

# PrEP in Europe Summit 2019, Warsaw

## Final Report

### Executive summary

PrEP in Europe is a partnership of European NGOs whose aim is to co-ordinate campaigning and advocacy for HIV pre-exposure prophylaxis (PrEP) and for wider and more equitable access to HIV prevention and sexual health throughout the World Health Organization's (WHO) European Region.

It is a community-led organisation which seeks to establish better dialogue between actors and influencers across the whole community.

This report concerns PrEP in Europe's second summit meeting, which took place in Warsaw, Poland on 10-12 October 2019, with a smaller pre-meeting the day before and a Steering Committee meeting the day after. The first summit meeting had been in Amsterdam in February 2018.

The meeting had 170 attendees from 38 countries, 40% of whom were scholars with accommodation and travel fully paid for.

The meeting included grassroots activists and people new to HIV meetings, including representatives from the trans community and from black and ethnic minorities. It also included physicians and other healthcare providers, researchers and epidemiologists, NGO managers and programmers, independent patient experts, social media experts, and policymakers, including the national AIDS co-ordinators of two countries.

The meeting, whose aims and process of development are described below, was generally seen to be very successful. The meeting's logistics and efficiency were highly praised. The one issue singled out for criticism was that the programme was rather crowded with presentations – and that there was not enough time for panel discussions, breakout groups or the development of recommendations.

However, the meeting was highly successful in one of its principal aims of informing and empowering individual participants to initiate or take forward PrEP advocacy and programming work in their own countries. There is detailed feedback from participants on pages 16-20.

Decisions resulting from the second PrEP summit include:

- For 2020 PrEP in Europe would seek to organise two or three smaller meetings for specific disadvantaged minorities, (disadvantages either as people or geographically) rather than one big summit.
- Our intention would be to organise a third pan-European summit in 2021.
- The PrEP in Europe summit, and our work in general, is funded by a mix of pharma industry support and NGO/philanthropic sector money. We are seeking to increase the proportion of governmental and non-governmental funding.
- We intend to structure PrEP in Europe on a more formal constitutional basis and will convene a structure and constitution group to manage that change.
- We will also convene a strategy and programming group to devise a strategic work programme and act as the programming advisory committee for specific meetings, with powers to bring in representatives from specific populations and local reps from the meeting locality.

# Main report

## PrEP in Europe

PrEP in Europe is a partnership of eight European NGOs – AIDES, AIDS Action Europe, AVAC, EATG, NAM/aidsmap, the National AIDS Trust, ECOM, and PrEPster. The first six of these were founder partners.

PrEP in Europe was born out of a meeting convened by UNAIDS and EATG in June 2015. It followed a couple of one-day special EATG European Community Advisory Board meetings on prevention in 2013 and 2014.

Dialogue within the European HIV community following these and the results from the PROUD and IPERGAY studies had been centring on the need to adopt new definitions of safer sex and preventative behaviour, new guidelines on prevention, and new campaign and social-marketing aims for organisations working in the HIV sector.

It was also motivated by the fact that although *Truvada* (TDF/FTC) PrEP was recommended by the US FDA in 2012 and started to be adopted immediately, at the time of that first meeting it was yet to be approved by the European Medicines Agency (who eventually approved it in July 2016). It was felt therefore that there needed to be a co-ordinated campaign for PrEP throughout the region.

A website was set up at [www.prepineurope.org](http://www.prepineurope.org) and a grassroots PrEP access report commissioned written by Rebekah Webb, formerly of PATH. We also set up PrEP in Europe's [social media page on Facebook](#). At the time however PrEP in Europe was operating with no funding, and by activists donating their time for free.

After a couple of Steering Committee meetings enabled by AIDS Action Europe, a co-ordinator was appointed, and a secretariat established at NAM/aidsmap in London. This enabled us to fundraise further for the two European PrEP summits we have organised.

At present PrEP in Europe is quite informally organised. Financial responsibility is borne by NAM/aidsmap and final decisions around programming are taken by the Steering Committee. During summits we have also convened subcommittees that have handled the selection of scholars and attendees, travel, and local logistics. In the Warsaw summit in particular, the involvement of local professionals and activists was key to its success, and one of the reasons we chose Warsaw as the locality. Joining us at conference calls and meetings are members of multilateral organisations including UNAIDS, ECDC and WHO Europe, who have performed an important advisory and support role.

The informal organisation of PrEP in Europe has been an advantage in terms of making decisions quickly and informally but has been a disadvantage in seeking funding and in being a stable organisation with a medium-term strategy. One of the resolutions arising out of the Steering Committee following the Warsaw summit was to write a more formalised constitution and memorandum of understanding describing the way the partnership worked – see “Post-summit Steering Committee” below on page 21.

## Our mission

PrEP in Europe provides information on the effectiveness and availability of PrEP. It provides news and advice to help strengthen advocacy for PrEP throughout Europe. It aims to help organisations develop guidelines, recommendations and consistent policy demands for PrEP, and to provide networking opportunities for people working for PrEP access in different capacities throughout the continent to develop practicable PrEP programmes and ways of advocating for them.

We bring together researchers, providers, policymakers, physicians and the community of affected individuals. We aim not only to help increase access to PrEP throughout the WHO European region, but also using the energy involved in PrEP advocacy as a catalyst for better HIV testing and treatment, and for better sexual health and health equality for HIV-affected marginalised groups in general.

