

## **PrEP in Europe**

**First Summit meeting, Amsterdam: 09-10 February, 2018**

### **Final report for UNAIDS**

PrEP in Europe is a partnership of six European advocacy organisations: [AIDES](#), [AIDS Action Europe](#), [AVAC](#), the [EU Civil Society Forum](#), the [European AIDS Treatment Group](#) and [NAM/Aidsmap](#). See [www.prepineurope.org](http://www.prepineurope.org) for more details. PrEP in Europe is run by a secretariat based in NAM/Aidsmap.

PrEP in Europe's primary aim is to support progress towards wider, better and more equitable access to HIV pre-exposure prophylaxis (PrEP) throughout the WHO European region for everyone at risk of HIV who wishes to use PrEP.

PrEP in Europe, as its particular contribution, aims to address the fragmentation and lack of co-ordination in the provision of PrEP in the European region that has led to slow adoption of PrEP programmes. We will do this by providing **information** on PrEP; supporting **advocacy** for it and helping PrEP advocates and PrEP users develop their self-advocacy skills; **networking** with policymakers and providers to provide community input on PrEP policy; and helping PrEP seekers and users, and healthcare professionals and researchers, develop supportive relationships.

PrEP in Europe's secretariat and the provision of our website, social media page and information materials, was already supported by grants from ViiV and Merck, with translations supported by UNAIDS. However we considered it important to have an inaugural summit to bring together PrEP activists and providers in a meeting that could both inform participants about the current state of PrEP provision in Europe and also suggest strategies for increasing access to it. This meeting would be called the European PrEP Summit and was planned for early 2018.

### **Overall outcome of Summit**

The specific outcome proposed for the summit as an intervention was that *"afterwards, delegates would be better able to engage in activity designed to accelerate progress towards the implementation and rollout of free or subsidised PrEP in countries across Europe, and to accelerate progress towards its equitable provision to all individuals and populations in need of it."*

### **Aims and outputs of the summit**

The aim of the summit's activity would be to bring together the people potentially of most influence in hastening access, and equality of access, to PrEP throughout Europe. It would aim to do this by providing opportunities for

1. the dissemination and mutual provision of information about PrEP;
2. provide a space for discussions of successful methods for the advocacy of PrEP;
3. allow a safe, non-hierarchical opportunity for the three most important groups involved in developing PrEP to talk to each other and collaborate on developing policies for PrEP provision. These three groups are:
  - a. healthcare professionals such as doctors and nurses;
  - b. healthcare providers such as civil servants, managers and funders; and
  - c. community advocates for PrEP who can pass upwards to the other two groups the concerns and needs of their populations.

### **Funding and finance**

There is actually a considerable amount of campaigning energy being devoted to PrEP in many European countries but local advocates and workers are often ignorant of what is going on elsewhere and the summit would provide an opportunity for networking and communication between them.

Initially we approached pharma and other funders with an ambitious plan for a meeting of more than 250 people. However the number of bodies interested in funding the meeting was lower than anticipated. Two key issues became apparent. One was that the pharma company that was at that point the main provider of PrEP in the US was concerned that supporting a meeting in Europe would run foul of EU regulations. The other was that philanthropic-sector funders tended to have policies of supporting action on specific countries or regions, but the idea of a pan-European activists' network supporting prevention was not one they catered for.

PrEP in Europe applied to Aidsfonds for funding to support its inaugural meeting Aidsfonds agreed to support the Summit with €40,000, enabling us to take the decision to plan for a meeting in February 2018.

With that level of funding, we calculated, we would be able to support 40-60 participants, depending on the level of support we gave for accommodation and travel. This was at the lowest end of what we felt would be worthwhile, so additional income was sought from out steering committee members and from bodies that had acted in an advisory capacity such as ECDC, UNAIDS and WHO.

