

HIV EUROPE

A network of organisations

Minutes of a meeting held in London
at the offices of the UK Coalition of People Living with HIV and AIDS
December 3rd and 4th 2005

Meeting sponsored by Gilead Sciences (Europe)
and the Ensuring Positive Futures Partnership (UK)



Present:

		Organisation
Henrik Arildsen	Chairman	HIV Denmark
Bernard Forbes	Host	UK Coalition
Gus Cairns (Sunday only)	agency	UK Coalition
Marcella Ferracci		NPS Italy
Corrado Valvo		NPS Italy
Ritva Karjalainen		Positiiviset Finland
Leila Vaananen		Positiiviset Finland
Per Miljeteig		HIV Norway
Inger-Lise Hognerud		HIV Norway
Andreas Berfloh		Riksförbundet för hivpositiva, Sweden
Lasse Lindberg		RFHP, Sweden
Peer Aagaard		HIV Denmark
Wojciech Tomczynski		Polish National Network of PLWHA
Caroline Suter		AIDS Hilfe Switzerland
Percy Stefansson		Alnæmissamtökin, Iceland

Apologies were received from:

Albert Adalsteinsson (EATG), Brett McClean (Northern Ireland / UKC), Rosario Iardino (NPS, Italy).

Additionally, Peter Smit had been due to attend in a personal capacity from Holland, but was unable to do so due to family illness – the meeting sent their thoughts to him at a difficult time.

1 *Opening and Introductions*

Bernard Forbes, Chairman of the UK Coalition of People Living with HIV and AIDS (UKC) opened the meeting by welcoming everyone to London, thanking the sponsors for their generous support.

Henrik Arildsen gave a brief summary of the meeting in Copenhagen, minutes for which had been circulated. Individuals then introduced themselves and the organisations they represented.

2 *Taking the Copenhagen meeting forward*

2.1 Network membership criteria

This was debated at length. It was agreed that the intention was to be as inclusive as possible, that nowhere was it to be assumed that membership was only available to national organisations, local groups would also be welcomed.

The primary criteria was agreed as demonstrable commitment to the principle of Greater Involvement of People Living with HIV and AIDS. Beneath this, it was agreed:

Membership of HIV Europe will be available to

- National or local organisations of people living with HIV
- Organisations predominantly driven by people living with HIV

It was agreed that network members will decide on admitting new members who must be agreed by a two thirds majority of the existing network members.

2.2 Which definition of Europe to use

The meeting agreed to use the same definition of Europe as that used by the World Health Organisation. The list of countries included within that definition is appended to this document as Appendix 1.

3 *Immediate actions needed*

3.1 Formalising the network's status and the need for a small steering committee

The meeting was concerned that the network was not to be seen as a gathering of "friends", but a plausible meeting of experts. There was a need to be professional despite the challenges that formality would bring.

The timescale for formalising the network as a stand-alone organisation was unanimously agreed as not to impede progress or losing any impetus on the broad issues identified at Copenhagen as in need of action. There were examples given of existing partnerships where one partner takes a lead role as accountable body for any funding and also takes full responsibility for evaluation of what happened to the money, what the partnership achieved, etc.

The meeting agreed that this network was a not a new body, but a new way of communicating and collaborating on issues that affected people with HIV across Europe. As the issues carried the most importance, the bureaucratic expense of supporting a formal network and organisation were viewed as secondary.

As any organisational representative would have to consult their organisation regarding being the “host” or lead and accountable body, no decision was taken on which organisation should be asked to take on this role. It was not seen as an issue to be delegated to a steering committee, the entire network membership would have to make the hosting decision once potential hosts had the opportunity to consider whether they could undertake this role.

It was agreed to form a small steering group to be geographically representative of the network area:

	North	
West	Central	East
	South	

It was seen as important that steering group members not only needed to give a solid foundation to the network, but also had to be people with their own networks, particularly to organisations not currently represented on HIV Europe. Members of the steering group had to be people with the skills and commitment to succeed.

There was an identified need to communicate that HIV Europe should not represent a threat, but intended to fill any gaps in meeting the needs of people with HIV across the European region.

The steering group members were elected as follows:

	Henrik Arildsen	Denmark	(Chairman)
North	Per Miljeteig	Norway	
West	Gus Cairns	UK	
Central	Wojciech Tomczynski	Poland	
South	Rosario Iardino	Italy	
East	vacant.		

The Eastern European position was left vacant as an overt signal of the need to move fast to engage with organisations in states to the East.

One of the priorities for the steering committee to investigate would be funding for the network's future. This would include sending a message back to GSK that, having started a process in Brussels and supported the meeting in Copenhagen, they and other private sector colleagues needed to grasp the concept of supporting HIV Europe as a whole, rather than patchy individual in country support to participating member organisations. The example given was of Positive Action's willingness to support individuals to attend the London meeting, but not to fund UKC to facilitate all the arrangements. Overall, it was less work for a host agency to engage with industry with one bid for support, than for 45 or more in-country organisations making multiple applications to their local industry representatives.

