

EUROSUPPORT V

“Improving the sexual and reproductive health of persons living with HIV in Europe”

Institute of Tropical Medicine in
co-operation with SENSOA

NEWSLETTER 1

Summary Report on the EUROSUPPORT V kick-off meeting

Date and location: May 6 and 7, 2005,
Institute of Tropical Medicine, Antwerp; SENSOA, Antwerp;

Participants:

Present at meeting:	
Gabriele Schmied European Centre Social Welfare & Research Vienna - Austria	Graça Diogo-Gonçalves & Isabel Nabais Associadad para investigacao e desenvolvimento da faculdade de medicina (AIDFM) Lisboa - Portugal
Birgit Mumelter Medical University of Innsbruck Dept Medical Psychology and Psychotherapy Innsbruck - Austria	Danica Stanekova NRC HIV/AIDS Slovak Medical University Bratislava - Slovakia
Ivo Prochazka (Univerzita Karlova V Praze) Institute of Sexology Prague – Czech Republic	Victoria Gordillo Universidad Complutense de Madrid Faculty of Psychology Madrid - Spain
Nikos Dedes Synthesis Awareness, Research HIV AIDS Athens - Greece	Peter Csépe Semmelweis University/Dept. of Public Health Budapest - Hungary
Gloriana Bartoli University of Padova Comitato assistenza e ricerca AIDS pediatrico (CARAP) Padova - Italy	Iveta Kelle Latvia's Association for Family Planning and Sexual Health/PAPARDESZIEDS Riga - Latvia
Giulia Gallotta Fondazione Centro San Raffaelo del Monte Tabor Milan -Italy	Tomasz Niemiec & Asmaa el Midaoui Institute of Mother and Child Dept. of Obstetrics and Gyneacology Warsaw - Poland
Sibylle Nideröst University of Aargau Nordwestschweiz, Dept Soziale Arbeit BRUGG - Switzerland	Koen Block & Katy Declercq & Ruth Borms SENSOA Antwerp - Belgium
Christiana Nöstlinger & Bob Colebunders & Veronica van Wijk Institute of Tropical Medicine Antwerp - Belgium	
Not present at meeting	
Frank-Detlef Goebel LMU Munich München - Germany	Ed Wilkins Pennine Acute Hospitals NHS Trust Manchester – United Kingdom

Objectives of the meeting:

The meeting served as the kick-off event for the EUROSUPPORT V project on "Improving the sexual and reproductive health of persons living with HIV in Europe (PLWH)"; its objectives were to:

- Constitute the new ES V study-group on sexual and reproductive health (SRH) of PLWH, in particular to integrate the new members (in particular those representatives from organisations of countries recently having joined the EU);
- Build consensus among the ES V study group members regarding the project's research agenda;
- Discuss all relevant organizational and administrative topics;
- Constitute the project's steering group;
- Brainstorm on issues to be included in qualitative research and make a preliminary selection on issues to be included;

The meeting started out with a general introduction by *Bob Colebunders* on the EUROSUPPORT research and support initiative (see first two slides of the power point presentation / annex 1) and with a general introduction of all participants.

(1) Building consensus among the ES V study group members regarding the project's research agenda

Christiana Nöstlinger presented the general research agenda based on two documents, the approved proposal to the European Commission's Public Health Programme (DG V/SANCO) and a concept paper, which was prepared as a background document for the kick-off meeting (see attached annex 2).

The aim of this presentation was to translate the general research framework as presented in the original application into specific research questions, to introduce the research methodology to be adopted, and to have a general discussion on these topics.

During the morning session, two additional presentations were given to provide input and stimulate the discussion on secondary prevention and reduction of sexual risk behaviour as well as on fertility-related issues (→ see annex 3 and 4 respectively):

- Peter Csépe: HIV-risk behaviours among gay and bisexual men in Budapest, Hungary
- Tomasz Niemiec: Reproductive health of people living with HIV in Poland

Participants' statements about their main research interest in the topic of sexual and reproductive health of PLWH fuelled the general discussion on the research agenda and the specific topics of investigation. In what is to follow, we provide the key words mentioned by the participants:

Gloriana Bartoli, University of Padua (Padua, Italy):

SRH-issues relating to the target group of adolescents; understanding adolescent sexual behaviour and how it is affected by the experience of living with HIV; issues such as disclosure, social exclusion and how they influence sexual behaviour.