PrEP in Europe has four main aims:

- **Information.** We aim to provide information on the science, provision and usage of PrEP throughout Europe. As well as providing content itself such as summaries of the most important studies, PrEP in Europe aims to be a “knowledge exchange” where members can contribute information on PrEP science, programmes, and access.
- **Advocacy.** There are already energetic advocacy and support campaigns for PrEP in many European countries, and PrEP in Europe does not aim to do the same job. We aim to help build the skills and knowledge of advocates by providing training and advocacy materials and helping people in national campaigns to exchange ideas.
- **Policy.** Apart from its cost, the biggest barriers to the provision of PrEP are the entrenched attitudes of politicians and health system providers, and the complexity of European healthcare systems. PrEP challenges the institutional division between healthcare and public health seen in many health systems, and challenges received wisdom that influencing risk behaviour is the only effective and ethical way of preventing HIV.
- **Networking.** We are stronger together in this campaign than we are separately. PrEP in Europe had, as an original aim, a centralised web resource where people involved in advocating for the wider availability of PrEP could meet, exchange ideas, and gain strength from each other’s good examples. We are delighted that we have now been able to organise two conferences where PrEP users, community and NGO activists, healthcare workers, researchers and policymakers can meet in person and help each other develop new pathways to PrEP.

The Steering Committee Meeting after the Warsaw summit also decide on a set of three core **values** to guide our work. These are **inclusion, diversity and solidarity.**

PrEP in Europe disseminates PrEP knowledge via new stories, summary pages and factsheets on its own website [www.prepineurope.org](http://www.prepineurope.org) and also via our [social media page on Facebook](#).

PrEP in Europe has organised two successful PrEP Summits in [February 2018](#) (Amsterdam) and in [October 2019](#) (Warsaw). For the final report on the Amsterdam summit, [click on this link](#). This is the final report on the Warsaw summit.

## The Warsaw summit: aims

The overall aim of the summit, as declared in its web page, was:

*“To articulate how we, as members of the affected communities and their allies, want to be able to benefit from it. We are mobilising not just for the Right to PrEP, but the Right PrEP – provided in ways that most align to our needs for protection from HIV, and for good sexual healthcare.”*

The specific aims, listed below, were:

- To understand what barriers remain to implementing PrEP in Europe;
- To discuss how key stakeholders – healthcare professionals, healthcare providers, and community advocates – can collaborate in speeding up implementation;
- To discuss how PrEP and PrEP activism can contribute to an equal and effective approach to HIV prevention throughout Europe;
- To harness the energy and commitment of PrEP and HIV activism to help address stigma and human rights abuses against the key affected populations of Europe.

## Our model

Guided by the above set of aims, PrEP in Europe has adopted a model for its two meetings which aims to maximise community involvement. We aim to have at least 40% of attendees supported as “scholars”, meaning that almost the entire cost of their attending the meeting (travel, accommodation, conference fees, and catering) is paid for by PrEP in Europe. This of course means that our conferences have cost considerably more than they otherwise would, but it also means that we have been able to involve people who might not otherwise have been able to participate.

At the same time, we also ask every attendee to pay a registration fee: but this is on a steep sliding scale. At Warsaw this fee was €120 for professionals, €60 for NGO workers, €30 for self-financed activists, and €15 for activists from resource-poor settings (this had to be turned into £110, £55, £25 and £12 because NAM’s payment providers could not accept Euros). The registration fee is intended as a token of involvement and commitment to the meeting; its payment also has the function of acting as a conformation of registration. In a few cases of genuine hardship, it was waived entirely.

The scholarship structure also enables us to select a group of attendees who are more representative, both geographically and of under-served minorities. Because this is an important issue, and determines the feel and nature of the summits, the initial selection of scholars was made by a small sub-committee of our Steering Committee and Advisory groups, independently of the co-ordinator.

The disadvantage of this structure was that it made the application process quite complex. It involved would-be applicants completing an initial Application Form asking them if they wanted to be scholars, devising a Scholarship Application section of the form for them, and then communicating results to four different sets of people (accepted scholars, applicants rejected as scholars but still invited, people invited to register who did not apply for scholarships, and people who fell outside our attendee criteria – mainly because they lived outside Europe).

People accepted to register then had to complete a second, personalised Registration Form, which included paying the Registration fee. While this is something that would have been easy to handle for a larger organisation with an IT department, it was hard to co-ordinate when only the PrEP in

Europe co-ordinator and our IT consultant, who was also working at redesigning the aidsmap website at the same time, were involved.

Some registrants found having to fill in two different registration forms confusing, a few objected to having to pay a registration fee at all, and the payment website NAM/aidsmap uses did not accept payments in Euros and did not send out acknowledgements for the first few registrants. Dealing with registration enquiries took up a significant proportion of the co-ordinator's time and meant that less could be spent on programming. Nonetheless, a delegate group was assembled that was more geographically representative and diverse in terms of populations than had been the case at Amsterdam. See **participants** below for more.

### **Why Warsaw?**

Several different suggestions were made for the location of the summit, ranging from Kiev to London (the latter to go back-to-back with Fast-Track Cities.) The two that had the strongest backing eventually were Athens and Warsaw. Both had strong and motivated local teams that could help organise the meeting, and both in different ways are European 'frontlines' in HIV care and prevention – Poland because of the rapidly expanding epidemic it has seen in its gay and bisexual male population in the last decade, and because of its current political situation of economic expansion and liberalising tendencies colliding with a conservative Catholic culture – and Athens because of its frontier status within Europe and its challenges with its economy, with migration, and with harm reduction.

In the end the decision to choose Warsaw was largely taken on the grounds of expense, as both travel to Warsaw and hotels once there were considerably cheaper. The venue, The Sound Garden Hotel, was chosen because of its good value, its modern ambience and community-friendly feel, its superior broadband capabilities, and its friendly and accommodating staff. It turned out to be an excellent choice.

