OptTEST
OPTIMISING TESTING AND LINKAGE TO CARE FOR HIV ACROSS EUROPE

Tip sheet 2
What types of legal and regulatory barriers are common and how do they damage access?

Definitions

1. A ***legal barrier*** is one which is enshrined in law and can only be removed or amended by the proper legal process, which may involve your Parliament or a court case. An example would be a law criminalising sex work. A ***regulatory barrier*** is one contained in guidelines or even common practice which could be changed by executive action or by a committee decision. An example would be a regulation that HIV testing can only take place with mandatory pre-counselling. Matters which are regulatory in some countries may have been written into laws in others. An example would be whether a doctor needs to be present for an HIV test.
2. Legal and regulatory barriers can be ***active*** or ***passive***. An active legal barrier would be prosecutions for perceived exposure to HIV and a passive one would be the absence of laws protecting people with diagnosed HIV in employment and other rights. An active regulatory barrier might be a ruling that case managers can only be recruited from qualified social workers and a passive one would be a lack of any redress if confidentiality is breached.
3. Although these types of barriers can be caused in part by ***stigma***, and stigma also plays a role in the failure to identify and change them, they are different to stigma in that they are concrete, easier to identify and describe and potentially easier to challenge.

Common active legal barriers:

- Laws which criminalise sexual behaviours by people diagnosed with HIV can drive people away from services they fear might report them; discourage them from disclosure of risk activities to services that might help them better if they knew; discourage disclosure to casual partners or within potentially abusive relationships
- Laws which criminalise key populations (gay men, sex workers or people who inject drugs) also deter them from using state-run health services and may deter them from being honest about risk taking behaviours
- Migrants, undocumented ones in particular, may face a range of legal barriers to testing and treatment, from lack of access to state healthcare to fears, sometimes justified, of being reported if they do so.
- Trans* people may not be allowed to access healthcare under anything but their misgendered “legal” identity, which may no longer be how they live.
- The intersectionality of personal identities may also compound these legal barriers; for example, a male sex worker who is also an undocumented migrant or a trans*woman who injects drugs.

Common passive legal barriers:

- Some countries fail to include people with HIV within their laws protecting human rights. These may include employment protection, the right to goods and services or the right to family life. This can make it difficult, for example, for someone with HIV to ask for time off to attend medical appointments.

Common active regulatory barriers (may be legal barriers in some countries):
Most of these barriers relate to "custom and practice" or to a failure to keep regulations updated with advances in science. Occasionally they may be due to a profession operating "restrictive practices", using regulations to defend their personal interests.

- **What kind of tests can be used?** There may be restrictions on rapid testing because of misplaced concerns about its accuracy. Some countries allow community testing using saliva tests but not blood tests (despite their greater accuracy) due to regulations about blood tests or disposal of needles/sharps.
- **What kind of testing can be done?** Some countries have banned self-testing, using the same arguments previously used against home pregnancy testing – that people cannot be trusted to understand or may be distressed by the result. Others cannot do postal sampling, which is highly cost effective and reaches key populations such as MSM well, because of regulations about what can be put in the post.
- **Where can testing be done?** Some countries restrict testing to clinical centres out of an assumption that other settings cannot be "hygienic" or otherwise professionally conducted. Others allow testing by NGOs in community settings, but insist that anyone diagnosed through this must start again, being tested in a state clinic from scratch before they can access referrals.
- **Who can do tests or give results?** There are a wide variety of restrictions around who can administer an HIV test which range from everything including pre-test counselling to the blood test itself being done by a qualified clinician through to simply having to have a clinician in the building while testing is taking place, though they may not be involved in the procedure at all. Many services now operate successfully without any direct clinical involvement, using trained lay personnel who are often more acceptable to key populations.
- **Activities reserved to specific professions**: sometimes clinical or health service regulations stipulate that other jobs involved in testing and support need a particular qualification, like the case managers mentioned above who must have a social work qualification. Phlebotomists may want to be the only people allowed to take blood. This can cause extra financial costs or logistical delays to services, especially for NGOs. Such expectations or assumptions are often worth examining and asking "is this really necessary and does it restrict access, financially or logistically?".
- **Outdated guidelines**: when were your country/health region/hospital's guidelines for HIV testing and treatment last reviewed?
- **Barriers to referrals for NGOs**: as mentioned above, some regulatory systems put blocks on NGO access to healthcare systems, forcing newly diagnosed people to retest through the state system in order to access care. This delay or extra barrier causes some to drop out of the system, particularly those with a chaotic lifestyle.
- **Lack of anonymity/confidentiality**: some insurance-based healthcare systems are based on a family system, whereby it may not be easy to get an HIV test privately (or to get one at all if you are under 18 without parental permission). Others ask for proof of eligibility for healthcare before a test, despite it being in the interest of both personal and public health for people with HIV to be diagnosed.

Common passive regulatory barriers:

- **Failure to explain rights to healthcare**: can deter people afraid to ask about eligibility
- **Failure to show how confidentiality is managed and breaches addresses**: can lead people to assume that services are not genuinely confidential, or that criminalised behaviour may get them reported to the authorities.

See also: Tip sheet 3 on new testing strategies
Literature review on barriers
Barring The Way To Health website

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