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European Expert Meeting on Positive Prevention

November 9-11, 2005
Bergen, The Netherlands

The European expert meeting on positive prevention

Was organised for AIDS Action Europe by STI AIDS Netherlands

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The meeting was sponsored by:

General conclusions and recommendations

From 9 till 11 November 2005 more than 30 experts from 12 European countries came together to in the workshop on Positive Prevention, the prevention aimed at people living with HIV.

What is positive prevention?
One of the goals of the meeting was to formulate underlying principles of positive prevention. We discussed the underlying principles that are used in different countries and found a lot of similarities. Since most countries still have a discussion on what positive prevention should be and should not be, it is not possible to give a final set of principles. It is thought important that positive prevention focuses on the needs of people living with hiv/aids. And it includes interventions of both primary and secondary prevention.
How positive prevention is applied will depend on many individual country contexts and situations. Generally it was felt that we should resist a global document as no one document could be relevant to all countries, organisations or situations. Positive prevention has to be 'Tailor-Made'.

Tools and best practices?
The principles from the HIV/AIDS Alliance/UNAIDS/IPPF/GNP+ provide a useful reference tool but are clearly principles used in developing countries and not always applicable in western Europe. This list contains all kinds of issues that could be addressed while designing a prevention or care programme. They can be part of the Tailor-made approach.
The meeting was organised in order to exchange information on a European level. During the meeting various best practises illustrated that on a practical level different projects are being executed. You can find the presentations and discussions in this report. Many expressed differences are actually more an issue of semantics, we actually have a lot in common. In the projects that where presented professionals and people living with HIV/AIDS worked together in order to work out a shared goal: effective prevention for both people with and without hiv and adequate care for people with HIV.

Recommendations
Many different issues were raised and participants were taking back many discussion points which would impact on their positive prevention thinking and planning. The workshop did meet the expectance to clarify better what positive prevention can be in a constructive way.
Next steps should include exploring the possibility of a common strategy. The workshop focussed on western Europe and therefore there was a great emphasis on gay men. In the future there is a need to broaden this perspective to other European regions. And to women and migrants.

Ton Coenen
Member of the Steering Committee of AIDS Action Europe / Executive director STI AIDS Netherlands

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1 Positive Prevention in Europe

1.1 Introduction: Positive prevention in Europe

Mr. Ton Coenen, AIDS Action Europe

At the Open Forum in Brussels on AIDS Action in Europe (March 2004) it was agreed that prevention activities aimed at People Living with HIV/AIDS (PLWHA) should be one of the priorities in the Action Plan on the Rise of the Epidemic in Western Europe.
AIDS Action Europe (The Pan European NGO Partnership on HIV and AIDS) and STI AIDS Netherlands agreed to organise this workshop on the issue. Different experts from a range of Western European countries have been invited to consider what 'Positive Prevention' means and to explore the different approaches and emphasises in different Western European countries. Policy and best practice will be considered with the aim of establishing a European agenda on positive prevention.

1.2 Prevention strategies for People with HIV

Mr. Harry Walsh, International HIV/AIDS Alliance

The document the presentation is based on is viewable on the UNAIDS website. Comments are welcomed as the document is still in the consultation stage before it will be finalised.
The following websites are also recommended – *insert list from Harry*

EMERGING PRACTICE SERIES

Positive Prevention

Prevention Strategies for People with HIV/AIDS

Draft Background Paper

International HIV/AIDS Alliance | Draft Background Paper July 2003

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> Risky behaviour by positive people is not the norm. Most of us take extraordinary steps to make sure that we are not infecting our partners, and we're doing so without a whole lot of support. There aren't massive public health interventions out there. There aren't big campaigns supporting us staying safe in our relationships. We're doing it of our own accord.
>
> *Terje Anderson, Deputy Executive Director, National Association of People with AIDS, USA*
> *(cited in Collins et al. 2000)*

HIV/STI prevention strategies have often failed to address the distinct prevention needs of people with HIV and to acknowledge their significant efforts to avoid infecting others (Collins et al, 2000).

There is an urgent need to sharpen the focus on prevention among people living with HIV (Global HIV Prevention Working Group 2003).

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Primary prevention
Activities with both infected and uninfected people to reduce primary (ie. initial or new) HIV infections

Secondary prevention
Activities to maintain well-being of people with HIV (including wider sexual health), and delay disease progression

Positive prevention encompass elements of both primary and secondary prevention

WHY POSITIVE PREVENTION STRATEGIES ARE NEEDED

- One positive person is involved in each case of HIV transmission
- People living with HIV have the right to live well with HIV
- HIV prevention, treatment, care and support are inter-related

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WHY POSITIVE PREVENTION STRATEGIES ARE NEEDED

Preventive interventions with positive individuals are likely to have a greater impact on the epidemic, for an equivalent input of cost, time, resources, than preventive interventions focused on negative individuals.

A change in the risky behaviour of an HIV positive person will, on average and in almost all affected populations, have a much bigger effect on the spread of the virus than an equivalent change in the behaviour of a negative person.

Prevention efforts for +ve persons

require familiarity with some of the issues that lead to increases in high-risk behaviour in HIV infected individuals.

These include among others:

- prevention fatigue
- substance misuse (heroin, speed, Ecstasy, GHB, Viagra)
- efforts to enhance intimacy
- poor understanding of how the virus is transmitted
- poor understanding of personal health risks
- gender/sexual inequalities
- economic necessity
- optimism about the effectiveness of new HIV therapies

- Developers of strategies to help HIV-infected individuals adopt risk reduction behaviours and skills must take into account the difficulty of sustaining these behaviours over a lifetime.
- In some cases, maintenance of these behaviors may depend on the availability of and referral to other services such as substance abuse treatment and mental health services.
- It is crucial that availability of and access to these and other types of services be improved.

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GUIDING PRINCIPLES FOR GOOD PRACTICE IN POSITIVE PREVENTION

- Effective prevention is based on
  - merging of what is known to be effective (the evidence base)
  - meaningful participation of people with HIV in how best to apply this evidence base to their local context.
- Combine strategies to create enabling environments which facilitate the empowerment of people with HIV.
- Protect and promote human rights and ethical principles, including the right to privacy, confidentiality, informed consent, freedom from discrimination, and the duty to do no harm.
- Implement strategies in a way that keeps stigma and discrimination against people with HIV to a minimum, whilst still focusing on the particular needs and rights of people with HIV.
- Be gender/sexuality/culturally sensitive so that interventions address
  - the gender/sexuality relations and power dynamics of and between women and men,
  - recognise that these influence the effectiveness of positive prevention strategies.
- Balance the public health objective for HIV/STI prevention with the sexual well-being needs and rights of people with HIV.
- Confidentiality and informed consent are not only valid ethical principles, but also effective public health tools by which to protect both people with HIV and those not infected.

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Effective prevention works at multiple levels.

- Individual: components seek to influence individual's preventive decisions and skills. By themselves are insufficient to produce sustained behavioral change.
- Environmental: components address factors in the local environment that lower effectiveness of interventions or encourage risk behavior. E.g lack of access to condoms or clean needles in particular local setting/ they might try to change social norms regarding condom use.
- Structural: address laws/policies at both national and institutional level that interfere with prevention efficacy, e.g., laws regarding drug paraphernalia or policies on condom advertising. They might also seek to address operational issues, such as failures to encourage/enforce condom use in brothels, or failure to apply universal precautions in medical settings.
- Superstructure: address the large-scale social and political environments in which behavior takes place. May require, e.g. addressing gender/social inequalities which contribute to elevated risk for women or for marginalized populations such as sex workers and MSM.

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Strategies for positive prevention

should aim to support people with HIV

- to protect their sexual health
- to avoid new STIs
- to delay HIV disease progression
- to avoid passing their infection on to others.

Strategies for positive prevention are not stand alone, but work in combination with one another.

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Strategies for positive prevention

may be grouped under four headings:

- Individually focused health promotion
- Scaling-up, targeting and improving service and commodity delivery
- Community mobilisation
- Advocacy, policy change and community awareness.

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3.1 Individually focused health promotion	3.2 Scaling up, targeting and improving service and commodity delivery	3.3 Community mobilisation	3.4 Advocacy, policy change and community awareness
Strategy 1: Promoting voluntary counselling and testing	*Strategy 5: Ensuring availability of voluntary counselling and testing*	*Strategy 9: Facilitating post-test clubs and other peer support groups*	*Strategy 14: Involving people with HIV in decision-making for Positive Prevention*
Strategy 2: Providing post-test and ongoing counselling for positive people	*Strategy 6: Providing antiretroviral treatment for Positive Prevention*	*Strategy 10: Implementing focused communication campaigns*	*Strategy 15: Advocacy for Positive Prevention*
Strategy 3: Encouraging beneficial disclosure and ethical partner notification	*Strategy 7: Reducing stigma and integrating Positive Prevention into treatment centres*	*Strategy 11: Training people with HIV as peer outreach workers*	*Strategy 16: Legal reviews and legislative reform*
Strategy 4: Providing counselling for sero-discordant couples	*Strategy 8: Providing services for preventing mother-to-child transmission*	*Strategy 12: Reinforcing Positive Prevention through home-based care*	*Strategy 17: Advocacy for access to treatment*
		Strategy 13: Addressing HIV-related gender-based violence in Positive Prevention	

What constitutes effective HIV prevention?

Consider individual and environmental and contextual factors

- ***Providing information is not enough.***
- ***Understanding environmental and contextual factors is critical to enabling people to change behaviour.***
- ***A more realistic model of behavior change - addressing risk AND vulnerability.***
- ***Effective prevention works at multiple levels and with multiple components.***
- ***Involve and grow out of community***

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Discussion points following the presentation included;

We need to consider developing a new language for positive prevention as although certain words may be appropriate in other contexts they may not be so when engaging with positive people around prevention. One participant believed that the use of the word 'risk' stigmatises PLWHA. People make 'choices' rather than 'take risks' a consequence being that some of those choices may have risks associated with them. However, others felt that, generally, people do understand the concept of risk and indeed many people don't have the opportunity to make free choices at all times. Some agreements from this discussion were:

- Positive prevention needs to be done on a contextual basis. The risk someone may be at is part of that context.
- It was generally agreed that we do need clarity and understanding of how we use different words, recognising that individuals will react to certain words depending on their life experience.
- The issues of 'ethical partner notification' and 'beneficial disclosure' were both felt to need further discussion at a later stage.

2 Positive prevention in the various different countries in Europe, an overview

Participants shared the experience of positive prevention in their own countries, as follows:

Belgium
Little direct activity has taken place so far, although following a significant increase of new STI infections, prevention with PLWHA has been identified now as a priority.
Health care workers have been trained to discuss sexual health with PLWHA but have indicated that they have little time to do this. Sexual health issues are not seen as a priority by medical staff.
A leaflet targeted at positive gay men has been developed but generally there appears to be a lack of consistency in the advice and information available.
There is a need for advice and training on how to work with migrants living with HIV or AIDS.

Portugal
Positive prevention has been prioritised but is being used in a discriminatory way. Increases in new infections are being seen across different sections of the population but particularly amongst heterosexuals.
Access to treatments was the catalyst for developing positive prevention in Portugal with fears that PLWHA would spread drug resistant HIV. There is though a lack of tools and information and more community based approaches need to be developed.
Discrimination also needs to be addressed in the context of positive prevention.

Denmark
Government principles developed in 1987 still form the basis of HIV prevention in Denmark. Positive prevention work has to be done in the context that the Danish penal code criminalises PLWHA who put others at risk. Those people found guilty of this can face up to 8 years in prison if they don't disclose their status to potential sexual partners.
The historical consensus amongst prevention organisations was to treat positive and negative people alike using uniform messages for both groups. This was an active strategy to create solidarity.
However, since the mid 90's it was realised that PLWHA needed specific information and support.
Therefore, campaigns were adapted to provide different information for PLWHA, eg. A disclosure of status campaign looked at the issue from both sides.
There is significant support offered to PLWHA including; 1:1 counselling, support groups, peer support services and training, courses, research and outreach work.
Steps have been taken to ensure that PLWHA are represented at all levels of organisations working on prevention.
Over the next year work will begin on developing campaigns that specifically target PLWHA on positive prevention issues.

Norway
There are some similarities to Denmark, with a similar penal code and an increase in the number of PLWHA being convicted. A new leaflet has been developed entitled 'HIV and the Law'. There is also a rise in new infections and post exposure prophylaxis is not available for possible sexual transmission. Drug and alcohol issues are seen as a priority.
A programme is in place which co-ordinates PLWHA travelling nationally giving lectures and running groups for other PLWHA.
All HIV organisations in Norway have worked together to produce an 'HIV Manifesto', however it was only during 2004 that the issue of positive prevention started to be addressed.

Finland
Finland has a low prevalence of HIV infections but has close links with Russia and Estonia where rates are much higher. Half of new infections last year were from immigrant populations. There is very little disclosure of status due to stigma so HIV remains very hidden. Another contextual issue is

that Finland has the lowest rate of condom use in Western Europe. Sex tourism is also a big issue with many Fins travelling to Russia and Estonia to visit sex workers.
Prevention work has been focussed at specific target groups (gay men, migrants and young people) but there has been little work around positive prevention. There are a range of support services, including help lines and groups. A key challenge has been identified, that being, how to involve PLWHA in developing new positive prevention programmes.

France
In 2004 300 people attended the general assembly of PLWHA. Together with the Minister of Health this group developed an action plan to challenge discrimination in the workplace, support PLWHA around disclosure, advocate for better co-ordination of health care and research.
Following the general assembly a range of leaflets, courses and groups have been developed around positive prevention issues.
A policy is currently being developed on work place issues.

Greece
The state prioritises access to treatment and welfare benefits for PLWHA and this works well.
However, there is no prevention work from the state.
The church plays a major role and any campaigns that have appeared tend to be biased to their point of view eg, a campaign which focussed solely on having less sexual partners. The rates of testing are low and those people openly disclosing their status face high levels of discrimination. Indeed the main HIV organisation actively discourages disclosure in the work place and with dentists and health care professionals.
The gay community is not supportive with bars and clubs refusing to have any HIV leaflets on display.
A full prevention strategy is currently being developed.

Austria
Will be covered in a separate presentation on Friday.

The Netherlands
6 issues are currently influencing debate around positive prevention in the Netherlands;

- There has been a recent increase in the numbers of people testing in the Netherlands, from 50% to 60%.
- The issue of responsibility of PLWHA for their own health and that of others.
- Gaps in information provision.
- The issue of fatigue – however it is felt that PLWHA in the Netherlands are still actively seeking information, strategies and support. There is a recognition that PLWHA's interest, energy and enthusiasm will go up and down, so it is important to remember engagement may not be constant.
- A distinction between the agendas of workers and those of PLWHA needs to be made.
- More effective ways of working with migrant communities need to be developed.

UK
There is a strong ethic of volunteering in the UK and many different projects that are led by or involve PLWHA and aim to improve the quality of life for
PLWHA.
Many similar issues to those already mentioned in other countries with a particular issue being engaging effectively with migrant communities. Also criminalisation is becoming an increasingly important issue in the UK with a number of convictions now being made.
A range of positive prevention activities have taken place, including both detached and web based activities and also many different campaigns and leaflets. A recent project has worked closely with Faith Leaders to better access people from migrant communities.
It is felt that the different communities of PLWHA are far more united now with gay men and people from African communities working and meeting together to discuss issues.
Refering to the issue of 'fatigue' it is felt that it is the messages that are fatigued rather than the

PLWHA.
Examples of positive prevention work include outreach work in organised bareback parties and a leaflet looking at PEP from the positive persons perspective.