### **Funding and finance**

There will be a detailed financial breakdown in the Financial Report. Like many of our constituent NGOs and NAM/aidsmap itself, PrEP in Europe was initially unfunded except for a couple of one-off donations made to AAE to enable it to organise a couple of Steering Committee meetings.

We then received enough funding from pharma sources to engage a co-ordinator, who was then able to seek more funding to enable the two PrEP summits to take place as well as to fund our other activities such as our website.

It has always been important for PrEP in Europe to seek a balance of funding, not least because pharma as a sector has less incentive to fund a prevention modality that primarily, outside the US, involved generic drugs. However, it is also important that the philanthropic and governmental sectors support PrEP in Europe too. PrEP is at least as much an issue of social justice, health equality, and access for the stigmatised as it is of modern medicine and prevention science, and while so far, no national or international government source has supported PrEP in Europe, the support of philanthropic organisations has been crucial. In 2018, the support of Aidsfonds, both financially and logistically, made it possible for us to have our first summit in Amsterdam, though their support was conditional on receiving none from pharma, which limited the size of the meeting. However, Aidsfonds did a considerable amount of work in kind, sourcing and liaising with the venue and scholars' hotel, for instance.

In 2019, we did have pharma-sector funding to the tune of about €100,000 (two of the grants also covered other aspects of our work). However, it was a grant of \$50,000 from the Open Society Foundations' Health section that gave the "green light" and enabled us to put on the second summit.

By themselves these made a summit possible, but it would have been smaller. In addition to these major funders, other organisations donated either in cash or in kind. As had been the case at Amsterdam AIDES both covered the costs of its own staff and volunteers but also paid for approximately five scholar places: as well as funding its own back-to-back meeting (see below), UNAIDS donated the balance of \$10,000 after the back-to-back meeting costs for approximately another five places; AVAC donated \$5000 and also paid for three places for its staff and volunteers; AFEW paid for five places for attendees from eastern Europe through its Martine de Schutter fund; PrEPster paid for five of its workers/volunteers; and we also received €1000 from Anlaids Lazio, plus a considerable amount of publicity, which resulted in a large and active Italian contribution to the meeting.

Another important contribution was that WHO Europe paid for and sourced simultaneous translation into Russian for almost the entire meeting (except for breakout groups). This was an innovation both for PrEP in Europe and for NAM; it generally worked well for the 20% or so of attendees who spoke no or little English, and for a presenter who spoke in Russian. Technically, however, it was less easy to switch rapidly from English-to-Russian to Russian-to-English when panel members or audience members needed to make Russian-language contributions. We will work with translators in future to ensure audience and panel members who need to contribute in Russian (or other languages) are able to contribute on a more equal basis.

In terms of donations in kind rather than cash, Hornet, the gay and bisexual men's contact group, organised an interview about the meeting beforehand with its Senior Health Innovation Strategist Alex Garner and had a link on its opening page to the meeting's live streaming.

As we had done for the Amsterdam 2018 summit, we subcontracted one of our partners, EATG, to organise the travel for scholars, and paid them a sum in advance to cover the majority or all of the expected cost. Despite complications such as urgent visa requests (see participants below) and paying for participant's costs in obtaining visas, travel was generally arranged on time and within budget. Thanks are particularly due to EATG's Bojan Cigan for handling this task with efficiency.

## The participants

We had 240 applicants of whom approximately 170 (71%) attended the meeting. We say "approximately" because the statistics that follow come from several different lists with slightly different totals, both because of several last-minute cancellations and because of several attendances by local people living in Poland. The difference in totals is no more than about 5 places.

Interestingly, for the previous summit in Amsterdam we have more applicants, for fewer places (120 attendees out of 270 applicants – 44%). This may be for several reasons:

- Amsterdam is a better-known and more tourist-centred destination than Warsaw
- Conversely, Poland has received adverse publicity in the last few years as a country unfriendly to the LGBT community and black and ethnic minorities
- People who were not subsidised scholars may have had more difficulty finding the money and time for a 2.5-day meeting than a 1.5 day one
- PrEP maybe lacking the novelty status it had 18 months ago in western Europe.

Seventy out of the 170 places were fully subsidised scholars. The average cost per head of these 70 people was roughly €100 per person, so as well as being 40% of the attendees, their flights and accommodation also represent about 40% of the cost of the meeting.

There were 12 last-minute cancellations, of whom four were scholars (two failed, despite considerable effort from both PrEP in Europe and UNAIDS, to get visas, one had a death in the family and one a medical emergency). Ultimately there were 164 attendees of whom 67 (exactly 40) were scholars. There were six last-minute local attendees added, three of whom were able to make use of the three spare hotel beds, but it was too late to recoup air fares.

One learning to take from this summit, with a higher proportion of delegates from central Asia, is that it required more time and expense than anticipated to help them get visas. We will allow more time for this in future.

Attendees came from 36 different countries from the 52 of the WHO European region (69%), plus four delegates from the US and South Africa, who were there as steering committee members or invited speakers/facilitators.

Fifteen countries from western Europe, 12 from central Europe and nine from eastern Europe were represented. Countries not represented at Amsterdam included Albania, Estonia, Azerbaijan, Kazakhstan and Uzbekistan; two countries represented at Amsterdam (Austria and Bulgaria) were not represented at Warsaw. The countries with the most attendees were the UK (20 people), France Poland (18) and France (16), while Ukraine with seven delegates was the best-represented eastern European country. There were surprisingly few applications of delegates from the Scandinavian countries.