Funding was provided by UNAIDS to the tune of \$10,000 , and AIDES and contributed smaller sums up to the level of €17535.81, to support attendees. In addition, all attendees paid a sliding-scale registration fee ranging from €100.00 to €10. This provided another €5824.00 in income. See financial statement (previously supplied) for more.

This enabled us to plan for a meeting of about 120 attendees and we are very grateful for the proactive role UNAIDS took in enabling it to happen.

### **Selection of participants, logistics**

Aidsfonds found a suitable venue and blocked-booked a nearby hotel for scholars. One of our partner organisations, the European AIDS Treatment Group, booked travel for scholars.

PrEP in Europe's Steering Committee developed the conference programme in collaboration with the co-ordinator, and took overall decisions about the shape of the meeting. The co-ordinator in consultation with his line manager took the main role in fundraising and financial control. It was decided to offer a proportion of places (in the end, 47 out of 120 places, or nearly 40%) with all accommodation and travel costs paid: the only cost to these "scholars" was the sliding-scale registration fee. Other attendees paid for their own accommodation and travel.

A subgroup of the PrEP in Europe Steering Committee selected the scholars and non-scholars' places. We had enough funding for 120 places but had 277 applicants (2.3 times as many). The Subgroup used an algorithm to select scholars and non-scholars on the basis of geographical and population representation, expertise and experience, income and plans for dissemination of what was learned at the summit. 47 scholars out of 103 applicants were selected and 103 out of 174 other applicants – a ratio of 42.5% in both cases.

Of the 120 people selected, one never paid a registration fee and was therefore not confirmed and three had to cancel at short notice due to sickness and to theft of passport.

### **Participants**

Thirty-six countries were represented at the meeting among the 116 attendees. Eighteen countries were in central and eastern Europe (including Cyprus and Turkey) and 15 in western Europe (including Greece). England and Scotland were counted as separate countries because of their different health systems. There were also attendees from the US, Australia and Lebanon.

Numerically, only 27.5% of attendees came from central and eastern Europe as there were large numbers from England, France and Germany and CEE attendees were more likely to need support as Scholars. There was however good representation from Ukraine and Georgia.

Of the 116 attending, 24 (21%) were women including three trans women. There were two trans male attendees.

We asked people to self-define professionally. Participants paid a sliding-scale registration fee at the following rates:

€120 for professionals and government workers: N = 20

€ 60 for salaried NGO and CBO workers N = 39

€ 30 for independent activists and consultants N = 37

€ 12 for independent activists from lower-income countries N = 20.

We did not categorise or prioritise attendees specifically in terms of professional status, sexuality, ethnicity, age, HIV status or PrEP use. There was feedback in the final evaluation that in future people should be asked if they took PrEP themselves and people taking PrEP should be prioritised: in a 'straw poll', about 15 people put their hands up as PrEP users but this may underestimate the number there.

As can be seen from the registration fees, there was a reasonable balance between professionals and activists but possibly a smaller number of health professionals and providers than we might have liked.

### **Programme overview**

The 1.5-day programme that was developed included the following main sections:

- On the first day, an update in progress towards PrEP in a number of different European countries
- On the morning of the second day, a series of breakout groups considering barriers to, facilitators of, opportunities for, and the future of PrEP
- During the rest of the day, in the light of breakout group reports, presentation of PrEP for different [populations; in different healthcare settings; and in the media.

A detailed programme may be seen at <http://www.prepineurope.org/en/summit/programme/>.

### **Issues and recommendations**

At its heart this was an activists' meeting and the most important aspect of the Summit was probably the breakout sessions that explored facilitators and challenges to PrEP provision, opportunities to overcome those challenges, and future possibilities for biomedical prevention beyond PrEP.

One common theme that emerged from the breakout discussions was that PrEP needed to be 'demedicalised'. This means it needs to be placed within the mainstream of HIV prevention, and access to this extremely effective prevention method against a deadly disease seen firmly as a

matter of human rights, rather than just as a medical issue or one of public health. Indeed, PrEP could be a hostage to fortune if it is 'sold' to politicians and healthcare providers purely as a way to shrink a country's HIV epidemic – although other attendees commented that educating politicians and healthcare providers about cost-effectiveness and about the economic arguments for PrEP were also very necessary, and might persuade where human rights arguments, by themselves, do not.