The network also had to engage with other funders, like the European Union, as the business of the network went wider than treatment issues.

The eventual aim had to be for a broad spread of funding with a variety of contributions and contributors. A priority had to be given to supporting and/or subsidising participation from organisations that could least afford it.

3.2 Timeline for 2006

April Network meeting in Rome (NPS Italia to host)

15/17 May Moscow conference – Wojciech to represent HIV Europe¹

14-18 August International AIDS Conference, Toronto

On Toronto, members considered it presented opportunities to publicise HIV Europe. Many member organisations would be at Toronto, opportunity could be taken to recruit more and to explain what HIV Europe is about to others, as well as potential for a network meeting whilst there. Perhaps member organisations with NGO booths could all display a banner indicating they are members of HIV Europe?

Toronto needn't be the major focus of the next network meeting, the focus should be on how we present and promote ourselves, demonstrate how we can share experience and make use of success and failures in approaches taken by other countries.

¹ Wojciech circulated everybody with details of the Eastern Europe and Central Asia focused conference taking place in Moscow (EECAAC)

3.2 Evaluation of the arrangements for the London meeting

There was general approval for the way that UKC had led on obtaining funding for the London meeting and made all the travel and accommodation arrangements, including the venue for the meeting.

As this seemed to have worked so well, it was agreed to become the model to aim for in future meetings where member organisations had to be physically present, as opposed to other means of communication and discussion.

3.3 Website

Arrangements for a website were delegated to the steering committee with offers of help from Lasse Lindberg on design, and Bernard Forbes on domain registration, hosting and set up.

Whilst content management systems exist, there was a need to translate papers and web content into a variety of languages. There was a need to find people to undertake translation, but it had to be accepted that it would be an impossible task to even find funding for translation of everything into all potential languages. The network language for business was English, but unless the website and papers were translated into other common languages, it would exclude many people and organisations who should be included. It was agreed as important that the network was not seen as a club for people who speak English. If people see that their language is excluded, it then excludes them.

Russian, Spanish, Portuguese and French were amongst the priority languages. As long as in-country organisations had access to bilingual people who could translate for their own members, the choice of languages could be kept smaller.

3.4 Prioritising areas of work

It was agreed that HIV Europe did not need to replicate what other organisations were already successfully engaged in, that we needed to formulate agreed positions on issues. There was no capacity yet for much research to back up campaigning or action.

It was agreed to maintain that policy making should be made by the large group. A way of working might be that the steering group chooses an issue and the member organisations are asked for and bring forward their experience in the subject ("show and tell"). Then the whole network could decide what to campaign on across Europe.

It was hoped that, despite the language barriers, in country organisations would be able to see that connecting their local experience, contributing

their practical examples, would persuade them of the value of taking part and also giving HIV Europe some local application.

It was generally agreed that the “show and tell” process was a good one, that HIV Europe was already broadly representative, could show what member organisations have done and what they have difficulty with. Most importantly, HIV Europe could collate the issues that member organisations have the most difficulty putting on their national agenda, present a report on the European situation, circulate best (and worst) practice, what appears to work and what doesn't, identify common ground and consider campaigning to correct lack of national action on the ground.

On policy issues, HIV Europe could only consider a formal policy on an issue once it had received the policies of member organisations on the issue; if all have the same or very similar policy, then that dictates the policy for HIV Europe. Formalising policy positions will follow the common ground, thus there was a need to increase the knowledge of member organisations' positions.

At the same time there was a need to maintain strength in consensus alongside providing space for different opinions. Constructive use of conflict coupled with passion for the issues was considered good, the example given was criminalisation where there was much common ground, but a range of other views too.

The network needed to also consider that taking a position on an issue like promoting a broader view on sexual harm reduction may well involve endorsing actions that are considered illegal in some countries.

It was agreed that there needed to be a workplan, that the steering group needed to ask for/suggest projects, send out announcements and use every opportunity (such as large international conferences) for HIV Europe to meet to conduct business as well as promoting the network.

The range of issues identified at Copenhagen were discussed at length and, in line with the decision on network membership criteria, the overriding issue of the GIPA principle was given primacy.

The meeting was unable to prioritise the other issues until some work had been completed. The current issues, in no specific order of importance, are:

Greater Involvement of People Living with HIV and AIDS
Quality of Life Health
Harm Reduction / Prevention / “Positive Prevention”
Stigma and Discrimination
Employment Mobility

4 *Next meeting*

NPS Italia were thanked for offering to host the next meeting of HIV Europe.

The weekend of 8/9 April 2006 was first choice of most participants, with second choice being 29/30 April.