Applicants were asked both their current gender (with an option of declining to say) and their gender at birth. The gender makeup of the attendees ended up looking like this:

- 112 cis men (two-thirds of attendees)
- 36 cis women
- 3 trans women
- 2 trans men
- 6 who declined to define their gender or who wrote 'other'.

So there were 11 (7%) of attendees who defined as other than cis male or female. Of note, two of the four scholars who had to cancel at short notice were trans people – one of the visa failures and the person with a medical emergency.

We decided, this time round, not to ask people about their sexual orientation. We may restore this question in forthcoming meetings.

We did ask people about their HIV status and whether they took or had ever taken PrEP. People in both cases had the option not to disclose. Out of 160 respondents, 33 (21%) said they were living with HIV. One-hundred and four said they were HIV negative, (65%) five – four from central and eastern Europe – did not know their status, and 18 preferred not to say

With regard to PrEP, out of 158 respondents, 32 said they were currently taking PrEP and 18 said they used to. Interestingly, two respondents – both non-English speakers from eastern Europe – said they were HIV positive and taking PrEP. They were asked about this and said they thought the question was about antiretroviral therapy (ART). If these two cases were discounted, then 19% of respondents were currently taking PrEP and 11% used to.

One cis woman and two trans people were currently taking PrEP, while four trans people used to. Of those currently taking PrEP, six were in central Europe and four in eastern Europe. A disproportionate number who said they used to take PrEP – seven – came from eastern Europe, which may reflect access difficulties.

Apart from gender we did not otherwise ask about population status, but we did ask participants which groups they worked with or on behalf of, giving them a non-exclusive list of nine population groups plus an open option to state “other”. The participants stated as follows:

- **Prompted groups**
  - MSM 109 (70 exclusively)
  - Women 36
  - Youth 19
  - Migrants 18
  - Sex workers 16
  - Trans people 15
  - People who inject drugs 14
  - People from ethnic minorities 10
  - Prisoners 3
- **“Other” (non-prompted) groups included** Heterosexuals including men; people with mental health issues; chemsex users; people taking PrEP; clients of sex workers; queer people/LGBT community; and women with HIV. One person said “Organisers!”



## Programme development – the template

The 2.5-day programme was established by the co-ordinator writing a draft programme template which was then modified by conference calls.

One challenge was that we did not feel able to organise the programme in detail until we had definite funding and a date secured. This had also been an issue at Amsterdam. One recommendation we will make for subsequent meetings is that a Programme Subcommittee should work on the development of a programme template, possibly with suggested keynote speakers, further in advance.

One big difference between Amsterdam and Warsaw was that the Amsterdam structure was determined by the PrEP in Europe Steering Committee and that representative speakers were then invited to contribute. In Warsaw, we made an open call to participants to submit proposals for presentations, both abstract-driven and others. This call was very popular and resulted in far more proposals than we originally had time for. The call for submissions was one reason the programme eventually became more crowded and we had originally intended and with less time for panels and breakout groups.

The rough structure suggested was:

The Thursday evening would be an introductory or training session largely aimed at the Scholars and others new to PrEP activism who needed to update or improve their knowledge of the state of PrEP in Europe.

The Saturday would consist of a couple of plenary sessions of 20 minutes each on subject topics plus the first of a session of shorter 10-minute presentations with topics ranging from data on PrEP programmes of key interest, dubbed the “PrEP show”.

The first Saturday plenary consisted of four presentations dealing with progress towards PrEP in Europe: an epidemiological study on PrEP availability; a model-based discussion of the public health effect of PrEP and how it could be isolated (or not) from other developments in testing and treatment; a well-received introduction to cost-effectiveness analysis for PrEP; and a presentation in Russian from a Russian activist detailing the challenges of promoting PrEP among that exceptionally burdened country.

The second plenary session was on community awareness campaigns, featuring work to spread PrEP awareness in Poland and elsewhere in central Europe, among women, and on social media.

There would also be a long outbreak-group session on the Saturday consisting of presentations and panels on particular minority population groups. The idea was to provide a good amount of time where representatives of groups such as trans people, sex workers and ethnic minorities and migrants would have time to discuss issues affecting them and come out with a series of recommendations.

The Sunday morning would start with a session on emerging issues in PrEP science and drug development, presented by representatives of our three funding drug companies – ViiV, Gilead and Merck – plus a special invited lecture of PrEP pharmacokinetics and drug absorption in different population, a topic thought to be of particular interest, especially for non-MSM populations.

The drug discover session was the only place in the summit where we looked at what may be in the PrEP pipeline.

This would be followed by the second “PrEP show” and then the afternoon plenary session would look at four countries – Ukraine, Poland, Spain and France – representing the development of PrEP programmes in diverse areas of Europe, with requests to the speakers to confer and speak on areas of challenge and opportunity in common, differences and the way PrEP can catalyse other developments in sexual health. We originally had only one western European country – Spain – but France was chosen as the country with the longest-existing PrEP programme, in contrast to Spain, where government agreement for a health service PrEP programme was only announced a few days before the summit (it was presented by that country’s HIV co-ordinator, Julia del Amo).

One reason we chose four specific countries was that the Amsterdam PrEP summit had featured a number of short updates from numerous countries on the first evening, and the feedback was that many of these were rather similar and that considering regional challenges was a better idea.

This would then leave time for a second breakout session and final plenary discussion to synthesise a series of recommendations on PrEP.

### **Programme development – as it turned out**

One difference between the Amsterdam summit and the Warsaw one was that we put out an open call to participants to suggest presentations and abstracts. This received an encouragingly enthusiastic and diverse series of proposals. Some were selected for the “PrEP show” sessions but to do justice to some of the others we arranged a poster exhibition too. This did not greatly increase costs but did increase the amount of preliminary logistical work necessary.