Spain
There is a strong focus on human rights issues for PLWHA in Spain.
A website has been developed to submit cases of human rights violations and a campaign developed from this. A second campaign on health rights is currently being developed.
The positive prevention debate tends to be conducted in the context of morals and responsibilities.

Discussion

Following these summaries and the various views expressed a discussion was had about what we actually mean by positive prevention.
Positive prevention could have 2 aspects;

- Primary prevention – preventing new infections
- Secondary prevention – maintaining and improving the health of PLWHA

There was some agreement that the emphasis should be placed on the second of these aspects. This theme would be revisited throughout the meeting.

3 Principles and Policy of positive prevention in the different European countries.

3.1 Needs of PLWHA and risks (stigma and responsibility) and peer support of the HIV community

Mr. Julian Hows, Global Network of People Living with HIV

Key discussion points

When does 'prevention' become 'positive prevention'? There is some evidence to suggest that the majority of new infections are passed on from people who are not aware of their HIV positive status. Therefore, voluntary counselling and testing programmes need to underpin any positive prevention programmes.

PLWHA need to be involved with positive prevention at a strategic and policy level, not just 'rolled out' to tell their stories for prevention purposes.

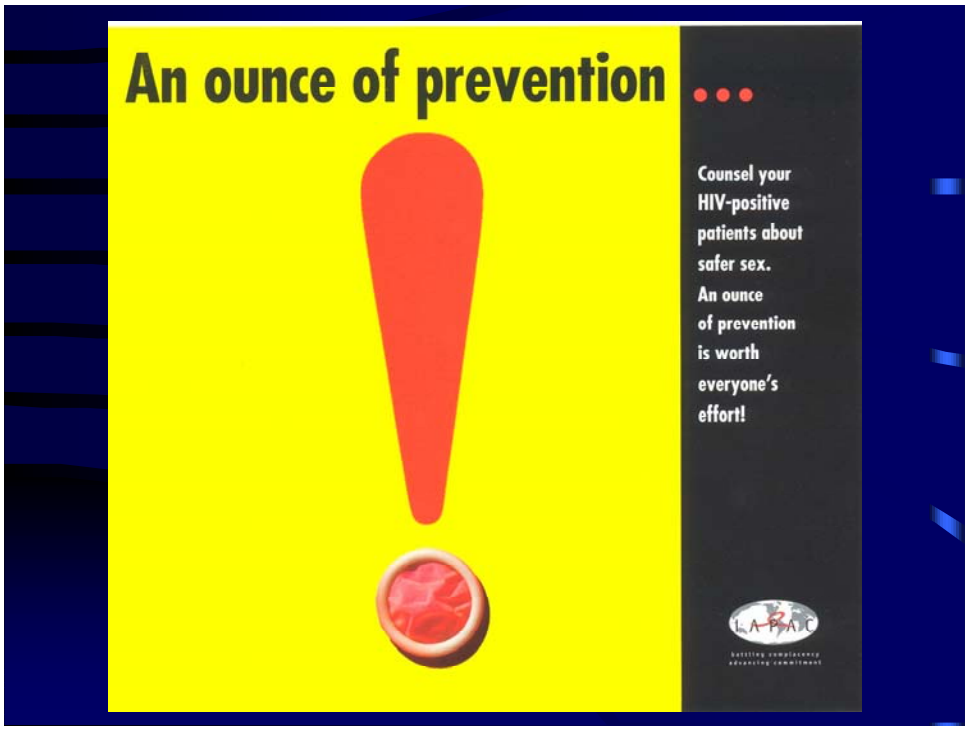
Need to continue advocating and fighting for change in the policy environment e.g. More rights and benefits for migrants, equal access to services, changes in criminalisation laws.

All discussions and development around positive prevention mustn't generalise but be inclusive of the different needs of different groups. Diversity shouldn't be seen as an obstacle to effective working.

Should also recognise and acknowledge the successes many PLWHA have achieved. If 20% of positive men are reporting unsafe sex we should celebrate that 80% are not.

3.2 Viral load and Prevention

Mr. Rolf Appels



Factors for Transmission of HIV

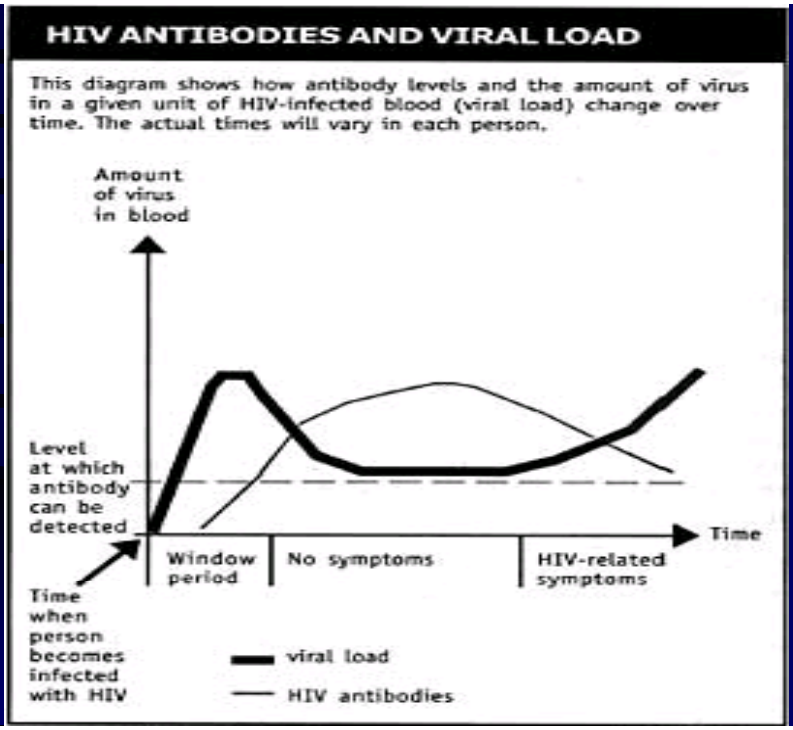
- Potency for transmission by the virus
- Susceptability of receiver
- Viral load in body fluids (incl. blood)
- Co-factors
  - Presence of an STI
- Port d'entree

SOAIDS

Viral laod after HIV infection and not on HAART

- U-shape curve
- Hyper-Viraemia in first weeks after infection
- Setpoint viral load after antibody production has started
- Increase of viral load when AIDS develops

SOAIDS



Viral load while on HAART

- Rapid decrease to low levels
- Depending on resistance patterns
- Small changes seen (BLIPS)
- Depends on adherence to HAART
- Rebound on treatment interruption

SOAIDS

Viral Load in Semen and vaginal fluid

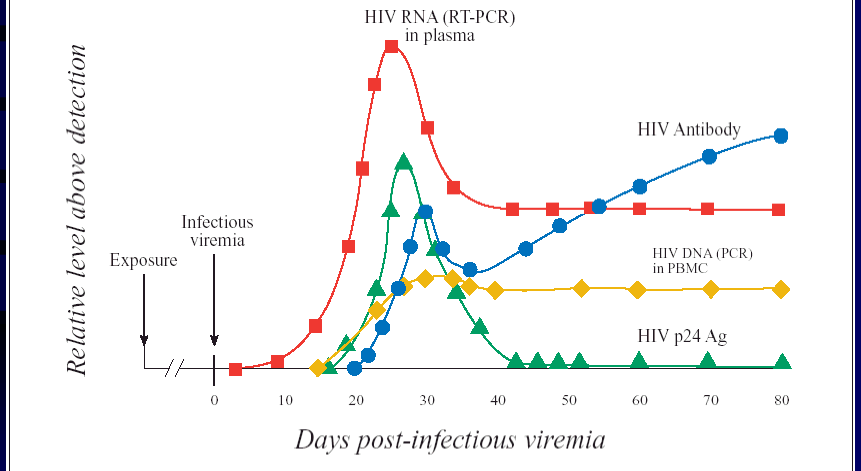
- Runs generally parallel with the viral load in blood
- Can be detectable while viral load in blood is undetectable and the other way around
- Increased in the presence of an STI

SOAIDS

Acute HIV infection

- Flu-like syndrome in 50-70% of infected
- High viral load
- 20-fold transmission chance
- HIV-Ab test still negative
- p24-test and viral load (HIV-RNA) become positive

SOAIDS



Using HIV-RNA test (or p24 test)

- Early detection possible
  - 1-4 weeks after infection
  - About 2 weeks before Ab's are formed and detectable (HIV test positive)
  - About 2-2.5 months before advised to be tested
- Expensive when used as standard

SOAIDS

Experience with HIV-RNA testing

- North Carolina experience 2002-2003 (Pilcher CD, et al. N Eng J Med 2005)
  - 109,250 people tested in one year
  - 583 HIV cases diagnosed with Ab-test
  - 23 only positive on HIV-RNA test
  - 18 more cases found through contact tracing
  - 48 high risk exposures prevented

SOAIDS

Effect of early treatment

- Low Viral load leads to low transmission chance
- Leads to lower set point level
- Long-term effect is not known
- Many pitfalls

SOAIDS

Possibilities for prevention in early stage

- Prevention and early and effective treatment of STI's
- HIV-RNA test when presented with acute HIV syndrome or STI or after high risk behaviour and HIV-Ab-test is negative
- Early treatment with HAART
- Education on the risks of neg-neg sero-sorting

SOAIDS

Possibilities for prevention in set point phase

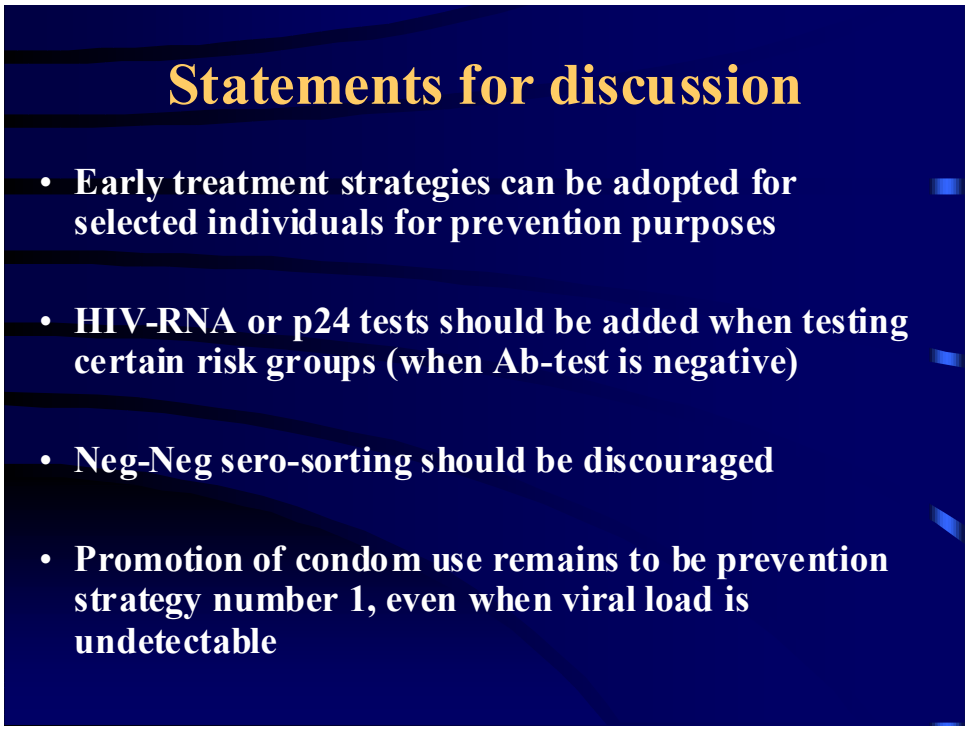
- Prevention and early effective treatment of STI's
- Screening (HIV-Ab-test) of all risk groups
- Early treatment with HAART

SOAIDS

Possibilities for prevention in late stage

- HIV-Ab screening for risk groups and people with symptoms of AIDS
- Prevention and early effective treatment of STI's
- Effective HAART

SOAIDS



Discussion points

- Should early treatment strategies be adopted for selected individuals for prevention purposes?
- Should HIV RNA or p24 tests be added when testing certain high risk groups/individuals?
- Should negative to negative sero sorting be discouraged?
- Even if viral load is undetectable promotion of condom use should remain the number one prevention strategy.

It is important that clinicians are trained to explain information about viral load clearly. A study in the Netherlands has shown that some people in sero-discordant couples have made choices to stop using condoms based on misunderstood information from their doctor.

3.3 Formulating the principles of positive prevention

The International HIV/AIDS Alliance worked out a set of guiding principles on positive prevention together with UNAIDS, IPPF and GNP+. In workshop 1 a number of participants of the expertmeeting discussed about the principles of positive prevention and they made a number of changes. The following list was put together.

Positive Prevention…

- … aims to protect PLWHA's health, avoid re-infection, new STIs and other infections, delay disease progression and avoid passing the infection to others.
- … increases the self-esteem and confidence of HIV positive individuals.
- … intends to tackle stigma by promoting safer environments to discuss HIV openly and increase solidarity.
- … needs to be implemented within an ethical framework that respects the rights and needs of people living with HIV to enjoy sexual relationships.
- … needs a supportive legal and policy environment.
- … is based on the realities and perspectives of people living with HIV. E.g., acknowledging that many people with HIV need explicit information and practical support to be able to negotiate safer sex with their partners.
- … efforts should include those who influence or restrict behaviour, options and choices of individuals living with HIV.

- … requires the meaningful involvement of people with HIV.
- … is focused on communication, information and support; it does not blame, judge or stigmatise.
- … recognises that HIV positive people are individuals with varying needs and desires.
- … promotes human rights and ethical principles that ensure that rights to privacy, confidentiality, informed consent, freedom from discrimination and the duty to do no harm are respected at all times.
- … recognises that HIV is fuelled by inequalities in power due to gender, sexuality, life-style and poverty. HIV prevention strategies must respond without further stigmatising the most marginalised in our communities.
- … puts responsibility for reducing transmission of HIV on everybody. Silence and stigma spread HIV. Openness, communication and information about sex and sexuality are the most effective tools to reduce the spread of HIV.
- [Something about the responsibility of PLWHA in safer sex. Ethics in society don't exist in a vacuum and are not to be imposed by one individual upon another]

Further comments/suggestions

- Principles are only useful when unambiguous, clear and not open for interpretation.
- Shorter; no shopping lost, clearer focus, focus can be added depending on circumstances
- This is not a definition; these are ethical principles
- Mainly to be used as an advocacy tool, not a step by step guide

3.4 Formulating the necessary policy frameworks

Flipchart notes

Promoting Voluntary Counselling and Testing (VCT) should be done because;

- Increases treatment options
- Politically wise
- Public health benefit
- Gives epidemiological data for planning

But VCT has to be run alongside advocacy efforts for example access to treatments, decriminalisation

Post test and ongoing counselling should be encouraged for the same reasons as above and available for all.

- It is important to stress that <u>not</u> having counselling is a choice too.
- Counselling needs to be well linked into other services and quality and appropriateness need to be monitored closely.
- Should distinguish against counselling and advice giving.
- Different settings for counselling to take place should be explored eg. Doctors.
- Good training for all those doing counselling should be provided and include awareness of needs of different groups.