Giulia Gallotta, Fondazione Centro San Raffaele del Monte Tabor (Milan, Italy):

Secondary prevention of seroconcordant couples; counselling for child desire in seroconcordant couples; SRH of migrants and how does it differ from non-migrants (national citizens); implications for counselling.

Koen Block, Sensoa (Antwerp, Belgium):

SRH of men who are having sex with other men (MSM); how do they define their own risks (for themselves vs. risk for others)? Perceptions of risk behaviour (e.g. different sexual practices) and influencing factors on risk behaviour (alcohol and drug use, partners, sexual problems, "HIV-optimism"). Illusions of safety within stable relationships, differences between sexual behaviour within and without the context of a stable relationship;

Ruth Borms, Sensoa (Antwerp, Belgium):

Causes and effects of sexual problems and patients' own cognitions and perceptions about this; how does it affect counselling?

Katy Declercq, Sensoa (Antwerp, Belgium):

How to improve the communication related to sexuality, issues relating to migrant sexuality and risk behaviour, need for culturally sensitive campaigns for topics such as breast-feeding and involved risks of HIV-transmission.

Gabriele Schmied, European Centre for Social Welfare Policy and Research (Vienna, Austria):

Information and knowledge of HIV-positive women relating to body functions and HIV-transmission risks.

Birgit Mumelter, Medical University of Innsbruck Innsbruck, Austria):

Partnership related communication about sexuality and sexual behaviours, and safer sex behaviours including condom use; power-relationships, discordant couples; long-term progressors: how can they maintain safer sex practices over long periods of time, basically life-long? Need for improved guidelines.

Danica Stanekova, National Reference Centre HIV/Aids, Slovak Medical University (Bratislava, Slovak Republic):

Issues relating to social exclusion, legal issues; concern about sensitivity of the issues at stake; research should be framed in a way to help PLWH.

Ivo Prochazka, Institute of Sexology, Prague University (Prague, Czech Republic):

Knowledge of STI, HIV-risk among PLWH; heterosexualization of gay sex; different meanings of sexual practices for MSM (e.g. oral sex); emotional issues and intimacy; reproductive issues: dual use of contraceptives; legal issues.

Lazare Manirankunda, Institute of Tropical Medicine (Antwerp, Belgium):
SRH-related needs of migrants; cultural significance of fertility and pregnancy.

Sibylle Nideröst, University of Aargau (Aarau, Switzerland):
Risk behaviour of heterosexual men; desire to have children of men; changes in sexuality with serostatus; changes in body concepts and how this may affect sexual behaviour.

Iveta Kelle, Latvia's Association for Family Planning and Sexual Health (Riga, Latvia):
Information and support for PLWH, channels of information and how to reach them, discrimination and trust, risk behaviour of PLWH.

Graça Diogo-Goncalves/ Isabel Nabais, Hospital Santa Maria (Lisbon, Portugal):
Relationship between adherence and safer sex behaviour; body-changes due to ARV's and how this affects sexuality; sexual risk behaviour among newly infected people (young people, drug users); specific needs of illegal migrants with respect to SRH.

Tomasz Niemiec, Institute of Mother and Child (Warsaw, Poland):
SRH-related needs of adolescents living with HIV; adolescents living with HIV and their sexual behaviour (HIV-positive adolescents getting pregnant resulting in a second generation of HIV-infected children).

Asmaa el Midaoui, Institute of Mother and Child (Warsaw, Poland):
Impact of HIV on the family; family planning needs and assisted reproductive technologies.