In a final session, that drew together aspirations and actions following the meeting, participants expressed, among other things, the following 'asks':

- 1) Develop a road-map cascade of PrEP access, learning from each country's experience. Including challenges and opportunities countries came across.
- 2) Issue a call for EU bodies to remove barriers that block PrEP access. Lobby at EU level to have a European PrEP Directive (EU elections are coming up).
- 3) Do another summit with successes and follow-ups
- 4) Trials for new/alternative PrEP combinations.
- 5) "Affordable PrEP for everyone who needs it" statement by EACS; WHO; UNAIDS
- 6) Find ways to scale up the infrastructure – make it faster and cheaper and easier to deploy
- 7) Establish global information sharing about solutions; more education about PrEP at all levels – communities of users (current or potential), providers, state/political actors.
- 8) Choosing five individuals who we want to target and educate in each country
- 9) Real time dashboard of country updates including PrEP prices, methods of accessing PrEP, national resources.

### **Future plans**

After the meeting, there was a Steering Committee meeting in which future plans were further solidified. These include:

- 1) Constitutional work (establishing a Memorandum of Understanding giving greater clarity to the roles of Steering Committee, Secretariat, Co-coordinator etc):
  - a) *This remains an unfulfilled ambition so far partly due to time demands on the steering committee.*
- 2) Liaison on key policy and scientific issues with other European organisations:
  - a) *After the summit, three members of the PrEP in Europe SC had a meeting at Geneva with representatives of UNAIDS and WHO to plan future meetings and activities.*
- 3) Responding to the expressed need for some basic, consistent information on PrEP for European advocates
  - a) *We have started writing and uploading to our site factsheets of a medium technical level intended for advocates to use with home populations on issues such as drug resistance and then public health effect of PrEP.*
- 4) Community advocacy over several unresolved issues in PrEP. These included resolving the data and issuing recommendations or at least clarity on intermittent and finding scientifically valid ways to include PrEP metrics into the 90/90/90 structure.
  - a) *I am attending the Fast Track meeting in Lisbon on 1q2 October to start addressing this.*
- 5) Further liaison with non-MSM affected groups including at risk heterosexual women, people who inject drugs and female sex workers.
  - a) *One of these was a meeting at the Amsterdam International AIDS Conference with European reps of key populations that have hitherto expressed suspicion of PrEP – female sex workers, people who inject drugs – or who have had difficulty in accessing it – trans people, migrants.*

Looking at what we hoped to achieve, the summit was regarded as on the whole a great success by its attendees and by people who watched it on the net (almost the entirety of the summit was live-streamed online, a technical innovation).

We completed a report on the summit within two weeks of it taking place and uploaded it to Aidsmap, where it was widely read and disseminated. See <http://www.aidsmap.com/HIV-prevention-Its-time-to-stop-accepting-the-status-quo-PrEP-Summit-concludes/page/3218821/>

### **Learnings from the summit**

There were things we hoped to achieve but did not or did so with limitations. These included:

- We would like to have had more professionals attending. In particular, we had very few people who were funders (partly due to a decision to exclude pharma, which was a requirement of Aidsfonds) healthcare planners, civil servants and parliamentarians. These are often very busy people with full diaries and in future we will try to plan meetings with long timelines.
- The meeting was an important opportunity for activists to meet, but sessions concentrating on debriefing and recommendations could have been better planned, as could a programme of post-summit activities.
- PrEP in Europe is run by a steering committee and co-ordinator who have other jobs and the plan for better organisational autonomy and funding should be carried forward. One of the most problematic aspects of funding this partnership has been reconciling the different requirements funders have for a partnership one of whose *raison d'être* is to bring together people from different layers of the HIV world who may not normally talk to each other.