Focussed Education Campaigns

- Information provision is important and valuable if done in context.
- Campaigning is just one means of education and mustn't be done in isolation.
- Good monitoring and evaluation is very important.
- A campaign is needed that challenges myths.
- Explore harm reduction vs risk elimination
- Campaigns need to be well pre tested with the appropriate target groups.

How do we advocate for positive prevention?

- Need to reach key policy makers/people/dinicians with advocacy messages.
- Don't make positive prevention a meaningless mantra.
- The term 'positive prevention' may be useful for advocacy purposes but actually the activities it covers are nothing new.
- Criminalisation is a key issue for effective positive prevention because it frames what we can do and how we can do it. Access to treatment is a key issue for similar reasons.
- Positive prevention should also focus on the needs of the partners of PLWHA.

4 Best Practices in Positive Prevention

4.1 Sexual Health support in HIV treatment settings

Mrs. Nicole van Kesteren, University of Maastricht

Sexual health support in HIV treatment settings for HIV+ Men who have Sex with Men

Nicole van Kesteren, Harm Hospers, & Gerjo Kok

Maastricht University

Why prevention with HIV+ MSM?

- Sexual risk behavior in HIV-positive MSM may be more common than was previously believed (Reports on prevalence UAI ranges between 11-54%)
- Sexual risk behaviour in HIV+ MSM may lead to transmission of HIV and STIs to uninfected partners
- But can also have adverse effects in HIV-treatment response if such behaviour leads to co-infection with another STI or HIV-superinfection

Why prevention with HIV+ MSM?

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  Therefore, targeting sexual risk behavior is an important strategy to prevent further spread of HIV and STIs within gay community

Intervention Mapping

- Protocol, decision aid or project planning tool, for theory- and evidence based design of health promotion programs
- Series of 'what?', 'why?', 'who'?, 'when?' questions
- Program planners are asked to answer questions on the basis of empirical and theoretical evidence

Intervention Mapping Phases

- Needs assessment

1. Specifying program objectives
2. Selecting methods and strategies
3. Creating the program
4. Planning program implementation
5. Planning program evaluation

Preliminary research

- **Qualitative study among 30 Dutch HIV+ MSM**

- HIV+ MSM suffer from sexual problems after diagnosis with HIV
- Discrepancy between feelings of personal responsibility and actual behavior
- Contextual factors (e.g., social norms) determine whether or not their personal norms are translated in actual behavior
- Lack communication and negotiation skills and skills to resist pressure to engage in sexual risk behavior

(Van Kesteren, Hospers, Kok, & Van Empelen, 2005)

Preliminary research

- **Quantitative study among 296 HIV+ MSM**
  - Personal norms were most important determinant of intended condom use with steady and casual sex partners
  - Sexual motives negatively influences intended condom use with casual sex partners, but not with steady sex partners

(Van Kesteren, Hospers, Van Empelen, Van Breukelen, & Kok, under review)

Preliminary research

- **Quantitative study among 296 HIV+ MSM**
  - Personal norms were most important determinant of intended condom use with steady and casual sex partners
  - Sexual motives negatively influences intended condom use with casual sex partners, but not with steady sex partners

  Thus: enhance intrinsic motivation to use condoms for anal sex, and learn HIV + MSM how to plan, initiate and maintain sexual behavior change

(Van Kesteren, Hospers, Van Empelen, Van Breukelen, & Kok, under review)

Intervention Mapping Step 1

Proximal program objectives:

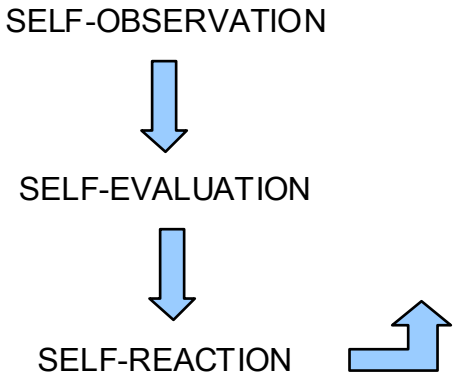
Immediate objectives that need to be achieved in order to reach the general health promoting behaviors

Intervention Mapping Step 1

Health-promoting behaviors:

1. Promote satisfactory sexual functioning
2. Promote safer sex, primarily condom use

Performance objectives



(Aspinwall, 2002; Clark & Zimmerman, 1990; Thoresen & Kirmil-Gray, 1983)

Performance objectives

Self-regulation of satisfactory sexual functioning	
1	Self-observe sexual functioning and compare to personal best
2	Identify when a problem exists
3	Generate multiple adaptive coping strategies
4	Implement selected coping strategies
5	Evaluate implemented coping strategies and return to self-observation
Self-regulation of safer sexual behavior	
6	Self-observe sexual behavior and compare to standard of safer sex
7	Identify when a problem exist
8a	Decide to use non-penetrative sexual techniques; or
8b	Decide to use condoms for anal sex
9	Implement selected actions
10	Evaluate actions and return to self-observation

Identifying determinants

Satisfactory sexual functioning	Safer sexual behavior
Personal ● Awareness ● Attitudes and cognitions about sexuality ● Self-efficacy/skills	*Personal* ● Awareness ● Attitudes ● Personal norms ● Subjective norms ● Self-efficacy/skills ● Sexual motives
External ● Social support from significant others ● Reinforcement by HIV nurses	*External* ● Social support from steady/casual sex partners ● Reinforcement by HIV nurses

Matrices of proximal program objectives

	Awareness	Attitudes	Self-efficacy/skills	Support from significant others
Observe sexual functioning and compare with personal standard	-Describe what is meant by sexuality and sexual functioning -Relate how HIV and treatment may affect sexuality -Relate sexual problems to a variety of factors	-Recognize the need for psychological and sexual adjustment to diagnosis of HIV -Consider the meaning of sexuality for one's own sex life	-Say to be able to analyse one's own sexual functioning and to recognize sexual problems	- Significant others support self-observation of sexual functioning

Intervention Mapping Step 2: Searching methods

1. Main methods based upon *self-regulation theory*: self-re-evaluation, environmental re-evaluation, value clarification, decisional balance, modelling, feedback, confrontation and interpretation. In addition, action and coping planning were selected for implementation of health-related behavior

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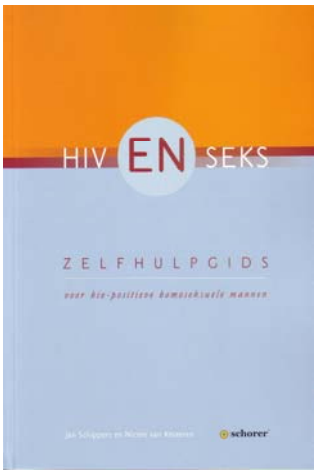
For example: sexual imaging to promote sexual arousal or reach orgasm.

Selecting strategies

- Self-administered bibliotherapy
  - Use of written material to help people solve their problems; self-administered bibliotherapy is form of self-care behavior
- Motivational Interviewing (Miller & Rollnick, 1991; 2002)
  - Express empathy (i.e., non-judgemental listening)
  - Develop discrepancy (i.e., highlighting difference current behavior and personal goals and values)
  - Roll with resistance (i.e., avoid persuasion and conflict)
  - Support self-efficacy and skills

Intervention Mapping Step 3: Creating the program



HIV EN SEKS: PROTOCOL VOOR HIV-POSITIEVE HOMOSEKSUELE MANNEN

Dit protocol wordt gebruikt ten behoeve van de verpleegkundige zorg aan homoseksuele mannen met hiv ter ondersteuning van seksueel welbevinden en veiliger seks. Het protocol is gebaseerd op de principes van motiverende gespreksvoering. Deze principes zullen per fase kort worden toegelicht. De onderstaande drie fasen kunnen, afhankelijk van de tijd die de patiënt nodig heeft om na te denken over deelname aan het onderzoek, in drie of vier consulten aan de orde komen.

Protocol hiv en seks voor hiv-positieve homomannen	
Fase 1: introductie van het onderzoek (ziekenhuisconsult)	**Tijd in minuten**
1. Informeren naar bezorgdheden rondom seksualiteit	2-4
2. Introduceren onderzoek	3-6
3. 'Informed consent' en vragenlijst	(20-30)
4. Toelichten en meegeven zelfhulpgids	3-6
Totale tijd	**8-16**
Fase 2: faciliteren van verandering (ziekenhuisconsult)	
1. Inventariseren bezorgdheden rondom seksualiteit	3-6
2. Inventariseren bereidheid tot verandering	10-12
→ Exploreren van belangrijkheid	
→ Vergroten van zelfvertrouwen	
3. Optioneel: de voor- en nadelen balans	8-10
4. Vaststellen van doelen en actieplannen	10-12
Totale tijd	**23-30**
Fase 3: terugkoppeling (telefonisch consult)	
1. Terugblik op vorige gesprek	2-4
2. Bespreken van voortgang	10-12
OF: voortborduren op voor- en nadelenbalans	
OF: bespreken van actieplan en inventariseren van obstakels	
3. Bieden van steun en positieve bekrachtiging	3-6
4. Afsluiting en evaluatie	3-6
Totale tijd	18-28

Opmerking ten aanzien van fase 1: de vragenlijst kan de patiënt in het ziekenhuis of thuis invullen. Hier hoeft zelf niet bij aanwezig te zijn.

Program structure, theme and channel for delivery

- The scope of program was to reach the health-promoting behaviors in a 3-month time period

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- HIV nurses employed in HIV treatment centres represent a potentially effective channel for delivering HIV prevention to HIV+ MSM

  ⇨ 58% had an HIV treatment centre visit at least every 3 months; 71% had seen an HIV nurse during their last visit (Verdult, 2005)

Program structure, theme and channel for delivery

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- The theme of the program: 'To get into control of one's sexual and social life as HIV-positive MSM'
- HIV nurses employed in HIV treatment centres represent a potentially effective channel for delivering HIV prevention to HIV+ MSM
- To develop, pretest and produce the program materials, a group of researchers, HIV prevention specialists, HIV nurses and sexologist was assembled

Structure and content self-help guide

Chapter	
1.	Introduction and reading guide
2.	Change plans and changing thoughts
3.	Where am I?
4.	Your personal strategy
5.	Overcoming sexual dysfunction
6.	Making and keeping contacts
7.	Safer sex

Change plans and changing thoughts
Planning for change
- Step 1: Where am I?
- Step 2: Where do I want to be?
- Step 3: Which actions to take?
- Step 4: How to plan my actions?

A method for changing thoughts

Structure and content self-help guide

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Where am I?
- More about sexuality
- Am I suffering from sexual problems?
  - Generalized/situational
  - Primary/secondary
  - Filling out the questionnaire
  - A first diagnosis
- How do I deal with contacts?
  - Influence of homosexuality
  - Influence of HIV-positive status
  - Appearance
- What do I think of safer sex?
  - Guidelines for safer sex
  - What are you doing and with whom?

Structure and content self-help guide

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Overcoming sexual dysfunction
Low libido
  Generalized low libido
  Situational low libido
High libido
Erectile dysfunction
Orgasmic dysfunction
  Premature ejaculation
  Ejaculatory inhibition
Anal pain

Structure and content counseling protocol

Facilitate change (face-to-face)	Time in minutes
1. Assess concerns about sexuality	3-6
2. Assess readiness for change → Explore importance → Assess confidence	10-12
3. Optional: decisional balance	8-10
4. Determine (sub)goals and action plans	10-12
Total time	**23-30**
Monitor change (phone call)	
1. Review past consult	2-4
2. Monitor progress	10-12
3. Support and reinforce progress Or: elaborate on decisional balance Or: discuss action and coping plans	3-6
4. Closing off and evaluation	3-6
Total time	**18-28**

Based upon guidelines for behavioral change consultation in a health care setting, see Rollnick, Mason & Butler (1999)

Intervention Mapping Step 4: Planning for implementation

1. Linkage system was created *from the beginning of the project:*
   - Representatives of research and development team
   - Dutch Gay and Lesbian Organization
   - the expertise centre for HIV/AIDS and other STIs (STI AIDS Netherlands)
   - HIV patient's organization Netherlands
   - Department Medical Psychology, Free University of Amsterdam
2. Implementation day was organized in cooperation with funding agency
3. Concerted efforts were made to build support for the intervention within HIV treatment centres

Intervention Mapping Step 4: develop an implementation plan

1. HIV nurses were identified as key adopters as well as implementers of program

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Intervention Mapping Step 4: develop an implementation plan

1. HIV nurses were identified as key adopters as well as implementers of program
2. To ensure program fit additional research was conducted among HIV nurses
3. Based on the study outcomes, a one day course on MI was developed
4. Specific goals of course:
    1. Have knowledge of principles and techniques of MI
    2. Display a client-friendly, non moralizing attitude
    3. Recognise and cope with resistance
    4. Recognise and work on ambivalence

Intervention Mapping Step 5: Planning for evaluation

- Effectiveness of the intervention is currently evaluated in a 'cluster randomized waiting list control group trial'
- Primary outcome measures: QoL (standardized questionnaire to measure sexual dysfunction) and behavioral outcomes (PO's). Secondary outcome measures: determinants and proximal program objectives
- Process evaluation will seek an answer to questions such as to what extent did the HIV nurses implement the program and how did they and the target population evaluate the program

Conclusion

- How IM may explicate processes involved in intervention development

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Thank you for your attention!