The biggest challenge facing the programme development – apart from finding keynote speakers – was that representative of disadvantaged and minority groups fed back that they felt that the breakout group structure risked further marginalising them. On the contrary, they emphasised, they wanted their concerns and issues to be communicated to and discussed by the whole meeting.

Their concerns were fully accepted by the Steering Committee – the breakout group structure had always been a suggestion – and in the end we organised two plenary sessions on migrants and black and ethnic minority gay men, and on trans people and female sex workers.

These were acknowledged in the feedback forms as interesting and important sessions but lengthened the Saturday and meant less time for the panel discussions and the plenary groups we did have. The session on trans people would have been even longer – and more interesting – if a key speaker working with trans sex workers had not had to cancel owing to a serious personal health issue, and an attempt to have her present by video link could not be arranged in time.

Another issue – albeit a welcome one – is that a large number of non-scholars also wished to attend the Thursday evening introductory session in the end, over 100 out of 167 attended and we had to use the main plenary room (at no extra expense) instead of the smaller room intended. The session consisted of a series of short updates on developments in PrEP science, PrEP failure, PrEP and STIs, and how to get PrEP, especially in resource-limited settings.

We also heard a presentation from a representative of the back-to-back meeting that took place before the main summit – see below.

All the slide presentations are on the PrEP in Europe site at <http://www.prepineurope.org/en/summit-2019/presentations-and-video-feeds/> and the video feeds are also available on our YouTube channel at <https://www.youtube.com/channel/UCO0XbISl->

[XSXltlqjyoQ1NQ](#). Most of the presentations also have simultaneous Russian translation and can be viewed [here](#).

The YouTube channels also includes some interviews with individual presenters: two examples are [here](#) and [here](#).

There are also three reports on Aidsmap picking out specific aspects of the summit here:

- <http://www.aidsmap.com/news/nov-2019/some-european-governments-are-paying-eu3-month-prep-while-others-are-paying-eu850>
- <http://www.aidsmap.com/news/nov-2019/polish-prep-activists-creating-services-and-building-demand-difficult-environment>
- <http://www.aidsmap.com/news/nov-2019/prep-services-france-are-changing-order-engage-more-people>

Among plenaries of note that were particularly mentioned in the feedback forms were:

- [The plenary on cost-effectiveness](#), which was praised as a simple and comprehensible guide to a potentially technical topic. It garnered feedback that people aiming to persuade their governments to put on PrEP programmes in their country were interested in asking the presenter to do a country-specific cost-effectiveness study
- [The plenary from Russia](#) was widely praised as a bleak but comprehensive look at the challenges of informing a population about PrEP who had largely had to rely on partial and informal social-media sources. Presentation was in Russian with English-language slides (simultaneous English translation did not start till 05:24 owing to tech issues).
- [An inspiring blog](#) presentation by a young nonbinary activist about how PrEP and campaigning for it had changed their lives.
- A couple of challenging presentations about stigma against PrEP and its users within the Netherlands and western Europe (YouTube links [here](#) and [here](#))
- A presentation from a young Zimbabwean woman taking PrEP, which was followed by a panel discussion on women and PrEP ([YouTube link here](#)).
- [A very interesting presentation](#) from AIDES about how they came into contact with a group of vulnerable, trafficked Nigerian female sex workers in Paris and conducted PrEP and prevention work with them.
- A lengthy but fascinating talk by two trans/transmasculine men [about working with trans men's sexual health in general and PrEP needs in particular](#). This was, some attendees remarked, the first time they had ever been given this information.
- The invited lecture on [PrEP PKs and drug levels](#) was also widely praised as a clear explanation of a potentially complex subject.
- The sessions by [Merck](#) and [ViiV](#) were the only ones (apart from Cindra Feuer's opening one on Thursday) that looked at the PrEP pipeline and the development of new drugs and formulations. Some found these interesting and useful, though some found the presentations a little too technical, not being HIV treatment experts.
- However the talk by Staci Bush of Gilead instead directed at the experience of trying to help women in the US get access to PrEP and [the challenges of designing PrEP trials for women](#). Although this did not directly address the European dimension, it did prompt questions as to how to adapt trials of access programmes for women in Europe, and attracted positive comment from some African attendees.

These are just a hand-picked few, other presentations of interest have already been mentioned.

## The back-to-back pre-meeting

Before the main summit on 10-12 October, EATG, ILGA Europe and AIDS Action Europe, supported by UNAIDS, held a small one-day meeting for 15 activists from three specific countries in central Europe – Poland, Hungary and Turkey. PrEP in Europe, along with EATG as travel partners, arranged the logistics for this meeting. The feedback from this meeting was presented during the Thursday session and [is on YouTube here](#).

The purpose of the meeting and of selecting these three countries was not PrEP-specific or even health-specific. Rather, it concentrated on the legal and social environments where, to different degrees, the HIV prevention situation is particularly challenging, combining as they do, increasing incidence among the LGBT community with cultural and political environments that are unfriendly to the development of community- or government-based projects to address these needs. The meeting's attendees included representatives from the trans/nonbinary communities in all three countries.

One interesting aspect of the meeting was to look at the legal environment for gay people and trans people – not only in terms of laws that oppress the LGBT community, but ones that could be used potentially as ways of defending them (eg anti-discrimination laws, if there are any).

From the point of view of PrEP in Europe and the larger summit, the model of having a pre-meeting for specific activists is an interesting one in that it puts together, trains and empowers activist who may have little experience of larger meetings – as many did not – so that it helps them contribute more powerfully to the larger meeting. This is a model we may adopt ourselves for smaller PrEP in Europe meetings for specific populations that feed into larger conferences.

