working Group presentation May 2016)
(67) Casabona, J., Introductory remarks, OptTEST/EDAT joint meeting, Madrid (May 2016)

(68) Evidence brief: HIV Testing in Europe, Monitoring implementation of the Dublin Declaration ECDC (2015)
(69) Wolfe et al, Treatment and care for intravenous drug users with HIV infection: a review of barriers and ways forward; Lancet 2010; 376; 355-66
(70) Thematic report: HIV and People Who Inject Drugs, Monitoring implementation of the Dublin Declaration. ECDC (2015)
(71) Thematic report: HIV and Treatment & Care, Monitoring implementation of the Dublin Declaration, ECDC (2017)
(72) Thematic report: HIV and Men who have Sex with Men, Monitoring implementation of the Dublin Declaration, ECDC (2015)
(73) Reeves et al, National sex work policy and HIV prevalence among sex workers in 27 European countries, Lancet Vol 4 No 3 e134-40 Mar 2017
(74) TAMPEP, Sex Work, Migration, Health (2009 report online)
(75) TAMPEP, Sex Work in Europe (2009 report online)
(76) Lazarus et al, Disparities in HIV clinic care across Europe, BMC Infectious Diseases Jul 2016
(77) EATG, personal communication from unpublished member survey, Jan 2017
(78) WHO, European Consultation Report on Draft Strategies for HIV, Viral Hepatitis and STIs, Copenhagen 2015
(79) GNP+, EATG, OptTEST, Barring The Way To Health website data (Feb 2017)
(80) Divan et al, Transgender social inclusion and equality, JIAS Vol 19 Supp 2 (2016)
(81) Poteat et al, Transgender social inclusion and equality, JIAS Vol 19 Supp 2 (2016)
(82) Scheim et al, Transgender social inclusion and equality, JIAS Vol 19 Supp 2 (2016)
(83) Lee SG, Criminal Law and HIV Testing, Yale J Health Policy Law Ethics 2014 Winter; 14(1):194-238.
(84) Byrne et al, HIV Criminal Prosecutions and Public Health, Medical Humanities 2013- 010366
(85) Thematic report: HIV and Sex Workers, Monitoring implementation of the Dublin Declaration, ECDC (2015)
(86) Thematic report: HIV and MSM, Monitoring implementation of the Dublin Declaration, ECDC (2017)
(87) Thematic report: HIV and Migrants, Monitoring implementation of the Dublin Declaration, ECDC (2017)
(88) Thematic report: HIV Testing, Monitoring implementation of the Dublin Declaration, ECDC (2017)

OptTEST PARTNERS

chip
Centre for Health & Infectious Disease Research

REGION H Rigshospitalet

Aids Fonds

EATG European AIDS Treatment Group

GNP+ Global Network of People Living with HIV

MEDFASH

Public Health England

Tervise Arengu Instituut
National Institute for Health Development

Inserm

SSAT
ST STEPHEN'S AIDS TRUST

Ministerio de Economía y Competitividad

isc Instituto de Salud Carlos III

Co-funded by the 2nd Health Programme of the European Union