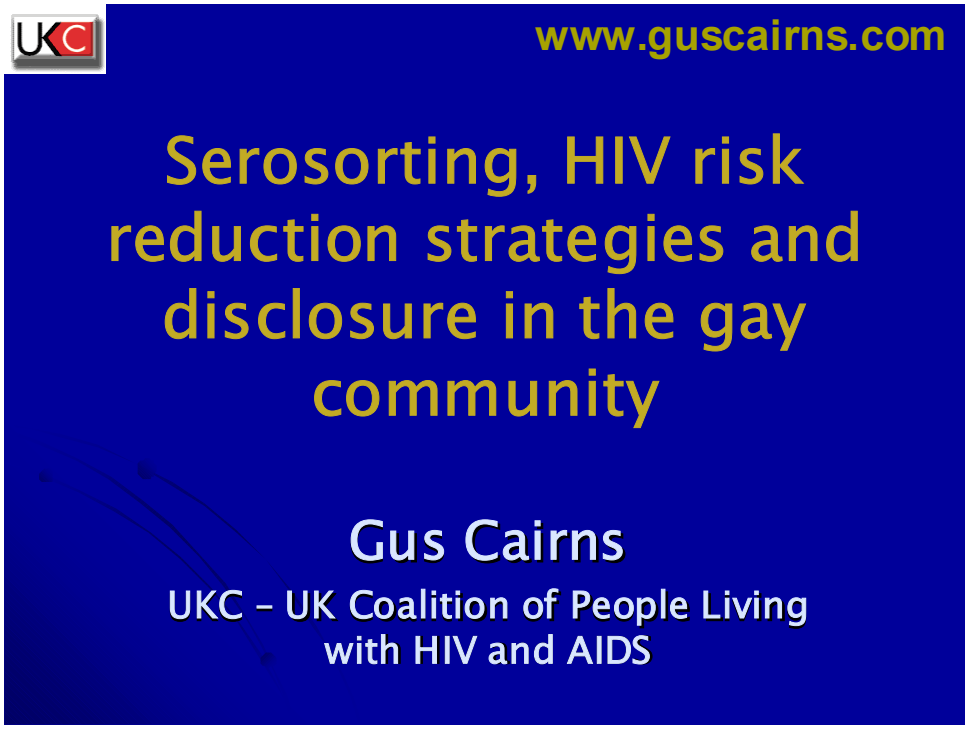
Discussion points and questions:

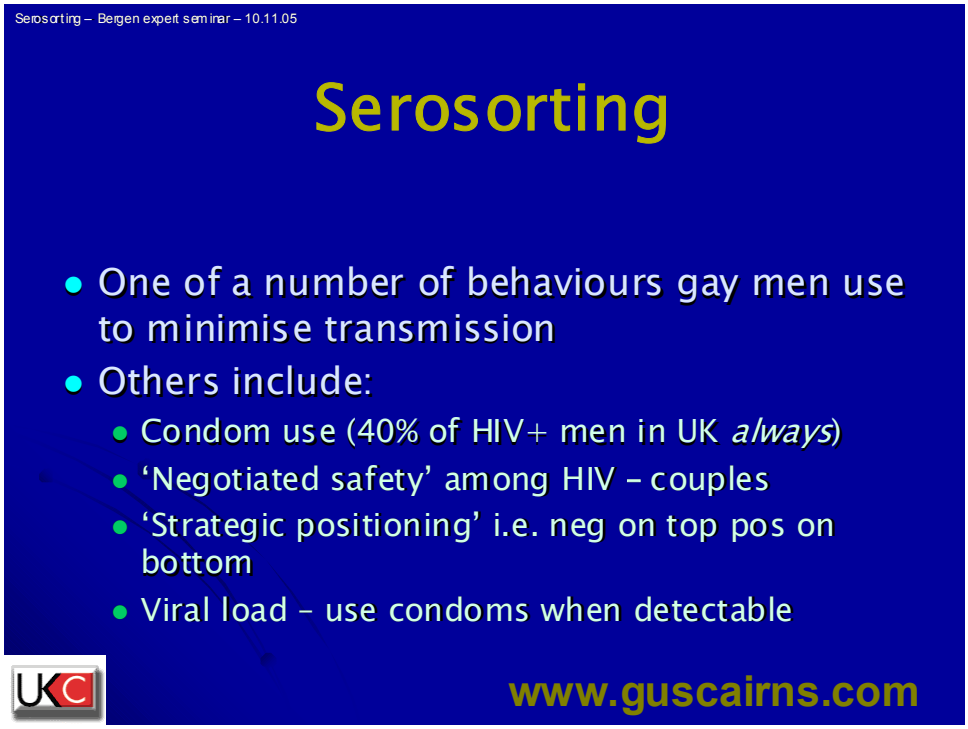
- There were two motivational interview sessions for each man.
- The idea that context is important was central to the development of the project and the nurses discuss context in their sessions.
- There was a debate on how much training was needed for nurses but it was generally felt that one day was enough.
- Nurses are very enthusiastic about the programme they see it as part of their job responsibilities.

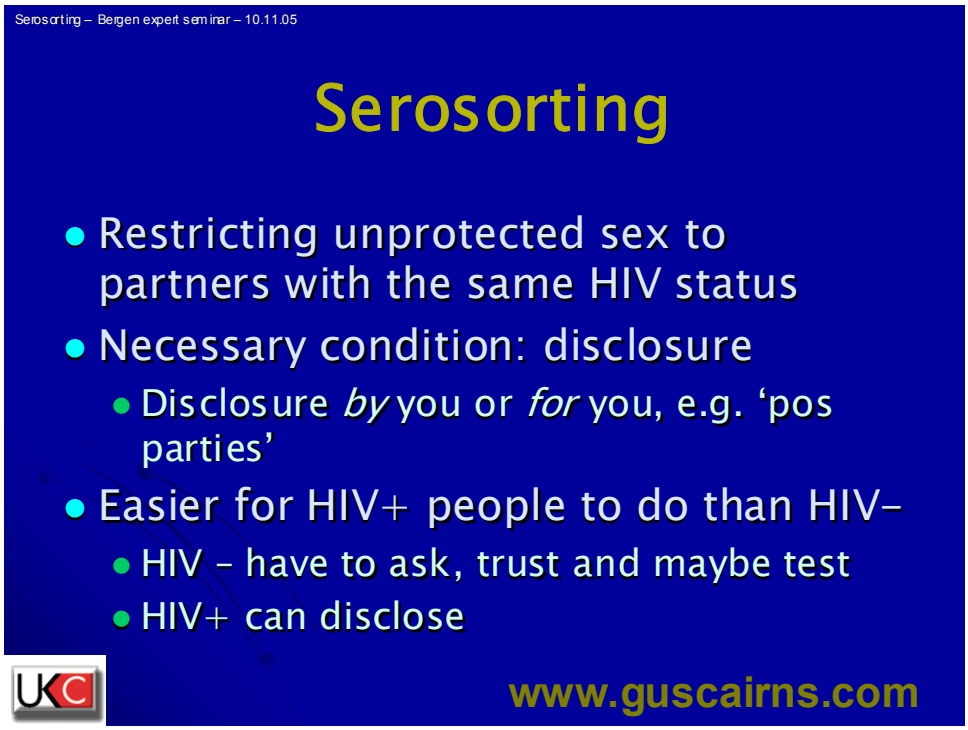
- The model could be adopted for use outside health care settings eg. The internet and other community settings.
- There are limitations to using this one hospital based setting but this is just a starting point.

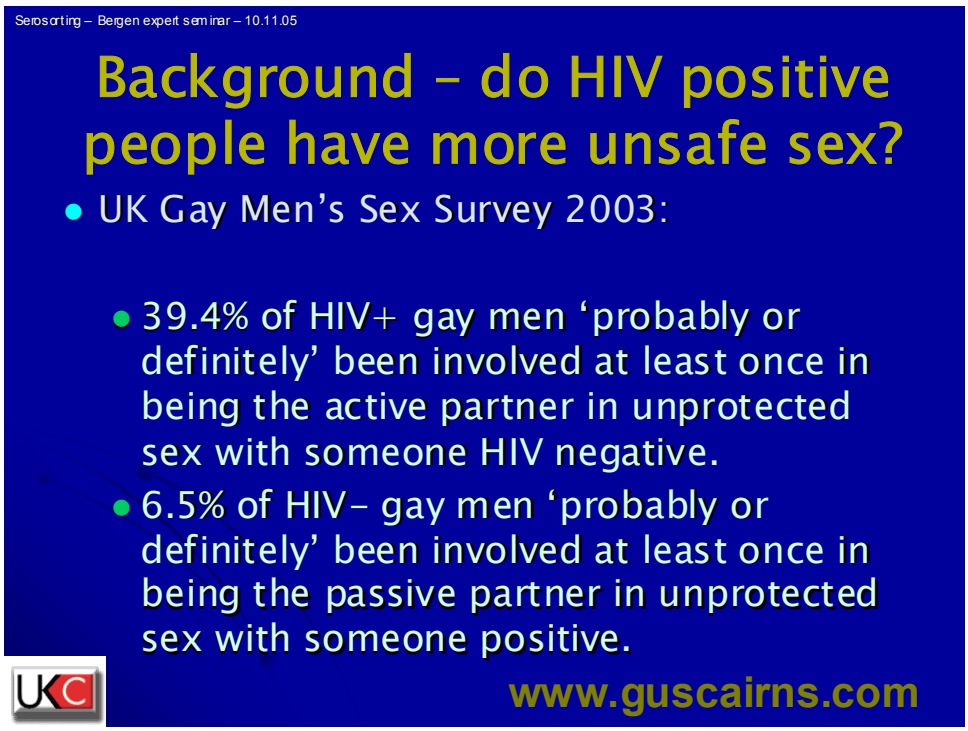
4.2 Serosorting, risk reduction strategies and disclosure in the gay community.

Mr. Gus Cairns, UK Coalition





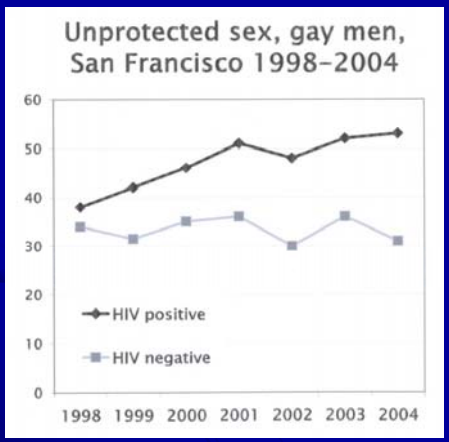

Serosorting – Bergen expert seminar – 10.11.05
Serosorting
Restricting unprotected sex to partners with the same HIV status
Necessary condition: disclosure
Disclosure by you or for you, e.g. 'pos parties'
Easier for HIV+ people to do than HIV–
HIV – have to ask, trust and maybe test
HIV+ can disclose
UKC
www.guscairns.com

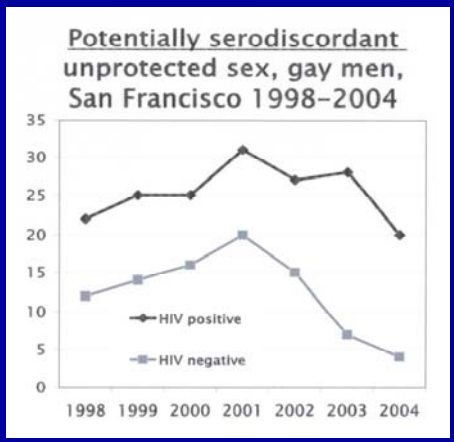

Serosorting – Bergen expert seminar – 10.11.05
Background – do HIV positive people have more unsafe sex?
UK Gay Men's Sex Survey 2003:
39.4% of HIV+ gay men 'probably or definitely' been involved at least once in being the active partner in unprotected sex with someone HIV negative.
6.5% of HIV– gay men 'probably or definitely' been involved at least once in being the passive partner in unprotected sex with someone positive.
UKC
www.guscairns.com

Statistics…

- HIV prevalence in London gay men = c. 12%
  - So 7/8 partners HIV+ men meet by chance will be HIV negative
  - Only 1/8 partners HIV- men meet by chance will be HIV positive
  - Most of the GMSS figure is serodiscordant sex with partners of *unknown* status – so the respondents are only stating the obvious

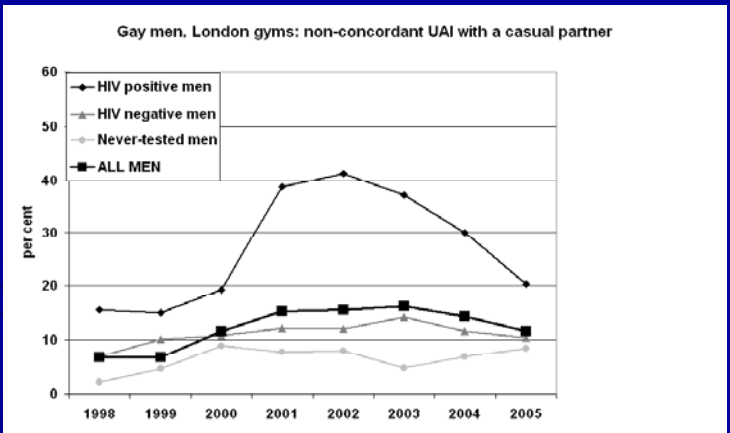
Unprotected sex is not necessarily unsafe sex





San Francisco Department of Public Health – HIV Epidemiology Annual Report 2004

Is the same starting to happen in UK?



Elford J et al. (2005). High-risk sexual behaviour among London gay men: no longer increasing?. Eleventh Annual Conference of the British HIV Association, Dublin, oral presentation abstract 014, April 20 – 23, 2005.

Serosorting – Bergen expert seminar – 10.11.05

Has it affected HIV transmission?

- NB. HIV *diagnosis* is not the same as HIV *incidence*: if more get tested the diagnoses will increase
- San Francisco: expected incidence in 2004 2.2%. Actually found to be 1.2%. STI clinic attendees 5.4 to 3.2% in same period.
- Also lower in LA (1.4%) than expected
- HIV incidence started to decline at a time syphilis cases went up 25-fold

CDC 2005. Centers for Disease Control and Prevention HIV Prevalence, Unrecognized Infection, and HIV Testing Among Men Who Have Sex with Men – Five U.S. Cities, June 2004–April 2005 *MMRW Weekly* 54(24): 597-601, 2005.

Buchacz K et al. Trends in Primary and Secondary Syphilis and HIV Seroincidence among Men Who Have Sex with Men in San Francisco, 1998-2002. 11th Conference on Retroviruses and Opportunistic Infections, San Francisco, 2004. Abstract 88.

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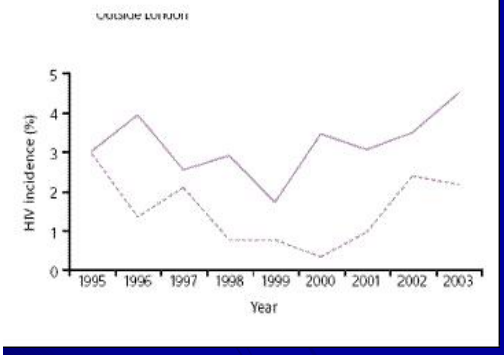
UK?

HIV incidence, gay men attending STI clinics: UK



- Incidence appears to have increased 1999–2003. But:
  - Anonymous samples left over from STI testing
  - Population may not be typical of all gay men
  - Not statistically significant

How gay men serosort: 1

- US young gay men 15–13 2005: 32x times more likely to have unprotected sex with other partners *perceived* to be HIV positive than with partners *perceived* as negative or unknown
- Gay men, London gyms 2001: HIV *negative* men only have seroconcordant unprotected sex (partner negative) with steady partners: HIV+ men just as likely to do it with casual partners ➔ disclosure??
- Internet survey 2005: HIV-positive men using internet were significantly more likely ($p < 0.05$) to report concordant unprotected anal sex, and status disclosure, with a partner they met on-line rather than off-line
- ➔ Disclosure is better than guessing

Lightfoot M et al. The Influence of partner type and risk status on the sexual behaviour of young men who have sex with men living with HIV/AIDS. *JAIDS* 38(1), 61-68. 2005.

Elford J et al. (2001a). HIV positive and negative homosexual men have adopted different strategies for reducing the risk of HIV transmission. *Sexually Transmitted Infections* 77:224-225. 2001.

Serosorting – Bergen expert seminar – 10.11.05

How gay men serosort: 2

- Internet survey 2005: HIV-positive men using internet were significantly more likely ($p < 0.05$) to report concordant unprotected anal sex, and status disclosure, with a partner they met on-line rather than off-line
- ➔ Disclosure is better than guessing

- Bolding G et al. Gay men who look for sex on the internet: is there more HIV/STI risk with online partners? *AIDS* 19: 961 – 968, 2005.

Serosorting – Bergen expert seminar – 10.11.05

'Pos parties'

- POZ parties may spread HIV superstrain. UPI release, 28 September 2005
- Original paper entitled: "An emerging HIV risk environment".
- Probably the one thing it's not…

Clatts MC et al. An emerging HIV risk environment: a preliminary epidemiological profile of an MSM POZ party in New York City. *Sex Transm Infect* 81: 373-376. 2005.

