Tip Sheet 4
How can I identify and verify local barriers to testing and treatment access?

No country has a system that is perfect in providing fast, easy access to HIV testing and treatment because technological advances can move faster than guidelines and health systems. Every system has some parts that work better than others, and it is important to find out not only where a system works least well, but also why it doesn't work well, before you can fix it. To get people to change something you need to present a good case about what is wrong, but also what can be done to change it for the better. Here are a few tips to help you in that process.

There are a variety of ways of showing what isn't working.

1. Identifying potential problem areas where barriers may exist:
- do some background reading (like the literature review in this toolkit) to familiarise yourself with the range of barriers you may encounter
- if you can, construct a continuum of care (also sometimes called a care cascade) to show you where any gaps may be – see Tip Sheet 5
- clinicians should have access at least on a local basis to hospital data showing drop-offs and time lapses between first testing and confirmation testing; between this and first appointment; between this and getting onto treatment; and the percentage on treatment reaching undetectable levels of the virus
- increasingly, community groups involved in testing and support are likely to be able to also identify where some patients may fall out of the system or not return.

2. Identifying what the actual barrier/s may be
- ask the patient: although anyone can (and should) do this, self-help and community HIV groups are best placed to solicit informal feedback about the testing and access process from newly diagnosed members, asking what went well and what did not; community groups supporting specific populations such as gay men or sex workers should also be able to ask people why they may be reluctant to attend for testing or were put off by something within the existing system
- where there is access to a substantial number of people (e.g. within a clinic or community group), it should be possible to conduct a more formal survey (possibly with the help of researchers or students) to make the data as robust as possible. For ways of doing surveys, see Tip Sheet 6
- Documentation is vital in getting this taken seriously – whatever format you choose, document responses clearly and ensure confidentiality for individuals who contribute
- Once a barrier is identified, anonymised personal stories (qualitative data) showing exactly how it operates to deter people may be useful alongside the numbers (quantitative data) showing how widespread the experience is.

3. Prioritising your actions if there's more than one barrier
- which is the greatest barrier that needs change? (you may need time to plan and research)
- which is the easiest target for change? (an early win can motivate people and attract support)
- which will demonstrate the value of change the quickest? (showing the benefits may help your credibility in tackling bigger and tougher targets)

- which will cost the least to achieve change? (sometimes money is a tougher barrier than behaviour)
- who will oppose change? (try not to pick a fight with people you may need on another front – if possible, start with something where clinicians and community can work together)

4. Identifying solutions
- has any other country or area had the same problem and how did they tackle it? Check in with people like AIDS Action Europe or google the issue
- has any other medical condition had the same problem and how did they tackle it? Ask European patient groups and google as above
- ask patients and clinicians what they would do to break down the barrier

and, after doing your homework
- publish a paper with your evidence about barriers and any conclusions you have reached, including any cost/benefit information you have and alternative options for solutions
- call a strategy meeting (possibly a side meeting on a conference) and invite stakeholders (you may need to do some political befriending first) or get someone with more "influence" to do this on your behalf; present the issue; get as many people as possible to agree the best course of action.