## Feedback

We have given quite a lot of space to the feedback comments from participants as we believe these demonstrate better the way the meeting accomplished its goals

Eighty-eight participants – 53% – have so far filled in an online evaluation form that was sent to their personalised link.

They were asked:

- **One highlight of the meeting for me was:**
- **One part of the meeting that could have been better was:**
- **The most useful session for me was:**
- **One thing I will do as a result of attending the PrEP in Europe summit is:**
- **One thing I'd like PrEP in Europe to help me with is:**

They were also asked to give scores from one to five for the logistics, and for individual sessions, plus a final box for general comments (turned into percentages here).

**Logistics** generally scored highly and received almost no negative comments. Scores for specific aspects were:

Travel arrangements 89.2%,  
Literature and information 80.0%

Accommodation and catering 84.7%  
Sound, vision and translation 94.2%  
Meeting chairing and facilitation 89.8%

The relatively lower score for literature and information may be partly due to pressure on the website and getting/sending things like the programme and local travel instructions up rather late, but also prompts us to think about giving participants more background information on PrEP and on the conference's aims and structure before they come.

We asked participants to score sessions rather than individual plenaries as that would have been too many, apart from the opening four on the Friday (first full morning). Almost none scored below 80%. It is noticeable however that the scores for Friday's presentations were in the high 80s or low 90s (the first "PrEP show" session, on social and behavioural aspects of PrEP, scored 92%), whereas the Saturday sessions were 5-6% lower. We think this may reflect exhaustion and a general sense of people receiving too much information without time to digest it, rather than a comment on the individual quality.

Obviously, we lack the space here to provide more than a small selection of the comments to the open-box questions. We select what we hope are the most representative ones, both positive and negative, and especially picking out areas of different opinion.

#### **One highlight of the meeting for me was:**

General note: the aspect of the summit most mentioned was the opportunity to network with and discuss PrEP use and programmes with other users and advocates from all over Europe

- *It would be inappropriate to accentuate the highlights, as the meeting was exceptionally well organized, duly packed in content, it was hard to miss any session*
- *Having the more marginalised groups speaking on the plenary stage*
- *I felt part of an important movement*
- *It was from community to the community!*
- *Cianán and Max's speech was extremely good because it was the literally first time that we heard something from trans men*
- *Questions around PrEP effectiveness v efficacy and implementation of PrEP in trans men (need for further empirical research) – this presentation was mentioned several more times than these two examples*
- *PrEP and female sex workers/trans women and men: Alternative PrEP and treatment*
- *The significant diversity and actuality of information (presentations and discussions) at the summit*
- *Presentation of the radical fairy, sister Paweł Ziemia from Poznan*
- *Most useful: Pharma PrEP R&D (Saturday): STI epidemiology (Thursday)*
- *Finding out that there are a lot of new trials about other drugs and method for PrEP*
- *Seeing the huge differences in PrEP and STI diagnostics access across whole Europe*
- *We all know PrEP works. The highlight was raising awareness of how different (marginalised) groups need PrEP as well.*
- *Short, concise presentations following each other, no time to be bored*
- *Disparities in Europe are bigger than I thought (implementation, cost, awareness*

- *It put me back on track. Recently I was a bit unmotivated, due to lack of support and hostile environment back in Hungary, but meeting with such a great number of enthusiastic activists gave me my hope back*
- *I liked Staci Bush about PrEP in the south and in black people in the USA*
- *I had the opportunity to talk with a pharma speaker and hear why the labelling on their drug in Europe differed from the one in the US.*
- *LOVED meeting people from different projects/places that I had never thought about - what a wonderful opportunity to bring together so many cultures and ideas!*

**One part of the meeting that could have been better was:**

General note: The most consistent criticism was that the programme was too packed and that there was lack of time for interactive discussion. Some, on the other hand, likes the relatively brief nature and Fast pace of presentations.

- *Interactive working groups. They were crammed in the last minute, last day, and rushed. I was expecting an opportunity to workshop an idea how to introduce PrEP in other limited source settings, but it did not come. The suggestion would be to allow more time to working groups, in lieu of presentations.*
- *I felt that the breakout sessions could have been longer with a more structured output.*
- *A different organisation of the programme that would have allowed for more direct participation and mixing and meeting (like teams, or learning groups etc) and longer time for discussions at least at one point.*
- *Data results from pharmaceuticals: a bit too technical, sometimes difficult to follow*
- *Hard to say but least useful, for me, was the more technical ones as I don't work in that field.*
- *More presentations on problems in countries with long-term PrEP usage experience. More time for discussions and networking*
- *The agenda was too packed. Also, in terms of the presentations, I would personally like it to be less data and what has been done but how things were done and how the challenges faced was overcome.*
- *additional short breakout session on the first day could help people to get to know each other better and facilitate networking. I find it a lot easier for me personally to give my opinion and ask questions in a smaller audience than in a larger one and suppose not the only one.*
- *More diversity in terms of regions and countries with regards to countries and presentations. It is great that best practices come from certain parts of Europe, but more efforts should be made for sub-regional discussions where participants can discuss from a "similar level" and find solutions that are more easily applicable in their local context.*
- *Long days that felt rushed at times. So many different aspects and points of view to accommodate that the program was packed.*
- *I think that most of the speakers gave an overall impression that PrEP is something mostly for gay people. There should have been a session titled PrEP and heterosexual people or something similar.*
- *I believe the use of PrEP should be recommended to anyone who is currently not in a monogamous relationship, no matter whether he/she is gay/straight/bisexual/whatever. There should have been a session titled PrEP and heterosexual people or something similar.*
- *There was little or nothing about trans\* women, trans people in Eastern Europe, their HIV coverage.*

### **The most useful session for me was:**

General note: virtually all sessions and many different presentations were singled out. The pharma session attracted three negative comments, mainly for being too technical, but was also mentioned as the most useful session by two participants. The presentation on trans men by Cianán Russell and Max Appenroth was the single presentation most mentioned.