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UK positive-only club night

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Health risks

- Superinfection. Estimates vary from low to very common. Some evidence only common in early infection. ?Clinical relevance?
- STIs:
  - **LGV:** 215 cases confirmed in UK, diagnoses doubled in July. Parallel: gay men 50x more likely than heterosexuals to get HIV. HIV+ gay men 50x more likely to get LGV than HIV- men.
  - **Syphilis:** 29-fold increase since 1995. HIV+ gay men 4x more likely to get syphilis than HIV- men
  - **Hepatitis C:** See next slide

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Hepatitis C: 1

- We can no longer say HIV is the most deadly STI (though it is the most common deadly one)
- HIV-positive patients coinfected with HCV up to 80% more likely to die even with HIV treatment
- Swiss HIV cohort: gay men who'd had UAI but not IDU 3.5x more likely to have HCV
- London: 45+ cases from 14 STI clinics. 20 cases of *acute* HCV identified between October 2002 and January 2003 at one HIV clinic in London. France: 29 cases detected
- Netherlands cluster. Of 30 recent partners of man with LGV, 7/30 had hep C and 4/14 with LGV, of which 3 *confirmed* infected at same time as LGV
- Indian slum dwellers: HCV+ men 12.6x more likely to be MSM
- Fisting? Not necessarily. French study: 38% of men with HCV/HIV had HCV in semen vs. 18% of HCV+/HIV- men

[Hep C references]

- Aizen, K et al. Acute hepatitis C (HCV) in a cohort of HIV-positive homosexual men–patient characteristics, risk factors and outcomes. Ninth Annual Meeting of the British HIV Association, Manchester, abstract P45, 2003.
- Backus LI et al. *Effects of hepatitis C virus coinfection on survival in veterans with HIV treated with highly active antiretroviral therapy.* J Acquir Immune Defic Syndr 39: 613 – 619, 2005.
- Briat A et al. *Hepatitis C virus in the semen of men coinfected with HIV-1: prevalence and origin.* AIDS 19: 1827 – 1853, 2005.
- Gambotti L et al. *Acute hepatitis C infection in HIV-positive men who have sex with men in Paris, France, 2001 – 2004.* Eurosurveillance Monthly 10:5, 2005.
- Gotz HM et al. *A cluster of acute hepatitis C virus infection among men who have sex with men – results from contact tracing and public health implications.* AIDS 19: 969 – 974, 2005.
- Marx MA. Association of hepatitis C virus infection with sexual exposure in southern India. *Clinical Infectious Diseases* 15;37(4):514-20. 2003.
- Rauch A et al. *Unsafe sex and increased incidence of hepatitis C virus infection amongst HIV-infected men who have sex with men: the Swiss Cohort Study.* Clin Infect Dis 41 (On-line edition), 2005.

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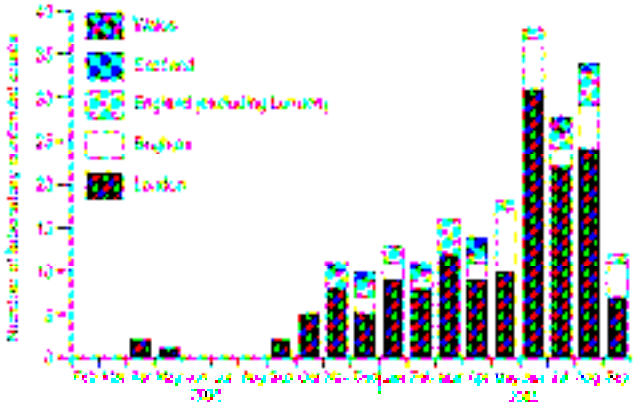
LGV

Figure 1 UK LGV laboratory confirmed cases by month and place of diagnosis to end September 2005 (n=215)



Communicable Disease Weekly 15 (40). 6 October 2005.

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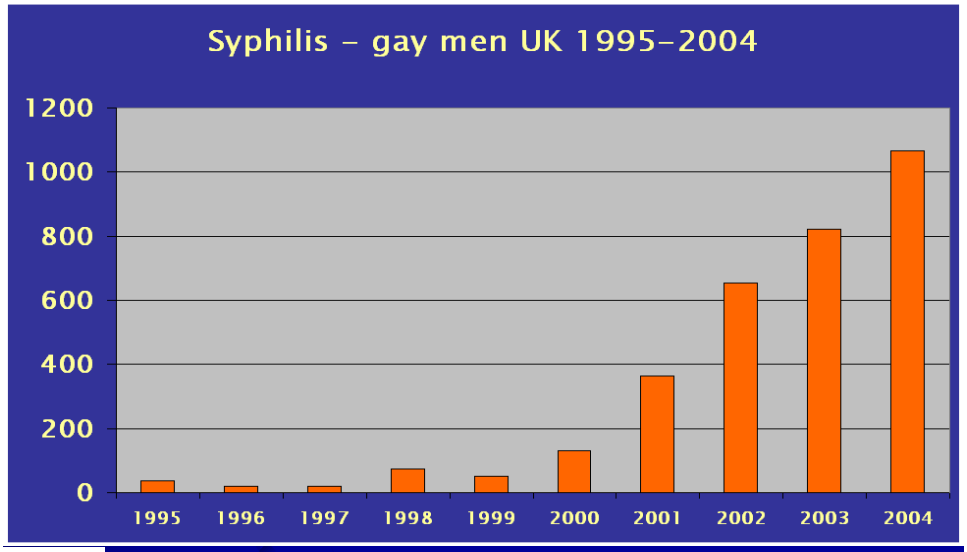
Syphilis



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Paradoxes of serosorting

- Gay men with HIV are attempting not to pass on HIV and to restrict unprotected sex to seroconcordant encounters
- In the process however they are at a risk of other STIs so high that, if the general or even the gay population at large was so affected, it would be treated as a public health emergency…

Other strategies to avoid HIV: viral load

- Goldhammer, San Francisco 2005: more than half of (HIV+ & HIV–) gay men estimated that they used HIV viral load disclosure to guide sexual decision-making in at least 70 per cent of their sexual encounters.
- Van de Ven, Sydney 2005: 39.4% of serodiscordant gay couples reported UAI when the partner's HIV last viral load test was undetectable as when it was detectable (20.8%).
- Crepaz 2004 meta-analysis found no evidence VL directed sex decisions *but* may be a recent phenomenon

Goldhammer H et al. Beliefs about viral load, sexual positioning and transmission risk among HIV+ men who have sex with men (MSM): Shaping a secondary prevention intervention. 2005 National HIV Prevention Conference, Atlanta, USA, presentation W0-D1201.

Van de Ven P et al. Undetectable viral load is associated with sexual risk taking in HIV serodiscordant gay couples in Sydney. *AIDS* 19(2): 179-184. 2005.

Crepaz N, Hart TA, Marks G. Highly active antiretroviral therapy and sexual risk behavior: a meta-analytic review. *JAMA* 292:224-36. 2004.

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The problem with viral load is…

- Taylor 2003 found one in 8 gay men had higher VL in semen than in blood
- Kalichman 2001 found *no* correlation between seminal and blood viral load in gay men with multiple partners
- However Wawer found linear relationship between VL and infectivity – in heterosexual couples

Taylor S, Sadiq T, Sabin C, et al. Seminal super shedding of HIV: implications for sexual transmission. Program and abstracts of the 10th Conference on Retroviruses and Opportunistic Infections; February 10-14, 2003; Boston, Massachusetts. Abstract 454.

Kalichman SC et al. Human immunodeficiency virus in semen and plasma: investigation of sexual transmission risk behavioral correlates. *AIDS Res Hum Retroviruses* 10;17(18):1695-703, 2001.

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Other strategies to avoid HIV: negotiated safety (HIV- couples)

- Guzman 2005: HIV- gay men in steady relationship
  - 51% had some sort of negotiated safety agreement
  - 25 % had unprotected sex with each other but total monogamy.
  - 4% disallowed anal sex with partners outside the relationship but allowed other sex.
  - 21% allowed anal sex outside the relationship as long as it was always protected.
  - 8% had protected sex *within* the relationship but allowed unprotected sex outside it – a stance protecting their partner but not themselves
  - HOWEVER – 29% of those who had an agreement had broken it in the previous three months.

Guzman R et al. Negotiated safety relationships and sexual behaviour among a diverse sample of HIV-negative men who have sex with men. *JAIDS* 38(1) 82-86. 2005.

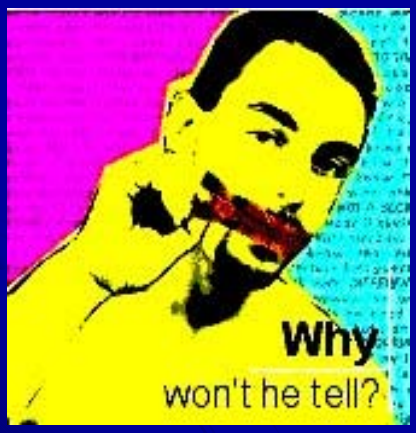
"Strategic positioning"

- Neg on top, pos on bottom
  - Est. 1/33 maximum chance of infection per exposure if HIV+ partner is insertive vs max. 1/166 if HIV+ partner is passive (at least 5x safer)
    - * Vittinghoff E. Per-contact risk of human immunodeficiency virus transmission between male sexual partners. *American Journal of Epidemiology* 150(3), 306-311. 1999.

Withdrawal

Serosorting – Bergen expert seminar – 10.11.05

Serosorting depends on disclosure…How *not* to encourage HIV positive men to disclose (sorry GMFA!)



- Campaign after GMFA survey found only 20% of HIV+ men disclose before first sex (whereas 70% of negative men expect disclosure)
- So why direct it at negative men?
- "He": the HIV positive man is An Other
- Campaign literature gave 33 reasons HIV+ men might *not* disclose. How disempowering is that?!

UKC

www.guscairns.com

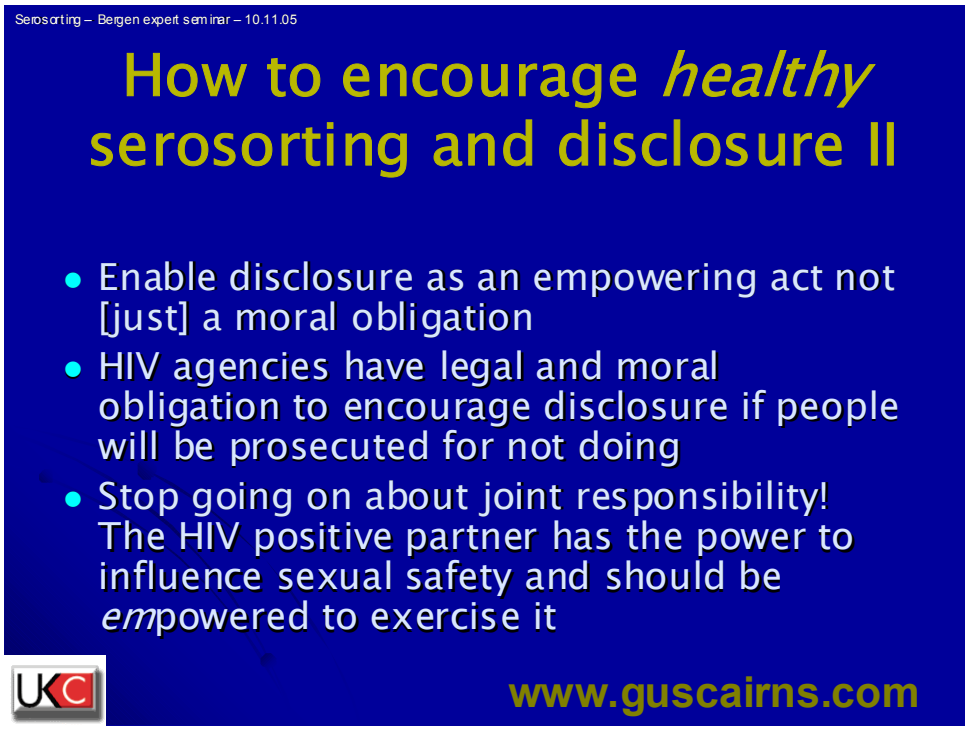
Serosorting – Bergen expert seminar – 10.11.05

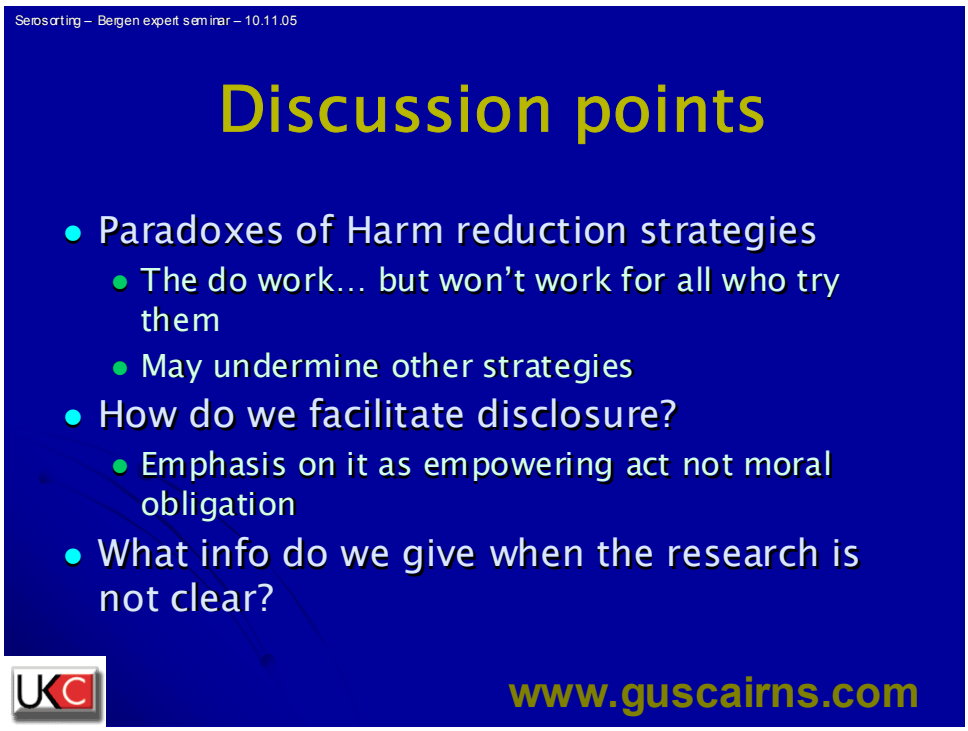
How to encourage *healthy* serosorting and disclosure I

- Appreciate paradoxes of serosorting: 'barebacking' as identity and activity in some circumstances may actually reduce HIV risk: strategies that work for some men may undermine others'
- Stop fixating on HIV! We need to talk about the sexual health of all gay men
- Positive and negative gay men are not separate communities and should not be addressed separately…
- …BUT HIV positive men are at *additional* risk of acquiring STIs and transmitting HIV, and should have *additional* resources directed at them

UKC

www.guscairns.com





Discussion points and questions:

- The gay community often don't understand the concept of harm reduction and the fact that it is not a zero tolerance strategy.
- The more people that test then the more likely it is that serosorting strategies will work.
- People collect information and facts but on different levels, some people want or need more information than others.
- There is often an inconsistency in available information, particularly when leaflets are out of date and not updated with new information. This was identified by PLWHA at a conference in the UK as a major problem.