Victoria Gordillo, Complutense University (Madrid, Spain):
Gender specific dimensions of sexual behaviour and problems. Heterogeneous groups of women living with HIV and their specific needs relating to SRH; cognitive skills needed for effective secondary prevention.

Nikos Dedes, Synthesis (Athens, Greece):
Role of health care providers and their perceptions; development of policy recommendations, developing guidelines on secondary prevention.

Peter Csépe, Semmelweis University, Department of Public Health (Budapest, Hungary):
Different kinds of risky behaviours (such as alcohol use and other more traditional risk factors) and their correlation with sexual risk behaviours.

From the subsequent discussion on these topics it has been concluded that there is a need to collect information on various background information, such as

- Legal regulations that shape the context in which PLWH are targeted for secondary prevention;
- National policies in which PLWH's sexuality is embedded (including access to contraceptives and abortion);
- Research carried out on these topics in the participating countries and regions (e.g. interventions)
- Guidelines that have been established with respect to these topics in the participating countries and regions

→ Consensus on the research agenda:

The ES V study group achieved consensus to adopt the research agenda and methodology as suggested and to carry out the research along the following research phases:

- Elicitation research (qualitative research using focus groups; hypothesis generating)
- Compiling evidence (quantitative research using a self-reported questionnaire)
- Assessing models of good practice (developing criteria and collecting models of best practice in the field of SRH and HIV).

→ Action 1 to be carried out:

The coordinating partners will review available documents (e.g. report compiled on legal issues and policies for the EU region); should the information available appear to be insufficient, the open questions will be summarized, and subsequently sent out to all partners with the request to review the situation and send respective materials.

→ Action 2 to be carried out:

The coordinating centre will finalize the research protocol on the basis of the consensus achieved and send it out to all project partners.

(2) Discussion of all relevant organizational and administrative issues

Organizational issues I: Project management

Christiana Nöstlinger presented an overview of organizational and administrative issues to the participants (see annex 5). The first topic referred to the project' management by work-packages and the project's milestones per work-package.

Organizational issues II: Financial issues

Budget as submitted to the European Commission

Veronica van Wijk presented the financial overview and the budget submitted to the European Commission. It was emphasized that the partners need to account for their own contribution as indicated in the budget by beneficiary form (budget form annex II c; see annex 6) and that this form will have to be signed by the person legally entitled to sign for the respective partners.

Partners will be requested to fill in time-sheets, preferably every 3 months to account for their input into the project.

Subcontractors

Subcontractors will receive an agreement between the ITM and their organization. This subcontract will stipulate the activities to be carried out and the payments as envisaged in the budget. The respective figures are based on those provided by organisations stemming from other New Member States. Negotiations with subcontractors took place during the preparation time of the proposal granting "best value for money". This process has to be documented towards the European Commission.

Additional own contributions and fund raising

In addition, the budget line "other funding application" was discussed. While the overall responsibility for raising the additional money needed lies with the main partner (=ITM), the associated partners were asked to contribute as much as possible in terms of fund-raising.

Subsequently, general principles of fund raising were discussed and the participants brainstormed on fund raising possibilities.

Several partners/countries saw concrete possibilities to raise additional funds or request sponsoring, such as for instance with national research foundations; ministries of health and/or social affairs and international companies (e.g. pharmaceuticals, producers of contraceptives and condoms). An application for a grant to be awarded to medical research with a profound social impact has already been submitted with the decision pending (June 2005).

Ideas on funding sources included among others:

- Application for grant in Belgium
- Private foundations
- Brochure, newsletter, conference: these products can be sold
- 'Unconditional grants': ask money from pharmaceutical companies
- Create folder for search extra funding: is being done by Christiana
- Private initiatives around World Aids Day or Aids Memorial Day
- International foundations
- Ministries of health, national science foundations,...
- Companies on contraceptives, Durex,...
- NGO's as IPM, IPPF,...
- Rotary, Lions

→ Consensus on fund raising:

It was decided that fund raising needed a coordinated approach; the following points were raised:

- The need to define which outputs of the project will eventually qualify for sponsoring (e.g. newsletter, best practice collection, project-related website; conferences and/or data workshops)
- It was agreed upon that unconditional sponsoring by pharmaceuticals was acceptable;
- International agencies such as pharmaceuticals should first be contacted on the international level and then on the national level by individual partners;
- The coordinating centre will approach international donor agencies and scientific foundations and the main associated partner (Sensoa), whereas the associated partners will approach national research foundations and private foundations.