- *The most useful session on new formulas and regimens of PrEP. though all the other sessions were also interesting.*
- *The breakout on the last day*
- *That of Valerie Delpech (Public health impact of PrEP)*
- *The Thursday warm up session, as it brought the subject together for the rest of the meeting. and the session about the prep gap.*
- *Daniela Rojas (risk compensation), PrEPster and the related with vulnerable groups, HIV and use of PrEP (PrEP Show 1 and 2). I also loved the summary of PrEP recommendation from AIDES and the work at BCN Checkpoint and Athens one*
- *Haru's talk about being a PrEP user as a woman*
- *PrEP -a concern or opportunity for STI control – presentation on Thursday evening*
- *Pharma PrEP and STI epidemiology in the introductory session*
- *Something new for me - cis trans people and health issues. Most interesting - cost effectiveness of PrEP. other countries experience on implementing issues, evidence-based PrEP.*
- *Presentation about transgender men and non-binary people, conducted by Max Appenroth and his colleague*
- *Most useful speech: dismantling the barriers to healthcare for trans people.*
- *The situation of HIV and PrEP. in Russia.*
- *Will's presentation. How to promote PrEP*
- *The presentation about the cost-effectiveness of PrEP was the most useful session of the summit. Having been informed on how PrEP use could save money and make the National Health System more effective, I believe I can more easily persuade people to use PrEP.*

### **One thing I will do as a result of attending the PrEP in Europe summit is:**

- *Follow up with colleagues about a social charter collective complaint regarding access to PrEP*
- *What I am already doing: we are in preparation of launching a PrEP prototype model in the Baltics*
- *Calculate the number of HIV infections averted in Poland since PrEP was introduced and publish it.*
- *I'll organize a seminar for public health students in my country about PrEP and HIV prophylaxis*
- *Soon I will organise workshops about PrEP for my colleagues, students, nurses, and teachers of our infectious diseases department in the Tashkent Medical Academy. So I would like to start PrEP campaign in Uzbekistan*

- *Be more open to recommending PrEP to women. Being more able to argue with people afraid of PrEP's adverse effects and its "inefficacy".*
- *I will talk about the main points of the meeting and show a phone video, I have a video recording at the face-to-face meeting of the Working Group of Trans People of the EECA Region on HIV Prevention and Sexual Health*
- *Consultation with our membership on PrEP advocacy in the Western Balkans*
- *Start working on Community Provided PrEP model in Georgia*
- *check if in Italy it is possible to buy the same tests for HCV that use some Spanish checkpoints and assess whether it is possible in Italy to print leaflets with strong images such as those shown by Georgians.*
- *Try to find support to scale up PrEP to populations at increased risk for HIV other than MSM in my country (MSM and serodiscordant couples are the only groups covered for reimbursement purposes)*
- *Try to change the terms and conditions of obtaining PrEP in Ukraine*
- *I got several ideas that could be implemented (with lack of funds...) in Hungary, but first, I will cooperate with Christos to prepare a chemsex survey.*
- *I'm going to contact coffee-shops in Cyprus asking whether I could organize a presentation about PrEP and invite mostly young people to attend. I have already contacted some coffee shops and I have received a positive answer from a coffee-shop in Larnaka.*
- *Use the Summit experience for conducting the ECOM Regional Community Consultation on PrEP in EECA*

#### **One thing I'd like PrEP in Europe to help me with is:**

General note: this was a mix of ideas and requests for PrEP in Europe to support them, with some notes for aspects of the summit people had found difficult and asking us to improve.

- *with preparation of launching PrEP prototype model in the Baltics. We will need experts from PrEP summit folks when the project is funded.*
- *In-depth understanding of PrEP as a choice of life, not just a treatment*
- *to make it more accessible for Turkey*
- *PrEP in Europe to help me and our organizations in Azerbaijan develop scientific research and investigation and pursue a coherent policy regarding PrEP, as well as provide networking opportunities for people working in various fields. And also to carry out projects and conduct educational activities.*
- *Make sure the needs and voices of minority groups are \*well represented\* throughout the conference...There needs to be much better representation of black people, PrEP users, queer men of colour and trans women.*
- *Sustain activities in entire European Region, information and updated last researches and best experience to share, creating a friendly PrEP mailing list.*
- *I remember someone saying they've put together a proposal for their ministry of health. I would love to learn how those proposals are done. As I said we do know what can be done but the question is how*
- *Help us challenge the neg. attitude of some medical experts towards U=U.*
- *Addressing EU level legal barriers in improving access to PrEP (ban on advertising prescription drugs, requirement in PrEP drug authorizations that treatment be initiated by HIV specialists)*



- *Contact the Dutch professor to do a study of PrEP cost-effectiveness for Poland to influence decision makers.*
- *Be clear on instructions to speakers or panellists. avoiding to be ashamed on stage!*
- *Medecins Du Monde is planning to start Community Bases On-Demand PrEP Pilot in Georgia in 2020; Since January 2020 we will start working on the service delivery model; Participation, expertise and technical support of PrEP in Europe would be helpful.*