4.3 Advice for couples where one is HIV positive
Mr. Marc Thompson, Terrence Higgins Trust

Our working definitions of HIV prevention

• Principles, background & context

• The programme development process

• The Intervention – Vive la difference

Primary HIV prevention

Activities with both infected & uninfected people to reduce primary (i.e. initial or new) HIV infections

Secondary HIV prevention

Activities to maintain the well-being of people with HIV, and delay disease progression

Principles

• The Ottawa Charter

• Making it Count

• Making it better

• Successful measures

The Ottawa Charter

"The process of enabling people to increase control over, and to improve, their health"
(WHO, 1986)

Making it Count

•All people whether they have HIV infection or not, are entitled to a satisfying & fulfilling sex life

•All people, whatever their sexual preference or identity, their consensual sexual behaviour or their HIV status, are entitled to the same rights and respects as other people

Making it better – Strategic Target

"To ensure sexual health promotion and primary prevention work is inclusive of the needs and rights of gay men with HIV"

Making it better – primary objectives

•Gay men with HIV are central to any effective intervention

•Gay men with HIV should be recognised as essential players in the prevention of HIV, but not perceived or portrayed as wholly responsible for HIV transmission

Making it better – primary objectives

•Gay men with HIV are not perceived as an homogenous group whose needs can be universally addressed

•The health, emotional and sexual well-being of Gay men with HIV is recognised as being as important as that of HIV negative or untested men

Successful Measures

•All interventions should recognise their possible impact on positive men as they are most likely to encounter them

•The best aims for interventions are those shared by men irrespective of HIV testing history or HIV infection status.

Background and Rationale

•Evidence from GMSS 2002

•Identified as a need by the CHAPS Partnership

•Identified as a need by gay men with HIV & their partners at the THT gay men's group

Background and Rationale

• 65.6% in a current relationship

• 7.9% in a current sero-discordant relationship

• 26.6% unaware of HIV concordancy or discordancy of current relationship

Background and Rationale

•63.6% both insertive & receptive AI. Of these 59.6% had occasionally engaged in UAI

•14.4% only insertive. Of these 50.4% had occasionally engaged in UAI

•10.0% only receptive. Of these 52.4% had occasionally engaged in UAI

•Overall, almost half (48.8%) of all men who had sex with men in the last year had any UAI.

Out & About (National Gay Men's Sex Survey 2002)

Intervention Aim

• Gay men in Sero-discordant relationships are aware of the appropriate information & support available

• Provide those working with men in Sero-discordant relationships with appropriate knowledge to support men.

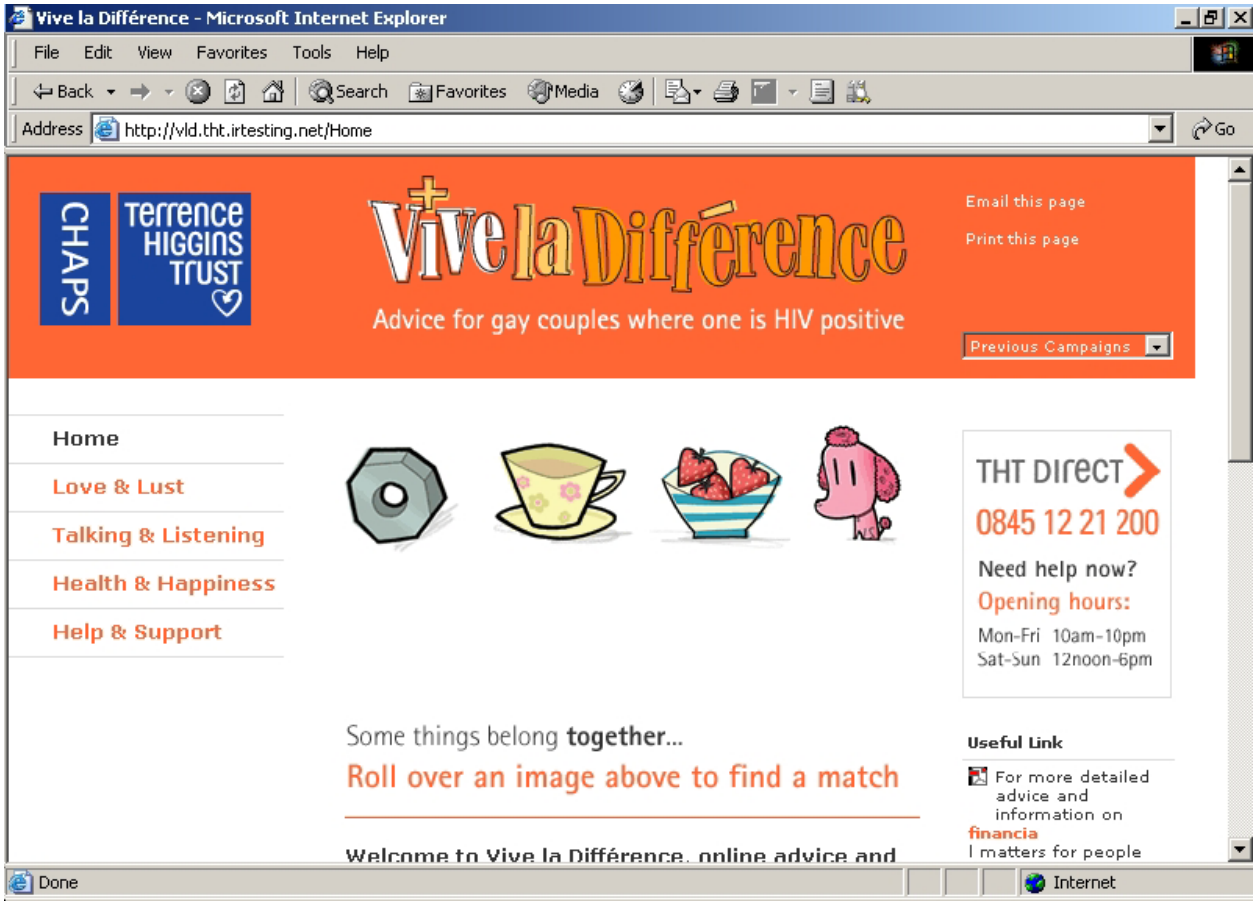
Outcomes of the campaign

•Men in SD relationships are aware of information and support available to them

•Men are aware of the possible solutions to the issues which they may face if in SD relationships

•Men are aware of the availability of PEP

•Men aware of solutions to reduce condom failure



Web based intervention

•Personal stories/testimonials from men in sero-discordant relationships

•Issues/'dilemmas' are presented & advice is provided by THT/PACE counselors & 'real life' solutions from men in SD relationships

•Advice for overcoming a range of problems (both sexual and non-sexual) within SD relationships

•Coping with disclosure in a new SDR

Web based intervention

• Support information and referrals for negative partners in sero-discordant relationships

Discussion points and questions

- This was a positive prevention campaign with the aim of improving the well being of PLWHA however there was also an element of primary prevention.
- The campaign was developed following a thorough needs assessment with the target group and then the content was developed.
- An end user evaluation is attached to the website.
- It was felt to be very important to target this resource at sero-discordant couples as very little has been done with this group in the past.

4.4 Assessing European strategies to improve the sexual and reproductive health of PLWH (EUROSUPPORT V)

Mrs. Christiana Nostlinger, Institute of Tropical Medicine, Belgium

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EUROSUPPORT V
"Improving sexual and reproductive health of PLWH"

Christiana Nöstlinger, Bob Colebunders
Institute of Tropical Medicine
Ruth Borms, Koen Block, Katy De Clercq, SENSOA, Antwerp

European Expert Meeting on Positive Prevention
Bergen, November 9-11, 2005

Supported by the European Commission, grant agreement nr. 2004314

EUROSUPPORT – General Overview

The general **EUROSUPPORT** philosophy:

To evaluate the support needs of people living with HIV (PLWH) and to detect shortcomings in the actual service provision through cross-sectional research carried out by a **network of HIV treatment centres**, **HIV service organizations**, and **research institutions** with the overall goal **to improve care and support** for PLWH.

Supported by the European Commission, grant agreement nr. 2004314

EUROSUPPORT – General Overview

EUROSUPPORT I (1996-1998): Access to health care, euthanasia, HIV-testing, financial aspects

EUROSUPPORT II (1998-2000): Effects of HAART on adherence

EUROSUPPORT III (2000-2002): Effects of HAART on sexual dysfunctions

EUROSUPPORT IV (2003-2004): Psychosocial needs of families affected by HIV; impact on children and family functioning, disclosure within the family…

Supported by the European Commission, grant agreement nr. 2004314

Background and Rationale

- Prevention and care traditonally not well integrated areas
- Persons living with HIV (PLWH) have been an understudied population with respect to HIV prevention and sexual behaviour
- Health care providers have a unique opportunity to adress prevention issues in the clinical context
- ES V network: setting to investigate issues relating to the improvement of SRH-needs of PLWH

Supported by the European Commission, grant agreement nr. 2004314

Expert Meeting on Positive Prevention November 10, 2005

Background and Rationale

Key-concept "sexual and reproductive health":

Comprehensive definition of optimal sexual and reproductive health as specified in the guiding principles of the Cairo Conference Programme of Action, 1994:

"Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"

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Evidence on sexual health

- Number of new HIV infections increased by 23% in 2002 (Hamers & Downs 2004)
- Increase in specific STIs/"outbreaks" documented
- Net-effects of opposing forces: effective ARV-treatments vs. risk behaviour ? (Katz et al. 2000)
- Considerable debate about the role of "HIV-optimism" (Pickett et al. 2003)
- Evidence for sexual risk behaviour (Fisher et al. 2005)
- Existence of false cognitions and myths relating to HIV transmission (Kippax 2003)
- Side-effects of ARVs and emotional distress may also influence sexual behaviour ("sexual problems") (Florence 2004; Schrooten, Colebunders et al. 2003)

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Evidence on reproductive health

- Effective ARV treatment resulted in increase in desire to have children (Sherr et al. 2004)
- Women living with HIV (and couples!) may want to plan pregnancy, limit their family, or avoid pregnancy…
- Contraception: Interaction with ARVs → implications for counselling (Mitchell & Stephens 2004)
- French SEROCO study: 20% no contraception, 24% unplanned pregnancies, one third terminated by abortion (De Vincenzi 1997).
- Human and reproductive rights issues: unsafe abortions, forced sterilizations, access to treatment and counselling…

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Previous Eurosupport results (1)

Female caregivers' sexual and reproductive health (SRH) (N=484)

SRH indicators	n	%
Delivery since HIV-diagnosis	274	39,1
Circumstances		
— diagnosis during pregnancy	102	38
— diagosis before/child planned	95	35
— diagnosis before/unintended pregnancy	74	27
Number of children since HIV+ diagnosis		
— mean number of children (s.d.)	1,3 (0,52)	—
— median number	1	—
— range	1 - 3	—
Pregnancy termination since HIV-diagnosis	106	22
Number of terminations		
— mean number of terminations (s.d)	1,5 (1,4)	—
— median number	1	—
— range	1 - 4	—

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Previous Eurosupport results (2)

Reproductive health		**Migrant women** N (%)	**Non-migrant women** N (%)	p
Number of children	1 child	56 (36)	151 (54)	0,0013
	2 children	60 (39)	94 (33)	
	3 or more	39 (25)	37 (13)	
Desire to have children	Yes	72 (44)	83 (28)	0,002
	No	91 (56)	214 (72)	
Children since HIV-diagnosis	1 child	63 (72)	127 (72)	ns
	2 children	23 (26)	43 (24)	
	3 children	1 (1)	7 (4)	
Reasons for carrying pregnancy to term	Related to child	63 (79)	148 (89)	ns
	Related to health	58 (72)	146 (86)	0,013
	Partner-related	48 (64)	116 (71)	ns
	Too late for termination	54 (67)	97 (60)	ns
Number of terminations	1	30 (77)	45 (67)	ns
	More than 1	9 (23)	22 (33)	
Total		163 (100)	297 (100)	

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EUROSUPPORT V: General Objectives

To promote the SRH of PLWH and to prevent further transmission of HIV by supporting PLWH in the adoption of healthy sexual lifestyles:

- To improve current strategies of prevention practices targeting PLWH (i.e. supporting PLWH in adopting safer sex practices).

- To empower PLWH to take informed choices about fertility-related issues (such as family planning and pregnancy-related issues).

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EUROSUPPORT V: Specific Objectives

- Identifying SRH needs of men and women living with HIV.
- Identifying, analysing and disseminating models of good practice across Europe that effectively address SRH needs of PLWH.
- Developing policy recommendations and to disseminate them among the Member States.
- Setting up a network of HIV treatment centres and service organisations in the field of SRH and HIV/Aids in selected Member States of the European Union.

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Translation into research questions

1) Taking a comprehensive definition of SRH into acount, what are specfic **support needs** of PLWH (e.g. contraceptive needs, desire to have children, sexual risk reduction, avoiding relapse behaviour, maintaining safer sex behaviour….)

2) What are **conditions** and **predictors** than enable PLWH to adopt and maintain healthy sexual behaviour?

3) How can **optimal strategies** for SRH-services and counselling in HIV-care settings be defined (aiming at improving the SRH of PLWH)?

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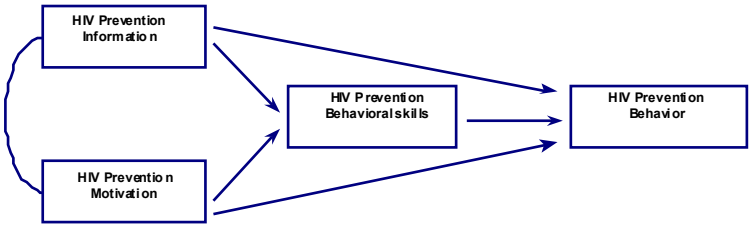
Theoretical framework (2)

Figure 1: Overview IMB model (J. Fisher & W. Fisher, 1992, 2000; W. Fisher & J. Fisher, 1993)



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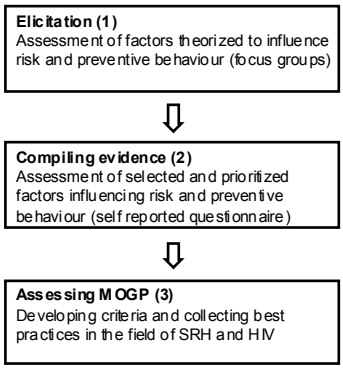
Methodology (1)



← Carrying out three steps of data assessment

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Methodology (2)

Elicitation research (data assessment phase 1):

- Qualitative research
- Using focus groups
- Different target groups (Health care providers; PLWH: heterosexual women and men, homo/bisexual men, minority groups, …)

- Compiling focus group discussion guidelines (=tool)
- Translation
- Hypotheses-generating…

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Methodology (3)

Compiling evidence (data assessment phase 2):

- Quantitative research (survey)
- Using an anonymous, self-reported questionnaire based on the qualitative data collection
- Main areas: sexual behaviour; fertility-related issues incl. contraceptive behaviour

- Piloting and translation
- Procedures: Ethical approvals and informed consent
- Data entry and analysis by the coordinating centre

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Methodology (4)

Collecting models of good practice
(data assessment phase 3):

- Developing needs-based criteria
- Collecting MOGP across Europe by means of a short survey
- Translation of the survey form
- Identifying field organizations
- Data entry and analysis
- Dissemination of results to field organizations

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Data analysis

Qualitative data:

Transcripts of FG session → coding and analysis → translation → comparative analysis and synthesis!