→ Action 3 to be carried out:

The coordinating centre will finalize a brochure/folder on targeting potential sponsors and will compile a general fund raising letter, which can be used and adapted by all partners.

Organizational issues III: Setting up and expanding the EUROSUPPORT network

In this session, the networking structure of EUROSUPPORT V was introduced (see annex 7); it was pointed out that one of the project's objectives is to disseminate information beyond the EUROSUPPORT network to other relevant organizations active in the field of HIV and SRH. It is thus one of the tasks of the partners to act as a local/regional focal point to identify key organisations in their region/country; these organizations will be included in the project's channels of distributing project-related information and results. Each partner should identify at least 5 other relevant organisations or stakeholders.

Next, a suggestion for appointing members of the project's steering group was appointed. It was suggested that next to the main coordinating partner and the main associated partner, one or two partners from Western European countries, one or two partners from Central European countries, and one or two partners from Southern European countries should be represented in the project's steering group. This group should assist the coordinating partner in guiding the project and decision-making. Members of the steering group can rotate in order to enable other organization as well to be part of the steering group (e.g. Poland expressed interest, but is not available at the moment because of time constraints).

→ Consensus on project management:

There was no objection to the suggested managerial principles and networking issues raised; it was decided that participants would informally

talk about potential steering group members and agree on the steering group's composition the next day.

→ Consensus on the project's steering group:

On the meeting's second day, the following seven project partners were appointed to the steering group:

- ITM: Bob Colebunders, Christiana Nöstlinger
- Sensoa: Koen Block, Ruth Borms
- Medical University Innsbruck: Birgit Mumelter
- Fondazione Centro San Raffaele del Monte Tabor: Caterina Uberti
- Semmelweis University: Peter Csepe
- Synthesis: Nikos Dedes
- University Complutense Madrid: Victoria Gordillo

(3) Brainstorming on qualitative research and preliminary selection on topics to be included

The morning session started with a brief introduction on the methodology of focus groups (see annex 8).

Participants indicated potential focus groups that they could carry out in their own settings:

Country	Target groups
Austria/Innsbruck	Heterosexual men, migrant women, non-migrant heterosexual women
Austria/Vienna	Gay men
Italy/Padua	Adolescent girls, young men
Poland	Heterosexual women, adolescent women; sex-workers
Hungary	Gay men, bisexual men
Latvia	Heterosexual young men, heterosexual young women
Czech Republic	Homosexual men
Slovakia	Homosexual men
Portugal	Heterosexual migrant women, heterosexual non-migrant women; sex-workers
Belgium/ITG	Migrants (heterosexual men and heterosexual women)
Belgium/Sensoa	Homosexual men, homosexual young men
Spain	Heterosexual women, migrant women, homosexual men
Greece	Homosexual men
Switzerland	Heterosexual men, migrant women, non-migrant heterosexual women

General issues methodological issues discussed referred to:

- Identifying key informants for recruitment;

- Carrying out some biographical interviews to prepare for focus-groups;
- Considering a training workshop/capacity building for facilitators (for which extra funding would be needed);
- Necessity to define common selection criteria for inclusion of subjects into focus-groups, e.g. newly diagnosed vs. long-term progressors;
- Focus-groups should reflect the epidemic's profile, i.e. target the groups most at risk;

Participants then split up in four small working-groups to brainstorm on relevant issues to be included in the focus group research. Working-groups were assigned according to four different target-groups:

- Homosexual men
- Heterosexual men
- Heterosexual women
- Migrants

In what is to follow we present a short summary on each of the working group results.

