Case Study 10
Establishing a community testing facility in a regulatory-restricted environment

What was the issue?
Until 2009, all testing for HIV in Slovenia was being done through either a single public HIV clinic in the capital, Ljubljana, or through people's family doctor. Legebitra, founded as an LGBT organisation, was already doing sexual health promotion and HIV prevention with condoms and leaflets but believed testing access needed to be improved and increased to take advantage of treatment advances.

Why was change needed?
Although Slovenia was a low prevalence country with only around 50 new diagnoses annually, the majority of these were in the relatively small community of MSM. Many gay men expressed their reluctance to test in traditional medical settings, either because of perceived stigma towards LGBT people and those with HIV, or because they feared a lack of confidentiality in primary-level healthcare. Data confirmed that testing rates amongst MSM were relatively low and needed to increase.

How could access be improved?
Legebitra staff observed the successful growth of community-based testing run by and for gay men in other European cities. In particular, they visited the Barcelona Checkpoint and saw how they had transformed testing for MSM in Catalunya through peer-run testing and support for HIV and other STIs. They also saw the growing adoption of rapid, point-of-care testing across Europe.

What/who were the barriers to change?
In Slovenia, there was opposition from clinicians and laboratories to the introduction of both community-based testing and rapid testing. They felt that rapid testing was not as reliable as traditional testing and offered too long a window period. They also expressed concern about potential lack of trained professional staff in administering community testing and whether it would use the same protocols that they did.

How long did change take and who was involved in making the change?
From deciding that something needed to be done to establishing a community testing facility took one year in Ljubljana and then a further three years to start outreach services in other cities. Legebitra worked with clinicians, laboratories and the National Institute for Public Health to ensure that their concerns were met and the Checkpoint run appropriately.

How was change made?
Trust: Legebitra had a series of meetings with the authorities – clinicians, public health institutions and laboratories. Their style throughout was compromise rather than confrontation.

Joint working: Legebitra already had a place on the National Committee on HIV through their prevention work. They used their contacts and goodwill from that work to approach key

stakeholders, such as the National Institute for Public Health. They worked together to write a new protocol for how a Checkpoint would work in Ljubljana, so that everyone could agree from the start that it was properly run.

Compromise: Legebitra agreed eventually to compromise on their original plans by not using rapid tests in their community testing facility. This meant that people had to come back a few days later for their results. When the authorities insisted that a nurse must do the blood tests, they hired one and they used an existing member of their organisation, who was also a medical student, as their counsellor. "*It kept them satisfied*" explains Bojan Cigan of Legebitra. Legebitra are not given data on whether people with reactive results are confirmed as positive by the clinic, but they often accompany the person to the clinic.

Turning restrictions to advantage: The use of traditional laboratory-based testing meant that enough blood was taken to allow parallel testing for other STIs, so those attending get a wider sexual health screening. The two day delay in giving results allows Legebitra to prepare linkage to confirmatory testing and care in advance and "failure to returns" are minimised by offering to give results by phone and following up on anyone reactive if needed.

Data: The National Institute for Public Health became an associate partner in COBATEST, a European-wide collaboration to establish and validate datasets for Checkpoints. Working with Legebitra, they set up robust data collection from the start. "*We established a level of mutual trust and the good data collection from the start showed them that the community facility was useful and had a valid role*".

European connections: Being linked with other Checkpoints and in particular participating in COBATEST enabled Legebitra not only to learn from others' experience but also to show that their community initiative was being taken seriously by European authorities such as ECDC.

Proof of concept: Starting with a pilot of just 50 tests at Pride in 2009, they showed that the concept was feasible and acceptable to MSM.

Incremental growth: After this pilot, the Checkpoint started out one day a week in Ljubljana in 2010, doing HIV, HBV and syphilis testing on Mondays with results given on Thursday of the same week. Tests have increased over the years to include HCV and now also swabs for oral and rectal gonorrhea. In 2013 they also started testing in other towns and at events, in collaboration with local organisations. They are currently working to add chlamydia to the range of tests that they offer. "*We tested 100 people in 2010, but 680 in 2016 and we are going to need additional hours soon*".

Are there any ongoing issues?

Funding is precarious. While the Slovenian Government acknowledges the importance of the project, their funding is neither systemic nor long-term and has not matched the growth of the service. Legebitra continues to seek additional funding. The use of medical staff and lab tests requiring return visits also means they are more costly than some other CBVCT services in Europe, though still very cost effective.

What lessons have been learned?

"Collaboration with others, including the sceptics, was important because it meant they got to know and trust us" says Bojan. "Now they see we are doing the right work, that we are targeting the right

people and that we are recognised beyond our country borders". Being part of a European-wide research project made a large difference and included some funding. User feedback was important, along with other data, in showing that they were meeting previously unmet need. "Trust is very important. Word of mouth brings us a lot of new people. We are from the community, but they know that we really are confidential, they are welcome here and they can talk about anything with us. We take them to the clinic ourselves if tests are positive and that linkage data is the most important. Testing is not enough, you must show good linkage to care even though it's hard to establish. You must have a system."

"It's very important to have flexible, committed staff and volunteers. We give everyone who works here some money now, but there have been times when we only had enough money to buy tests, not pay people – but they stuck with us and even went without pay for a while until we could get more funding."

Links:
Legebitra: http://www.legebitra.si/en/hiv-and-stds/

COBATEST (now part of EUROHIV-EDAT): https://eurohivedat.eu

Evaluation of community-based testing across Europe through COBATEST: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4828621/

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