Quantitative data:

- Descriptive analysis of SRH needs
- Bivariate analysis of demographic, psychosocial, and HIV-related factors with specific outcomes (e.g. sexual behaviour, unintended pregnancies, desire to have children…)
- Multivariate analysis (logistic regression) to predict selected outcome variables

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ES V - Partners

Table 1: Countries/Partners Participating in ES V

Country	Organization	City	Status
Belgium	ITM	Antwerp	Main Partner
	SENSOA	Antwerp	Main AP
Austria	European Centre	Vienna	AP
	University of Innsbruck	Innsbruck	AP
Germany	Ludwig Maximilian University	Munich	AP
Greece	SYNTHESIS	Athens	AP
Italy	CARAP	Padua	AP
	San Raffaele Scientific Institute	Milan	AP
Portugal	Hospital Santa Maria	Lisbon	AP
Spain	Universidad Complutense	Madrid	AP
UK	Pennine Acute Hospitals	Manchester	AP
Slovak Republic	National Reference Centre for HIV/Aids Prevention	Bratislava	AP
Czech Republic	University of Prague, Institute of Sexology	Prague	AP
Hungary	Semmelweis Clinic, Institute of Public Health	Budapest	Subcontractor
Poland	Institute of Mother and Child	Warsaw	Subcontractor
Latvia	Association for Family Planning and Sexual Health	Riga	Subcontractor
Switzerland ?	*University of Aargau*	*Aarau*	*Independent*

Supported by the European Commission, grant agreement nr. 2004314

Contacts

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ruth.borms@sensoa.be

Supported by the European Commission, grant agreement nr. 2004314

Discussion points and questions

- Particularly interesting will be to assess the differences between the perspectives of the health carers and those of the PLWHA.
- In some countries, eg. Slovakia, they have not been able to run focus groups as have not been able to access PLWHA.
- The research is funded by the EU but the team are still looking for match funding nationally.

4.5 Women and HIV; European Seminar

Mrs. Aurélie Verny, AIDES

Women : facing HIV in our wider Europe

Promoting community based approaches

Paris, France - October 7-8, 2005

AIDES

- **AIDES: French HIV/AIDS Association (1984)**
  Today in 100 French cities

- **AIDES International team :**
  –To benefit from best international practices
  –To make available the lessons we have learned (including mistakes made…)

- **In Europe:**
  The AIDS ACTION & INTEGRATION Projects
  Dedicated to support HIV/AIDS NGOs in Central and Eastern Europe : www.integration-projects.org

Objectives of the European Seminar :

- Main objective :**This seminar is design to promote the integration of established community-based methodologies to strengthen the work carried out on Women and HIV issues by local HIV/AIDS NGOS, especially in Central and Eastern Europe**.

- Secondary objectives: **to update knowledge on women and HIV related issues, promote informal networking opportunities, identify common priorities at the European Level**

Participants

This seminar is primarily designed for :

- Community based NGO actors
- Women living with HIV/AIDS
- Central and eastern Europe especially new and future member states
- Managing ongoing projects on women and HIV related issues
- **Working languages: French, English, Polish and Russian**

- Number of participants: 40 + 9 speakers
- Countries: 19

  Majority: new and future European Member states, 6 persons from non EU Eastern Europe
- NGOs

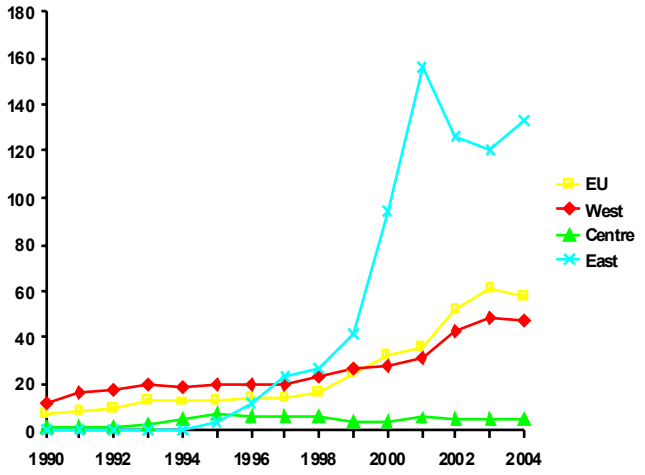
  People leaving with HIV/AIDS NGOs, HIV/AIDS NGOs, NGOs working & vulnerable groups

Why should Women and HIV issue be **fully recognized** by governments and **become a priority** ?

Epidemiology:

- In our European Continent, **women represent a growing proportion of newly diagnosed HIV Infection**: from 27% in 1999 to nearly 40% in 2004 (Euro HIV). First transmission route: heterosexual
- **Eastern Europe**: After several years of rapid spread of HIV among injecting drug users
- **BUT : NOW** Alarming situation due to the large numbers of young women currently living with HIV, sexual partner of drug users.
- **Heterosexual transmission and number of HIV positive women is increasing**

HIV infections newly diagnosed per million in women, by geographic area, WHO European region



EuroHIV

Women are more vulnerable than men due to biological specificities

- Why?

1. A **higher concentration of HIV in semen** than in vaginal fluid
2. The **larger surface area** of the vagina and cervix and the **fragility** of the membranes in these areas
3. **Young women** are more vulnerable to HIV because the **mucous membrane changes**, and transition is not often completed until late teens or early twenties. Immature genital track surface is less efficient as a barrier to HIV than a mature genital track

Other factors of vulnerability

- Socio-economical, cultural and legal factor increase vulnerability.
- Vulnerabilities are derived from:

1. **Unequal individual power** : safer sex negotiations, lack of knowledge, violence
2. **Unequal voice throughout societies** : political setting, decision making level, science
3. **Unequal access to resources and wealth** : economical dependency, sex for money, inability to terminate dangerous relationship

HIV + Women

- **Infected women are more vulnerable to the effects of HIV mostly because of the inequality they suffer**
- less access to treatment and care,health
- health systems not women-friendly
- **absence in clinical studies**
- stigma and discrimination
- violation of rights

Yet, all too often little consideration is given to this issue !

In the design of HIV/AIDS prevention, support, treatment and research programs

Advocacy priorities identified by participants

shared advocacy priorities at the European Level

Common priorities :

- **1) Support for NGOs**
- **2) Research**
- **3) Streamlining best practices**

1) Long-term support for community-based NGOs

- HIV/AIDS prevention and support which involves vulnerable women (including migrants, drug users and women living with HIV/AIDS) are essential components of the fight against HIV/AIDS
- Local civil society must therefore be involved in the design and implementation of national and European HIV/AIDS programs

Why community based NGOs ?

- Community based NGOs **place people living with HIV/AIDS at the heart of their preoccupations**
- NGOs: build structures for **PLWHA to express their needs** and get involved in NGOs actions

- Programs tailored to the needs of the people and **WITH them**
- HIV/AIDS NGOs in central and eastern Europe often **have very short term funding.**
- Situation is even worse in the **10 new member states**.

What should EU do?

- EU should pressure individual governments to commit to sustainable and long term support for local community based NGOs
- At the European level: Promote best practices and exchange of experiences
- Should the EU directly fund health services in some cases?

2) Long term support and funding for research on women issues

- More research is needed notably on the specific impacts of HIV treatments on women, the implications of HIV in terms of reproductive health, the specific health-needs of female drug users

- women-initiated prevention tools such as microbicides, we have to make it possible for women to become actors of their own protection and reproduction.

Women-initiated HIV Prevention Tools: necessary to meet women's needs

- Example: **Microbicides** are substances that can reduce the transmission of HIV and other STI pathogens when applied vaginally and, possibly, rectally.
- **They are not yet available.**
- **Formulation:** gels or creams (& applicator), in the future : & sponges, vaginal rings or caps
- **Action :** some will prevent pregnancy, other microbicidal but not contraceptive,
- **Good :** likely to be inexpensive, broadly available, possible use without partner's direct cooperation

Microbicide (2)

- **Benefits for HIV+ people** :Reduce risk of re-infection with other HIV strains, help protect both partners, reduce risks of other STIs, allow conception while protecting partner
- **BUT** Trials keep being delayed due to lack of money. As big pharmaceutical companies do not invest due to profitability reasons, development will require significant public money. **Advocacy is thus needed on this issue**.
- Learn from Female Condom mistakes, **training and acceptability campaign are needed**

Women specificities: Contraception in HIV+ women

- Clinicians treating HIV-positive women who are at risk for drug interactions should **review the need for possible use of alternative methods of contraception or dose adjustment**
- Family planning counselors should be trained to counsel HIV+ women
- Studies should be performed to evaluate the efficacy of Combined oral contraceptive in treated HIV+ women and interactions (ARV/COC)
- Too little information is available on the issue

3) Streamlined high-quality health services for women across Europe

- Everything should be done to enable all women to have access to an essential package of health services – including medical, psychological and gynecological care - which meets their needs for HIV prevention and treatment
- Priority access for vulnerable groups: migrants, drug users

Access to Gynaecological care: Cervical cancer in HIV positive women

- Case reports of unusual cervical cancers in AIDS patients led to the inclusion of **cervical cancer as an AIDS defining illness** by the CDC in 1993
- Recommendation : Complete gynaecologic evaluation, **Pap test : 2/ year, then 1/year if normal**, More frequent if previous abnormal, Known HPV infection, After surgical treatment, If symptomatic HIV (CD4<200/mm^3)

Basic standards of reproductive health in relation to HIV and women

- **Reproductive health problems – including HIV/AIDS - are the leading cause of death and illness for women of childbearing age worldwide and represent 32 per cent of all causes of death and illness in women worldwide.** United Nations Summit , September 2005
- **Need**: empowering women and improving access to reproductive health care

Vertical transmission, what can be done?

- On the European continent **we know what work** to reduce drastically vertical transmission.
- The benefit of antiretroviral drugs in reducing mother-to-child HIV transmission greatly outweighs any potential adverse effects of drug exposure or concerns related to development of drug resistance » WHO Technical Concultation, 2000
- Specific worries about the countries in **Eastern Europe**, wide number of young women with HIV.
- **Long term follow up** of HIV and ARV exposed infants
- **Support services** for family

Drug use, reproductive health and HIV

- Growing number of women become infected with HIV by injecting drugs.
- **All health care services** should be available for drug using pregnant women, without stigma
- Access to **harm reduction**. Outreach programs encouraging drug using women to seek counseling about RH and early entry into prenatal care when pregnant.
- All **treatment including substitution, counseling, and psychosocial support** should be free of charge or covered by insurance

Recommendations for couples living with HIV

- Access to ART for all couples with HIV
- Access to semen washing
- ART centres available and accessible
- Programs tailored to needs

Conclusion

- It is critical to mobilize **additional resources for HIV prevention** as well as for treatment and care for those already infected.
- People need an **essential package of services that both meets their needs for HIV prevention and treatment, as well as addresses other critical areas of their reproductive lives**
- **Gender equality and reproductive health** are not only prerequisites for poverty reduction, but also key to accelerating development.

THANK YOU !

Aurélie Verny

Discussion points and questions

- Work with women cannot be done in isolation from that with men. Women need to be involved in different ways at all levels.
- Some organisations are finding that funding is being lost due to becoming members of the EU. There needs to be European wide advocacy to ensure that the EU covers any such losses of funding.
- This meeting was just the beginning, a follow up meeting is planned.

- Work on microbicides needs to be prioritised. It was encouraging to hear that women at the seminar were also highlighting the need for rectal microbicides.
- Womens issues and rights do need to be recognised. However, it is important that women are not targeted in an ineffectual generic way but with recognition that they are part of other groups eg. migrants or injecting drug users.
- In Greece most women living with HIV have been infected through sex with men who have sex with other men.

5 How to improve the social climate for PLWHA

5.1 Creating a positive network of MSM

Mr. Jan R Mietinen, Gay and Lesbian Health, Norway

HIV-positive MSM

Invisible

No arenas/network

No influence

Isolation

>> more unsafe sex?

Statistics

INCREASE IN NUMBER OF NEW HIV INFECTIONS
AMONG MSM I NORWAY (2/3 IN OSLO)

2002 > 30

2003 > 54

2004 > 70

2005 > 35 (October 200

Change from within (peer to peer)

- New conference
- New network
- New brochure
- New arenas internet meeting/dialog
- New visibility

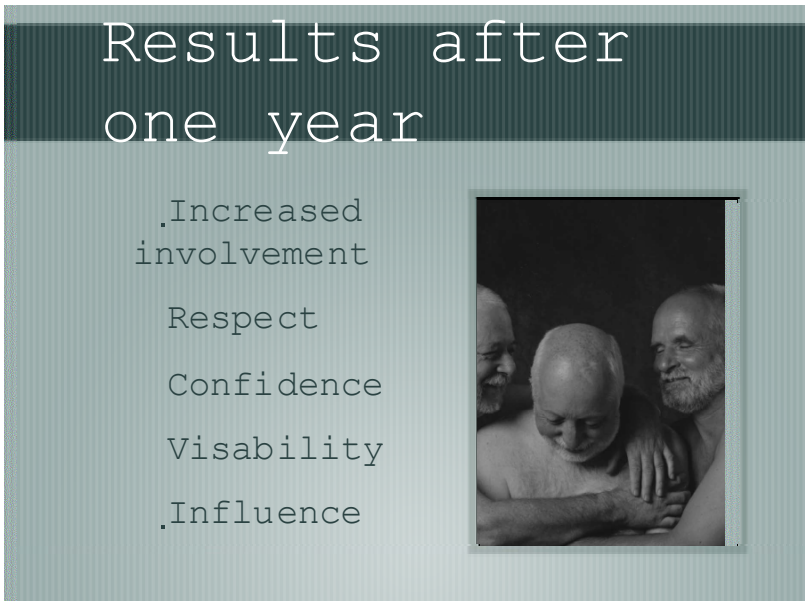
New brochure


NY TID
- NY INSPIRASJON
personlige historier
fra 7 hivpositive homser
Helseutvalget


Visibility


Internett meeting Gaysir.no
Topics
Disclosure/ outing
Responsibil ity


INTERAKTIV
29731
medlemmer,
1203
er her nå
Brukernavn:
angel_inc
Passord:
Husk bruker
Logg inn
Glemt passord? »
• Ikke medlem
i Norges største community for homofile, bifile og andre skeive? Det er helt gratis...
Bli medlem »
Sjekk meldinger på mobilen
www.gaysir.no/wap.wml
Helse&Livsstil
Stort engasjement i hiv-debatten
Av Jan Kolberg Larsen og Kim Fangen (31.10.05)
Etter "hivbombe"-debatten på forumet her på Gaysir siste uke, stilte Jan Kolberg og Kim Fangen opp sammen med Helseutvalget for å svare på spørsmål fra Gaysirs brukere mandag kveld. Mange hadde meninger og spørsmål om hiv, smitte, ansvar, opplysningsplikt og hvordan det er å leve med hiv.
Utgangspunktet for debatten var et spørsmål på Gaysirs forum fra en som lurte på om han burde "oute" en hivpositiv mann som søkte sextreff her på Gaysir fordi han mistenkte ham for ikke å fortelle sine sexpartnere at han var hivpositiv.
Mange spørsmål handlet om ansvar, plikt til å informere, hvorfor så få hiv-positive er åpne og hva Gaysir tillater på sine profiler og temagrupper.
Dette nettmøtet er avsluttet. Les svarene under.
VERDIDEBATT ELLER EN DEBATT RUNDT RETTIGHETER
Innsendt av: Knut Høeg
Dette tar opp saken som en verdidebat.
Er det ikke egentlig et spørsmål om rettigheter.
Denne debatten inneholder mange aspekter i forhold til både rettigheter og verdier. Det ene utelukker ikke det andre.
Hilsen
Kim,Jan og Rolf


Results after one year
Increased involvement
Respect
Confidence
Visability
Influence

Plans for 2006: Increased focus on HIV+ MSM

- Supportive network
- Support of people who are open about status
- Regular forums
- New conference on sexuality/disclosure/safer sex
  - When is it difficult?
  - Why is it difficult?
  - How to make it easier?

