

Tip Sheet 7

How and where do I find evidence for a change in policy?

If you want to change existing policy, it is important to not only know what change you want, but why it is needed. Evidence for change should be clear, understandable and support your case. It can come from a wide variety of sources. A lot of information can be found online or in existing publications (desk research) but you will probably have to do some work yourself to make the best case for local need (original research).

For the desk research, it is important to learn how to do good internet searches, using the right key words. If you're not sure how to do this effectively, read the following or use an [online tutorial](#).

What kinds of data can be used to lobby for change in how your country/city provides HIV testing & care?

Desk Research

- **Guidelines and best practice:** Are there international guidelines which recommend the course of action that you want? UNAIDS, WHO or (in Europe) ECDC and the EU may have published guidance based on existing evidence. Not only will their recommendations be handy for backing your case, but also the guidance documents may have references at the back to the original research the guidelines are based on, giving backing to your case (see 1c below). There may already be national guidance which is not being followed locally. Check out the OptTEST Toolkit list of useful documents as a starting place.
- **Global/regional comparisons:** You have an idea what best practice looks like, or you know there are other countries already doing what you think your country should do. Who is out there doing it? You can do an internet search with key words, as above, or you might want to ask for help on an appropriate Facebook Group ([HIV in Europe](#) is a good place to start) or a Listserv. There are datasets comparing country laws and regulations on HIV testing and care here on the OptTEST site ([Barring The Way To Health](#)), mirrored on the GNP+ site and more elsewhere which will allow easy comparisons and help you identify where to look more closely. Check out the [AIDS Action Europe](#) clearing house for similar projects, or relevant specialist European websites like [EDAT](#) for community testing, [TAMPEP](#) for sex work, etc. You can also, if all else fails, directly email relevant expert bodies like the [European AIDS Treatment Group](#), AIDS Action Europe or [HIV in Europe](#) and ask them if they know what countries e.g. have self testing pilots going on.
- **Research studies, economic data & existing survey data:** Similarly, you can search the internet for academic and other reports of research on the issue, including evaluations of projects elsewhere, indicators of how well a strategy worked and evidence of need. Try to ensure that any evidence of this kind is relevant to your country and as up to date as possible. A study showing how gay men in San Francisco reacted to a new type of testing service may not be applicable in Croatia and what suits sex workers in Kenya may not fit those in Finland. But a study showing that the change you want saved money and lives in France or in Latvia may well be useful elsewhere in Europe. If you want to quote academic or clinical research papers, you may need to provide a simple explanatory line or two –

- don't expect policymakers to trawl through pages of graphs and jargon. But always give references for the research you quote, at the end of any paper.

Original Research

Sometimes the evidence isn't already there, or isn't relevant enough to prove your point. What can you do to create good evidence for the change you need?

- **Academic or clinical research:** Proper formal research, as in the Ipergay trial (case study 3) can be invaluable in proving your case – but doing it takes a long time and usually a lot of money and jumping through formal hoops. If you're facing a long campaign to prove something will work, start early on this and make allies in academic institutions who will work with you to provide rigorous evidence. Peer reviewed, published research is the evidence best respected by most policymakers, but it isn't a quick route.
- **Case monitoring:** Many of the case studies proved their point by monitoring and recording lived experience, whether it is showing the waste of effort in prosecutions which are inappropriate (case studies 6, 7 and 8) or challenging damaging myths like treatment tourism (case study 1). Keeping a database of what is going wrong, or doing a retrospective check through anonymised records of previous work can back up your claims and have a strong impact. It can also provide examples which, again anonymised, can be cited to good effect in evidence to Parliamentary or other Expert Inquiries. It's a good idea for one organisation to act as a clearing house for such evidence, putting it in order and making it available centrally to all organisations that need it.
- **Patient feedback:** The best way to get any institution or organisation to listen to feedback is to get them to collect it themselves; they are more likely to believe it if they hear it directly. So the first strategy should always be to try and get the organisation you want to change to gather patient/service user feedback for itself and agree to share the aggregated results back with the patient group. But if they will not do this, then it is still worth getting a respected body to solicit feedback about, for example, what would have made it easier to test or what would make it easier for people to attend appointments, and using this to lobby for change such as easier referral arrangements, clearer confidentiality procedures or shared services on a single site.
- **Surveys & needs assessments:** If you want to collect evidence of need or problems faster than a long term formal academic study would do it, a simple survey or needs assessment can be just as informative and, if it is done well, just as acceptable to policymakers. Tip Sheet 6 gives you details of how to do this. There is plenty of advice online about how to conduct different types of surveys and needs assessments, but the keys are to ensure you ask a representative group; to have an advisory group including both professional researchers (to make the questions meaningful) and people affected (to get the right language and channels); to make the survey as short as you can to get the information you need; and to not ask too many open-ended questions that you can't process the responses from. How you ask things can be as important as what you ask. For example, online surveys are fast and cheap, but not good for people without the right language skills or private access to the internet – and these days they should be formatted for responses

from smartphones. Surveys can also act as awareness-raising tools, as they did in case study 3 in France.

- **Case studies/first person stories:** Most good evidence dossiers are a mix of statistics, facts and personal stories. This may range from a quote with a photo to a full first-person story illustrating the need for the change you are asking for – how people became more ill than they needed to because they went untested, or were unable to make appointments because the only clinic was far away and seldom open; how ignorance about being transgender or fear of being reported as a sex worker damaged their health and eventually cost the state more to treat them. If you are going to use people as “live” witnesses, whether it is in giving evidence to a Parliamentary Committee, meeting a Minister or doing a media interview, it is vital to give them support and ensure that they can handle any questions that may be asked, no matter how odd or intrusive. If you are using written case studies, unless the person concerned is clear that they are happy to be identified, it is important to anonymise anything that could identify them, such as name, home district or workplace.

If this all seems a bit much, remember – in many cases, successful campaigns for change started small, by documenting what was going wrong for people in one or two organisations (like case study 1) and then moved on, as alliances grew, to gather much wider proof and do more “solid” research. It’s worth taking a look at who you need to influence and what is most likely to have an impact on them (see tip sheet 1). Build alliances with researchers and experts, don’t be afraid to ask around and find out who has relevant experience. And once you have a case, try to make sure everyone is using the same data – there’s nothing more confusing than being confronted by different statistics from different organisations on the same issue.

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