3.1. Homosexual men

Organizational issues

Selection gay men for participating:

- Possible sites & modes: with the help of an NGO? Help of clinical staff? Recruiting in gay bars or other venues like bath? Ad in gay newspaper?
- Selection criteria: Age? Time of infection? Representative for any sub-groups?
- Incentives: No? Yes? If yes, which incentives?

Site of the group meeting

- NGO
- Clinical setting
- Academic setting
- Other like club, community venue, restaurant

Selection of leader of the focus group

- Skills needed?
- Should be a gay?

Modes of recording:

- Tape
- Notes
- Both

Information flow to the coordinating center

- Translation of the whole transcript?

- Analyzing and translating?

General principles, structure of the group meeting

1. Do not use direct questions at first!
2. Start with general questions, like lifestyle, way of living, free-time activities
3. Questions on relationships with:
 - Colleagues
 - Family
 - Friends
 - Female friends
 - Sex partners
 - Community (HIV positives, gays)
 - Health care workers
 - Social workers
4. Sensitive questions (knowledge, motivation, practice)
 - Number of partners
 - Number of occasional partners
 - Sexual identity (homosexual, bisexual)
 - Sexual practice (petting, oral, anal)
 - Safe sex issues (condom use, lubricants)
 - Changing in behavior after knowing HIV+ status
 - Different types of sexual partners (stable vs. occasional partners)
 - Sexual behaviours / context of sexual relationships
 - Agreements within relationships relating to safer sex

3.2. Heterosexual men

Information about sexual and reproductive health

- Do their health care providers talked to them about safer sex and sexuality?
- What do they know about possibilities to have children?
- What to the heterosexual HIV-positive men really know about super- and co-infections?
- Disclosure to partner(s)
- Communication about safer sex and sexuality: With whom they talk about their problems, fears and needs?
- Knowledge about HIV, condom use, sexuality with HIV

Sexual and Reproductive Health

- Experiences with sexuality before and after HIV-infection
- What is the meaning of sexuality?
- What importance has sexuality in their lives?
- What does sex mean to them? (only vaginal intercourse?)
- Child desire and reasons for child desire

Safer Sex and Risk behaviour

- Experiences with condom use
- How do they experience sex with condom?
- Attitudes about condoms
- Preparations/Condom planning: Do they always have condoms with them?
- Negotiations with partner and the role of partners willingness to use condoms
- The impact of stereotypic (health) beliefs on risk behaviour:
 - o E.g. beliefs like that they do not take any protection if they would have sex with a HIV-positive women
 - o Or beliefs about women like a woman who is ready for a one night stand is a slut anyway so I don't care if she got infected.
- The impact of different contexts or framings on risk behaviour (sex during holidays and at home, sex with a female sex worker and partner)
- Questions about responsibility of safer sex: Do they think that is in the responsibility of the partner to use condoms during sexual intercourse?
- Situational influences for having safer sex or unsafe sex: use of recreational drugs, use of alcohol, being in love, being aroused, being nervous, etc.

3.3. Heterosexual women

General framework

Underlying issues to be addressed should include:

- Gender equality in SRH
- Sexual relationships embedded in specific contexts
- Self esteem

Focus groups should use family planning needs (both with respect to desire to have children as well as contraceptive needs) as an entry point and assess both factors influencing sexual and reproductive health as well as needs (information needs, needs to develop specific skills, etc.)

Young people (adolescent women) need special consideration; specific questions to be developed;

Information and knowledge-related factors:

- What is the knowledge on contraceptives?
- Information on the options of having a child (MTCT, assisted reproductive technologies)
- Access to contraceptives (including emergency contraception)?
- Access to these services?
- What are preferred sources of information?
- Role of confidentiality

Motivation and attitudes:

- Impact of HIV on sexual behaviour
- Underlying economic issues
- Underlying power-issues in relationships (gender-dimensions)
- Influences of partnership-related characteristics on sexual behaviour (seroconcordant vs. serodiscordant couples)
- Sexual pleasure and how it does influence sexual behaviour (stereotypes such as condoms inhibit sexual pleasure)
- Self-esteem and self-value (how to convert self-esteem into skills?)