HIV-positive MSM

- Invisible
- No arenas/network
- No influence
- Isolation
- >> more unsafe sex?

Positive prevention

- Better social climate for PLWHA
- Better health and quality of life
- Safer sex practises
- More openness around HIV status
- >> Decrease in number of new HIV/STI infections?

Discussion points and questions

- The role of net meetings should be explored more, particularly in isolated rural settings.
- Other organisations in Norway are focussing on the needs of other groups such as women and migrants. These organisations meet once per month to plan joint advocacy and campaigning.
- 20% of new diagnoses in Norway are migrants who have been infected since arrival.
- 78% of MSM know their HIV status.
- 8 people have been sentenced in Norway for passing on HIV, they were all straight.
- 37 men attended the first conference and 19 the second.

5.2 Improving the social climate: Ethical, moral and juridicial aspects

Mrs. Claudia Kuderna, AIDS Hilfe Wien

Presentation

„Good morning, everyone. As you can see, I have not prepared a power-point-presentation for you, partly because of a lack of time, partly because as the last speaker of the meeting I finished my presentation just yesterday evening to leave out stuff that was already mentioned before, react of important issues raised by previous speakers and add a few facts/experiences and theories that have not been stressed so far.

My name is Claudia Kuderna, and I'm the manager/executive director of Aids Hilfe Vienna. We are Austria's largest AIDS-service organisation, offering a wide range of services. We have a staff of about 50 plus 25 free-lancers plus 120 volunteers. We offer
- VCT
- medical and psychosocial counselling for PLWHA
- a drop-in-centre
primary prevention targeted on MSM, women, youth, professionals in the fields of health-care, education, prisons, social work etc.
- self-help-centre: support for self-help-groups (organisation, administration, meeting ventures, finances).

Let me introduce my Austrian college Andreas Hudecek to you once again. Among a lot of other things Andreas is a member of the Austrian Community Board, a group of PLWHA who's main aim is to have the voice of PLWHA heard on national and international conferences. We have been working together on the topic of "positive prevention" quite a while now and organised a slot in the German/Austrian AIDS-Congress that took place in Vienna in June this year titled "Are PLWHA a target group for primary prevention?" and caused quite a stir. Upon receiving the invitation for this meeting, I asked Andreas to be included as well, because hardly anything we plan in the field of positive prevention is done without the "meaningful participation" of PLWHA. Since it is a given for all and every activities, I will not stress the point any further.

There is one thing I have to tell you about us up front: As an organisation dealing with thousands of different clients every year, we are very practice-oriented and pragmatic. Since our approach is more pragmatic than theoretical, our work in positive prevention is not so much based on formulated principles and policies (which, I'm afraid to tell you, have little practical values. When we talked about that topic yesterday, we didn't even ask who we were writing them for.), but on facts and experiences. So in the following few minutes I want to address these four topics:
- the legal situation in Austria
- addressing ethics/the role of the health care workers in AIDS-service organisations
- the myth of „shared responsibilities"
- the watering-down of prevention messages

Legal aspects

Austrian criminal law has punished HIV-positive people who have unsafe sex with HIV-negative people since the beginning of the epidemic. Even if no infection has taken place, it still is illegal to "endanger" somebody with a potentially life threatening disease. Even if the discordant partners agree

on unsafe sex, the HIV-positive person can be prosecuted, because it's a criminal offence against the "health of the nation", prosecuted by the state and not by an individual. As Julian said, these cases are actually pursued (although the case-numbers dropped rapidly in the last few years, when other European countries just put laws targeting PLWHA in effect for the first time).
As Austrian AIDS-service-organisations we had and have to react to these laws. We cannot pretend that they do not exist. We always had to tell our clients to always use condoms or use only sexual practices that don't involve the risk of HIV-transmission. Disclosure on the other hand could and can be dealt with in a 1:1 counselling setting, because it does not play a role in the legal context.
I don't advocate criminal law as a way of positive prevention. On the other hand I'm raising the question if every AIDS-service-organisation should fight such laws in every situation and at all cost. Unfortunately deepening the discussion on this point will go beyond the scope of this meeting.

Addressing ethics
As mentioned on Wednesday, al lot of people working with PLWHA (social workers, psychologists, doctors, medical staff) feel that there is no way to ask your clients to always practice safer sex on one hand and provide a climate that is not-discriminating and non-judgemental on the other hand. They have been lobbying the human rights of PLWHA for years, including the right to free and self-determined sexuality. It is much easier to focus on the rights of your clients than on their responsibilities/obligations.
In meetings like this everybody wants to present his or her success-stories. I'll share a failure with you. In 2001 we produced a brochure titled "Safer Sex for PLWHA" (one MSM, one heterosexual version). Every client should get a copy of this brochure, handed out personally by the case-workers. A small survey in 2005 (60 questionnaires returned out of 200) showed that only 50% know the brochure – we definitely have to find new and better ways to talk about positive prevention more pro-actively.

The myth of shared responsibilities
It is difficult if not often impossible to share responsibility. It is an unrealistic – male – assumption that two individuals share the same opportunities to protect themselves. Gender, economy, violence, the measure of emotional involvement, alcohol and drugs are just some factors that determine a statement like "when having sex, both partners regardless of their HIV-status share the same responsibilities for safer sex" as one of little to no practical consequences.
As Gus said yesterday, the HIV-positive person knows something his or her partner doesn't know, and that therein lays power. I totally agree with him. We do not empower PLWHA by understanding and legitimising every action they take, especially if it is harmful to others. Instead we just do not take them seriously.
Whereas the discussion about shared responsibilities is a difficult one, it is no solution to practice the opposite: "If we can't share responsibility, then neither of us is responsible.".

Watering down prevention messages
In the late 80's the first prevention workers aimed to establish the use of condoms as the social norm. Epidemiology shows us that we have failed to reach this goal. In times of increasing numbers of new infections it seems rather contradictory to weaken that goal even more by introducing concepts like "negotiated safety" and "harm reduction" into the prevention discussion – again very male and therefore gay topics – heterosexual women know that they don't work. I myself am born in 1967, the last year before the pill was widely used in Austria. I owe my existence to the failing of "withdrawal".
We already talked about how important language is in dealing with these issues. Let me give you a few examples to think about:
We are talking about "safer" sex and not safe sex, when it comes to condom use. Yet we talk about negotiated "safety"
Concerning the misuse of the term "harm reduction" I want to translate a German saying for you: "There is no such thing as being a little bit pregnant".

Thank you for your interest."

5.3 Discussion points and questions

- We reflect too often on failures rather than successes.
- By adopting and promoting harm reduction strategies, are we watering down our prevention messages? Generally the group felt this was not the case as it was important to provide strategies and information for those men who don't use condoms. Harm reduction does work

at a public health level but on an individual level there are of course no guarantees.
- Negotiated safety was developed as a strategy from within the community, so was not a top down approach. It is a robust strategy for negative couples but not so much for positive couples because of the risks from other infections.
- There is very little work on positive prevention in health care settings in Austria. Doctors have very little time but are also unwilling to do it. There is only one adherence nurse in the whole of Vienna.
- The Austrian leaflets say that 'PLWHA have the responsibility to protect their partners'. It does also talk about the legal and health benefits of having safer sex but with the emphasis on responsibility. The majority of PLWHA in Austria support this approach.
- Sometimes those PLWHA who are most vocal are not representative of the views of the majority of PLWHA. We need to find ways of doing needs assessment that reaches further than the 'usual suspects'.
- The term 'shared responsibility' has been misused and interpreted. Some terms such as this can't just be transferred from one group to another.
- A Dutch study found that the amount of responsibility is negotiated between couples.
- We should be educating negative people about how to receive disclosure from PLWHA and support PLWHA when they disclose.
- We should also be rewarding PLWHA around safer sex and adherence, finding ways to congratulate them on protecting partners.
- More needs to be done to assess in what ways criminalisation impacts on sexual behaviour and testing.

Discussion on Criminalisation

This is becoming an increasingly important issue in different countries.
The discussion raised the following issues:

- Is criminalisation becoming a surrogate marker for how PLWHA are treated by the state?
- Does criminalisation legislation have implications for how we do our work in terms of public health?
- With the largening Europe, is possible new entrants may adopt the same laws but then use them more punitively and prosecute more.
- As HIV organisations we should stay updated on criminalisation issues and developments across Europe.
- The legislation is not specific to HIV and could be used in some countries for other STI's for example hepatitis.
- Messages should be generally applied as the issues are not unique to PLWHA.
- The views of HIV prevention organisations and legislators do not coincide. If as organisations we talk about withdrawl as a strategy we need to be aware of the legal context and implications. Could someone argue that he/she had seen an advert discussing withdrawal which had encouraged them to break the law?

Appendix 1: First Call European Expert Meeting on Positive Prevention

20050905/rbe.doc

November 9-11, 2005, Bergen, The Netherlands

Introduction
At the Open Forum in Brussels on AIDS Action in Europe (Brussels, March 2004) prevention activities aimed at people living with HIV/AIDS - Positive Prevention - has become one of the priorities in the Action Plan on the Rise of the Epidemic in Western Europe. Positive prevention and sexual health is targeted at policy and activities that focus on the needs of positive people keeping themselves healthy in an enabling society. This needs to be done, with recognition of the diversity of different groups positive people. And – naturally – this needs to be developed including and involving different groups of people living with HIV.

In order to develop Positive prevention and Sexual health the workshop concluded it is needed that:
- The underlying principles should be formulated & implemented
- Evidence & experience driven actions should be implemented
- Stimulate support of Self support groups & NGO's
- Disseminate information & access to help lines

AIDS Action Europe (the Pan European NGO Partnership on HIV and AIDS) and STI AIDS Netherlands take the initiative to organise a workshop on this issue in November 2005.

Aim

Subject	***Goal***
Policy	to exchange current policies on positive prevention
Interventions	to identify and discuss current evidence based interventions on positive prevention
Underlying principles	to formulate underlying principles on positive prevention
Further Action	to identify action that is needed on a European level on positive prevention

Format
A three-day expert meeting in November 2005 with a select group of professionals (approximately 45 in total, with a maximum of four per country) in order to exchange experiences with current challenges in the field of positive prevention, share knowledge (research) and discuss responses in policies and implementation. The results will be distributed throughout Western Europe.

Intended for
This meeting is intended for professionals working on, or planning to work on positive prevention in Western Europe. The main focus is on NGOs, but best practises can also come from other areas such as science or health care. They should focus on different groups for whom positive prevention is relevant: gay men, heterosexuals, IV-drug users and people coming from countries that are affected most by the epidemic. The primary region is Western Europe, which will not be defined very strict. The idea is to attract people from Norway, Sweden, Denmark, Finland, UK, Ireland, Germany, Austria, Switzerland, Italy, Spain, Portugal, France, Belgium, the Netherlands. If necessary the number of representatives of different countries will be limited in order to make participation possible for a large number of countries.

How
Thorough and solid preparation for the expert meeting by means of:
- preliminary reviews of, or introductions to, discussion topics as input and background for discussion (divide the production of reviews amongst participating organisations);

- focusing on a limited number (e.g. ten) of related issues.

Possible issues for the expert meeting:

1.	Effective policy and interventions for an effective support on sexual health and safer sex of people with HIV
2.	Positive social climate for people living with HIV/AIDS
3.	Integration of prevention in medical care for people living with HIV/AIDS
4.	Effective policy and interventions on HIV-testing

During the meeting:

- There will be discussion on a range of promising approaches, with strong efforts (commitment) being made to arrive at shared conclusions and recommendations.
- Preliminary reviews and introductions will form the basis for joint discussion and will not be too detailed so that there will still be plenty of time for mutual exchange of ideas.
- The meeting will not be limited to the perspective of health professionals and researchers, but will try to clarify and understand the perspectives and choices of PLWHA themselves.
- The meeting will serve as a tool to stimulate NGO responses on positive prevention in Europe.

Programme

Wednesday 9 November	16.00	Arrival, registration and check-in
	17.00	Opening and introduction
	19.30	Welcome and dinner
Thursday 10 November	10.00 - 18.00	Introductions and discussions
	19.30	Dinner
Friday 11 November	10.00 - 12.00	Introductions and discussions
	12.00 - 14.00	Closing session

Costs

Participation at this meeting is free, the organisation will pay for your accommodation in the Netherlands from 9 - 11 November. We expect participants to take care of - and to pay for - their own travel arrangements.

Venue

Blooming, Duinweg 5, 1861 GL Bergen, The Netherlands, Telephone + 31 72 5820582

Results and products:

- Background document (a reader containing reviews).
- Final report of the conference (publication in English).
- Small-scale follow-ups depending on the outcome of the meeting

Organisation

Aids Action Europe: Mr Ton Coenen
STI AIDS Netherlands: Mr Ronald Berends and Mrs Wilma van der Meijden

Contact

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Funding

Appendix 2: Program European Expert Meeting on Positive Prevention

20051990

Wednesday 9th of November 2005

Evening	Positive prevention in Europe Chairman: Mr. Ton Coenen
16.00	*Introduction* Aids Action Europe, Mr. Ton Coenen
16.10	*Positive prevention in the various countries in Europe, an overview* Participants explain the situation in their countries (State of affairs, initiatives, bottlenecks), All participants, interactive
17.45	*Prevention strategies for People with HIV*, keynote lecture International HIV/AIDS Alliance, Mr. Harry Walsh
18.30-18.45	*Identify major issues which needs to be addressed during this meeting*
20.15	diner

Thursday 10th of November 2005

8.00	Breakfast
Morning	Principles and Policy of PP in the different countries Europe Chairman: Mr. Robert Witlox
9.15	*Needs of PLWH and, Risks (stigma and responsibility) and peer support of the HIV community* Global Network of People living with HIV, Mr. Julian Hows
9.45	Workgroup 1: Formulating the principles of positive prevention (Mr. Robert Witlox) Workgroup 2: Formulating the necessary policy frameworks (Mr. Ton Coenen)
11.00	Tea break
11.15	Plenary discussion/ conclusions/ consensus
11.50	*Viral load and prevention* Mr. Rolf Appels
12.30	Lunch

Afternoon	Best practices in Positive prevention Chairman: Mr. Wim Zuilhof
13.30	*Sexual health support in HIV treatment settings* University of Maastricht, Mrs. Nicole van Kesteren
14.15	*Serosorting, Risk reduction strategies and disclosure in the Gay community* UK Coalition, Mr. Gus Cairns
15.00	*Advice for couples where one is HIV positive* Therence Higgins Trust, Mr. Will Nutland / Mr. Marc Tompson
15.45	Tea break
16.00	*Assessing European strategies to improve the sexual and reproductive health of PLWH (EUROSUPPORT V)* Institute of Tropical Medicine, Belgium/ Mrs. Christiana Nöstlinger
16.45 - 17.30	*Women and Hiv; European seminar* Mrs. Aurelie Verny
19.30	Diner

Friday 11th of November

08.00	Breakfast
Morning	**How to improve the Social climate for PLWHA** Chairman: Ton Coenen
09.15	*Creating a positive network of MSM* Gay and lesbian Health Norway, Mr. Jan R. Mietinen
09.35	*Improving the social climate: Ethical, moral and juridical aspects* Aids Hilfe Wien, Mrs. Claudia Kuderna
10.00	Discussion
11.00	Tea break
	To Identify further action needed on Positive Prevention Chairman: Mr. Ton Coenen
11.30	Plenary, closing session
12.30	Lunch

Appendix 3: list of participants

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