

## Case Study 3

### Gaining access to PrEP in France

#### What was the issue?

The 21<sup>st</sup> century saw a steady decline in condom use by French HIV-negative gay men which, along with ongoing insufficient levels of testing, was a major contributor to high levels of HIV transmission. Although treatment as prevention (TasP) can drastically reduce transmission, people need to be diagnosed and on treatment. Many transmissions occur from undiagnosed people who may only recently have been infected themselves. Condom education and lifestyle changes prevent transmission for many people but do not work for all and are not enough to further reduce new diagnoses.

#### Why was change needed?

Early trials showed that certain HIV treatments could also act as preventative medicine (pre-exposure prophylaxis or PrEP) if taken by HIV-negative people. However, access to this form of preventive treatment was not approved or available through the state-reimbursed health systems.

#### How could things be improved?

The aim of the PrEP campaign in France was to raise awareness of the safety and use of PrEP alongside a policy change approving its implementation as part of the national prevention strategy (initially a “temporary recommendation for use” or RTU, a legal device which is renewable).

#### What/who were the barriers to change?

The major barrier to change was fear from some clinicians and parts of the LGBTQ community that either PrEP would not work or that it would “encourage promiscuity”, thus increasing STIs. Underlying the latter were moralistic agendas about sex and particularly homosexuality. Some HIV activists feared that PrEP would lead to a further decline in condom use and lack of unanimity led to conflicting messages. There were also concerns about taking what was seen as a potentially toxic substance when someone was not already unwell, voiced as worries about side effects or drug resistance. Added to this, the cost of supplying PrEP was relatively high and a concern to civil servants in the Health Ministry.

#### How long did change take and who was involved in making the change?

Research into PrEP in France began in 2009 when [AIDES](#) (the largest HIV community organisation in France) joined the [ANRS](#) (the French National Agency for AIDS Research) in planning the [Ipergay PrEP trial](#). [TRT-5](#) (a coalition of NGOs including AIDES) undertook community consultation in 2010. The [National AIDS Council](#) published a position paper on the potential benefits of PrEP in 2012 and the ANRS set up a working group to undertake a risk benefit analysis and consider the possible delivery framework for PrEP. A grassroots group, [#FreePrEPNow](#) ([#FPN](#)), was also founded to demand access to PrEP and raise awareness in the Gay community through social media and visibility actions. The eventual [Temporary Recommendation for Use](#) (RTU) was published in November 2015 and PrEP has been available to all who need it in France since January 2016. The French campaign brought clinicians and a wide range of both HIV and LGBT community groups together, led by AIDES, the largest national NGO.

## How was change made?

**Educating and mobilising the potential audience:** Alongside working with clinicians and potential long term users of PrEP in the Ipergay clinical trial, TRT-5 undertook a community needs assessment and AIDES set up a Facebook page where “PrEP warriors” could share experiences and mobilise. Many NGOs worked to inform their audiences about PrEP and its benefits. #FPN mobilised the gay community around Pride, tagging walls in the Marais (the Paris gay district) with their hashtag and slogans to increase interest.

**Using surveys and consultations to also build awareness:** In 2010, TRT-5 undertook a large scale community consultation on Ipergay. In 2014, with access looking increasingly likely, the [FlashPrEP](#) survey reviewed awareness of PrEP in key populations and willingness to use it. Effectively, surveying awareness was in itself a way of raising awareness within key communities and bringing PrEP to the attention of those who most needed it, alongside data gathering.

**Networking and coalition building:** Throughout the campaign there was strong inter-organisational networking, both within the NGO sector and between activists and clinicians. The clinicians on the Ipergay trial were able to educate their clinical networks and AIDES could explain Ipergay to the community while recruiting participants and supporting them throughout the trial. AIDES worked with #FPN, [Coalition Plus](#) and LGBT community groups to present a united front.

**Coordinated but separate lobbying and community activism:** [Paris ActUp](#), which had previously done most street activism, had become less active and AIDES found itself initially having to cover both roles. “*We were saying thank you nicely to the Health Ministry one week and organising direct action against them the next*” (Thieu Brigand, AIDES). #FPN, though close to AIDES throughout, was formed of independent activists and was able to take on the more confrontational (and occasionally not entirely legal, such as graffiti “tagging”) roles of demonstrations and direct action, allowing AIDES and the formal coalition to be the “nice cop” to their “nasty cop”. However, many individuals belonged to both groupings and there was always good communication.

**Involvement in clinical trials:** The Ipergay PrEP trial allowed AIDES to work closely with clinicians and with ANRS who ran the trial. This in turn added weight to their lobbying and brought key influential clinicians on board from the start, which increased the issue's credibility with other clinicians and with politicians, who are universally more likely to defer to things said by clinicians than by patients or activists.

**Working the system:** AIDES had extensive experience working with the Government. They understood the use of RTUs to force Government to address an issue, were already working with others to shape national recommendations for the management of HIV and mobilised to include PrEP in wider public health legislation in the latter part of 2015. They also used existing planned reforms in screening to ensure that PrEP was made available at new screening centres in 2016.

**Long term political relationship building:** AIDES were also able to use their existing strong reputation for prevention and other HIV campaigns to be taken seriously on this issue by Government agencies, even when it seemed risky. Additionally, they had long term friendly relationships with senior Government staff from previous work, some of whom were particularly receptive to their case.

**Using cost-benefit evidence:** The ANRS working group was helpful in setting out the cost-benefit arguments for PrEP alongside showing what would be needed to deliver it effectively. Having a clear plan of how to maximise the benefits of PrEP and showing what it would save in the long run were key arguments alongside its clinical effectiveness.

### Are there any ongoing issues?

Because the campaign was rooted in the gay community, with its long history of activism, there was greater engagement and a better understanding of PrEP there than in some of the other populations most likely to need it. AIDES and groups based within those communities are now working to ensure the benefits of PrEP are available to all in need.

### What lessons have been learnt?

*“The two main lessons were: the effectiveness of science in advocacy and the importance of role-sharing between many different parties”* (Theau Brigand, AIDES). *“Having #FPN, with its separate identity and activist focus, enabled a wider range of actions but informal links were always there”* (Vincent Leclerq, #FPN).

### Links

Ipergay trial results summary: <http://www.aidsmap.com/lpergay-PrEP-study-results-published/page/3018781/>

Approval for PrEP: <http://www.aidsmap.com/France-approves-PrEP/page/3016707/>

Presentation from AIDES:

[http://www.salute.gov.it/imgs/C\\_17\\_EventiStampa\\_212\\_intervisteRelatori\\_itemInterviste\\_2\\_fileAllegatoIntervista.pdf](http://www.salute.gov.it/imgs/C_17_EventiStampa_212_intervisteRelatori_itemInterviste_2_fileAllegatoIntervista.pdf)

Presentation to EATG (third speaker):

[http://www.avac.org/sites/default/files/event\\_files/EATG.AVAC\\_PrEP\\_Webinar.9.18.pdf](http://www.avac.org/sites/default/files/event_files/EATG.AVAC_PrEP_Webinar.9.18.pdf)

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