Behavioral skills:

- Problems with the use of contraceptives (dual contraception?)
- Problems with condom use
- Negotiation of condom use (how can you propose condom-use to a partner?)
- Disclosure and communication skills about HIV?
- What are preferred sources of skills building?
- Potential role of support groups?

3.4. Migrants

Potential target-groups:

Groups of men and women, French speaking, English speaking, Portuguese speaking, female sex workers;

Topics to be addressed:

- 1) Barriers o condom use; information about female condom (access, acceptability, availability, experience)
- 2) How o empower women regarding communication on sexual behaviour, condom use...
- 3) How to combine HIV-prevention and desire of having children in both serodiscordant and seroconcordant couples?
- 4) How to improve acceptability of HIV and reduce stigma?
- 5) How to disclose HIV to an intimate partner?
- 6) The influence of traditional medicine and spiritual healing on sexual behaviour?
- 7) Information needs about contraception (access, barriers, attitudes)?
- 8) How do migrants perceive the prevention messages provided in European countries?
- 9) Who has influence on migrants with regard to prevention (where does the information come from, e.g. nurses, doctors, peers, media, etc.)?

→ Consensus on the focus-group research:

- Each partners will envisage to carry a number of focus-groups according to the partner's potentials, accessibility of target-groups in the country/region (see table above);
- Content-analysis of focus-groups will be carried out by the partners themselves, in order to avoid costly translation of focus-group transcripts into English. Translations would also results in losing information. A common data-analyzing matrix will be developed to build content-related categories. Qualitative data will be analyzed by at least two independent raters to increase reliability. The result of the content-analysis will be translated into English by the partners to allow for overall summary and comparison across countries.
- The coordinating partners will prepare a manual on the focus-group methodology;
- The needs and feasibility of capacity building seminar will be further investigated, however, contingent on the financial requirements.

→ Action 4 to be carried out:

- Integrate the suggestions of the working-groups into draft guidelines for focus-group research in the envisaged target-groups (coordinating partners)

→ Action 5 to be carried out:

- Investigate potential additional fund-raising for capacity building seminar (coordinating partners; partners on national and regional levels)

→ Action 6 to be carried out:

- Consult expert advice for relevant decisions on how to best carry out the analysis of the focus-groups based on the current suggestions (i.e. consulting experts); (coordinating partners)

(4) Minutes of the steering group meeting

The steering group met to debrief on all the issues relevant to planning the next concrete project-related steps.

All the actions were summarized and confirmed (see above actions 1 to 6); in addition the following points were discussed in more detail:

4.1. Focus-group research

- Setting up a training manual for focus groups research;
- Setting up guidelines for the qualitative analysis to be carried out in the countries;
- Drafting a short demographic form for focus groups participants (Koen Block);
- Drafting an oral consent form for participants (Birgit Mumelter);
- Considering reimbursements and incentives for participants;
- Share the experiences of the first focus-groups conducted with the whole project group

4.2. Quantitative research

- Considering incentives for clinic staff to distribute questionnaires (second phase of data assessment);
- Considering different questionnaire modules for different target-groups to be included in the quantitative data-collection, however contingent on the outcomes of the focus-group research;

4.3. Networking issues

- Create a mailing list with all the project partners.
- Try to improve the participation in this mailing list and to improve exchange of information between the partners to have a lively and interactive network.

Annexes

- Annex 1: Presentation on research agenda
- Annex 2: Concept paper
- Annex 3: Presentation Peter Csépe
- Annex 4: Presentation Tomasz Niemiec
- Annex 5: Presentation on project management
- Annex 6: Budget forms as provided during the meeting
- Annex 7: Presentation on ES V networking structure
- Annex 8: Brief introduction on focus group methodology
- Annex 9: List of ES V participants