The matter of how often the network should meet to be discussed at the April meeting.

5 *Address by Member of the European Parliament*

Prior to lunch on Sunday 4th December, Michael Cashman, MEP, addressed the meeting and answered questions from participants about how to get issues onto the agenda of the European Parliament and the Commission.

Michael Cashman congratulated participants on the creation of HIV Europe and joined them in a champagne toast to celebrate the launch.

6 *Ensuring Positive Futures Programme*

Andrew Little, Programme Director of the Ensuring Positive Futures Programme (EPF), gave a presentation on work done by a unique partnership of HIV organisations in the UK on the issues of employability and back to work.

He outlined that EPF is designed to provide support and encouragement to plwha on back to work and remaining in work issues. EPF is the latest project in the UK, built on years of experience that started in 1997 with the UKC's pilot Back to Work Project.

EPF is part funded through the European Social Fund and this requires not only national work, but collaboration with other partners across the EU to share best practices that identify what are the best ways to encourage plwha and support individuals as well as employers on the issue of HIV in the workplace.

As part of the EU EQUAL Programme, EPF works with employers and trades unions to ensure good employment practices that live and work for plwha. At European level, all partner projects work solely or largely for the benefit of plwha. EPF is part of a partnership of partnerships, with EPF as the UK partnership, alongside trans-national partnerships in Finland, Germany, Poland, France and Spain.

In the UK, EPF consists of six main partners, with nine other partners. The Brussels aim is to learn and share success and mistakes, to avoid

waste of time and money repeating bad ideas. The involvement of beneficiaries is pivotal and systems are in place to ensure that things change and respond to the feedback of service users. Experience also indicates which issues are useful to lobby for at EU level.

As an example from the UK, the government recently introduced an amendment to the Disability Discrimination Act which now includes plwha, some cancers, and multiple sclerosis, within the definition of “disabled” from the point of diagnosis. Thus plwha are given protection under the law without having to prove that they are disabled. The law itself is a safeguard for plwha, but is not in itself an incentive to work: people don’t have to constantly focus on “what if” things go wrong, instead people can focus on being the best person for the job.

Networking with other EU trans-national partners helps identify issues at European level that partners can pick up to work together on so that Europe can do something back in response.

Andreas highlighted that In Sweden there is no strong incentive – plwha get a pension and have to balance this against the uncertainty of competing against everybody else.

Andrew explained there is a similar “benefits trap” in England (but it is now much harder for plwha to get the maximum rate disability benefits). This means that plwha need to achieve much higher level employment to match the loss of benefits.

EPF provides a range of services which can support people over years to develop confidence, skills, experience and in some cases prove that working makes them feel better, giving them a changing mindset including confidence on medication.

Gus Cairns contributed his experience of having been “one of those people” on the original UKC Back to Work Project in 1997 after six years with AIDS. He explained how he got office experience, spent some time volunteering with Positive Nation at UKC and was then offered a job. The job offer he described as like “jumping out of a plane without a parachute”. Overall, he considered that going back to work is about whether it is good for you.

Andrew Little advised that he was more than happy to give more information if required by anyone, and confirmed that it is one of his functions to feed issues in and lobby at European level. Some EU member states have a lot to learn while others have a lot to contribute. He was excited by the prospect of HIV Europe contributing to the debate on discrimination and employability issues.

Leila Vaananen commented that she was aware of the Finnish partnership and that the Finnish project was exclusive to marginalised groups who were reluctant to get involved. EPF would be visiting Finland in 2006 and there were opportunities to make more links – EPF were invited to make contact with Positiiviset Finland. Other invitations were extended to visit Sweden and Norway.

Henrik thanked Andrew for his informative presentation.

7 *Final wrap up session*

Henrik summarised the weekend meeting which was considered by all to have been very productive and exciting. UKC were thanked for what were described as marvellous arrangements and support.

Finally, on wishing everyone safe travel home, the next steps will include spreading the word on the creation of HIV Europe.

List of countries making up the World Health Organisation Europe Region

Albania	Latvia
Andorra	Lithuania
Armenia	Luxembourg
Austria	Malta
Azerbaijan	Monaco
Belarus	Netherlands
Belgium	Norway
Bosnia and Herzegovina	Poland
Bulgaria	Portugal
Croatia	Republic of Moldova
Cyprus	Romania
Czech Republic	Russian Federation
Denmark	San Marino
Estonia	Serbia and Montenegro
Finland	Slovakia
France	Slovenia
Georgia	Spain
Germany	Sweden
Greece	Switzerland
Hungary	Tajikistan
Iceland	TFYR Macedonia
Ireland	Turkey
Israel	Turkmenistan
Italy	Ukraine
Kazakhstan	United Kingdom
Kyrgyzstan	Uzbekistan