### **The Breakout Groups**

- *Could have been better allocation of time: too short... and didn't collate feedback properly*
- *Best part - good to get to think about things more actively and strategise.*
- *I think this could have been a little longer with a structured output like a key points report that would be shared with all groups?*
- *It was a good idea to divide the issues into several groups. I was in green one and made brainstorming and some conclusions in terms of what should be done and can be implemented in Central Asia*
- *It was a bit strange being randomly assigned a group, and in the end, I went to a different group from the one I was assigned, as I felt my experience more relevant to the marginalized groups breakout session. I'm not sure I got a lot out of it, as it wasn't really a discussion, it was more of individuals sharing. I*
- *The purpose of the breakout groups wasn't clear, and we should have had more freedom to sign up to the ones relevant to our work.*
- *Group members are from very different countries, so it is difficult to make general decision. Moderators should be very strictly. Try to prepare short questions for moderators with correct answers to choose from audience.*
- *Would have been better if people could decide in which group they want to go - we are not equally experts in each topic.*
- *There were too few people in my group and too little time for discussion.*
- *The breakout group at the end was a wonderful idea. It gave us an opportunity to expand on the summit and discuss barriers from all countries. It gave people an opportunity to learn good practice from each other.*
- *It was good but need to improve/ in general the 2nd summit was good compared to last year. Lots of improvement. I hope next time they will give more time for the delegates to know each other.*
- *Definitely there should be more events with groups. Maybe some part as an 'Open Space Technology' ?*

## Post-summit Steering Committee

The Steering Committee meeting, held on the morning after the summit, was an integral part of it. We noted as a group that it was the first time we had managed to meet in person rather than through conference calls since Amsterdam, and the lack of funding for supportive and structural aspects of PrEP in Europe, as opposed to conferences, was noted.

We took the opportunity to redefine our **values** as a partnership and, partly with the Summit acting as a focus for this, listed them as **inclusion, diversity and solidarity**.

We did not spend a great deal of time giving feedback on or conducting a “post-mortem” of the summit. This was because, apart from the issue of the overcrowding of the programme, which was acknowledged, it was generally thought to have been a success and achieved its aims.

It was acknowledged that the issue of the packed programme was an illustration that there are many populations and communities that need their voices heard in the battle for wider and more equitable access to PrEP and preventative sexual health.

Because of this, there was a proposal that in 2020 there should not be one big summit but that instead we should aim to put on several smaller meetings aimed at specific populations. The programming and to some extent the logistics of these could be delegated to **thematic subgroups** representing the specific populations.

*[Co-ordinator’s note: as I write we have started to organise a regional meeting for PrEP users and advocates in eastern Europe in Georgia in October; have applied for funding to conduct a meeting focusing on migrants and black and ethnic minorities in Lisbon in September; and are considering a small meeting on the biomedical PrEP needs of trans people, possibly in Amsterdam.]*

Several Steering Committee members commented that some of the information given at the summit – its knowledge aspect – could have been given as briefing documents sent in advance of the summit. These need not be restricted to factual information about PrEP coverage, cost, public health effects etc, but should do a review of the different kinds of structure possible in different countries, and, with the last plenary in mind, create an advocates’ “check list” of different possibilities. For lower-income countries who are transitioning away from funders like the Global Fund this could include suggestions about funders.

There was an in-depth discussion, conducted in smaller groups and then in full, about the structure and governance of PrEP in Europe. It has been operating as an informal partnership. While there was no strong feeling about relocating the secretariat or logistical and financial aspects of PrEP in Europe away from NAM / Aidsmap, there was a feeling that the strategic direction and programming of the organisation should be more formally constituted, with definitions of how strategy and programming are ultimately decided. Some participants also felt there needed to be a discussion on how PrEP in Europe was funded.

Gus as co-ordinator commented that at times, he had felt exposed during the run-up to Warsaw as there was no formal structure for supervising or reviewing programming decisions in advance. He is line-managed by NAM’s Executive Director but there are legalities involved in administering a meeting with a budget of nearly €200,000 and there had also been a security issue at Warsaw which was well managed but might not have been. At the same time, the informality of PrEP in Europe means that logistical decisions can be taken quickly.

It also means that exactly who contributes to decisions can be adapted to the nature of the decision. An example is the Steering Committee meeting itself. There are six founder members of PrEP in Europe: AIDES, AIDS Action Europe, AVAC, EATG, NAM and the National AIDS Trust, though the latter has been inactive recently. PrEPster, ECOM and an independent representative of the trans community were added in an ad hoc manner. There has also always been a wider “advisor group” consisting of people from multilateral organisations such as ECDC, WHO Europe and UNAIDS, along with some independent experts, who have played an important advisory role, helped with facilitation, and so on (one of them took the Steering Committee minutes). And finally, at Warsaw, the active involvement of an also formally constituted Local Team was vital to the success of the meeting, and two of these also attended the meeting.

The two themes – of the representation of marginalised populations, and of formalising strategy – met in a commitment to include more marginalised people within the Steering Committee structure. Another population mentioned was active PrEP users themselves – who, to refer to page 11, comprised less than 20% of conference attendees.

Two key actions were decided upon by the Steering Committee. The first was that a small group, consisting of representatives from the original six NGO partners, should write a Memorandum of Understanding/Terms of Reference document which would form the basis for a Constitutional Structure and Lines of Responsibility

We also decided on a different Strategy Group, including members from the wider advisory Group, that should devise a Strategy document. This would lay out the values and aims guiding our strategy in more detail and devise a broad Work Programme for the next two years. It would also act as the Programme Committee for future meetings, making decisions about the remit, structure, attendance and speakers at forthcoming meetings and co-opting in appropriate community and local representatives.