

Correlation Conference:
12-14 December 2011, Ljubljana, Slovenia



From Culturally-sensitive to Community-based?
Workshop organised by the BORDERNETwork Project
13 December 2011, 14:30-16:00 h

SPI Forschung, Berlin
Elfriede Steffan, Tzvetina Arsova Netzelmann
HESED, Sofia
Radostina Antonova



BORDERNETwork Workshop
From Culturally-sensitive to Community-based?
Participatory HIV/STI prevention with ethnic minorities and migrant communities

OBJECTIVE

To foster exchange on effective working concepts, to consolidate practice evidence for participatory involvement of marginalised communities in HIV/STI prevention, and to advance discussion among prevention practitioners, researchers and policy makers.

OUTLINE

- I. BORDERNETwork in focus: brief overview
- II. WP8 in focus : participatory community-based prevention in migrants/ethnic minorities
- III. Definitions in focus: Migrants, Ethnic minorities, Diversity, Complexity
- IV. Key Terms : from culturally-sensitive via cultural competence to community-based participatory HIV prevention with migrants and ethnic minorities
- V. Results
- VI. Challenges: points for discussion
- VII. The POL model – evidence of effective community-based prevention in Roma community through social networking and participation



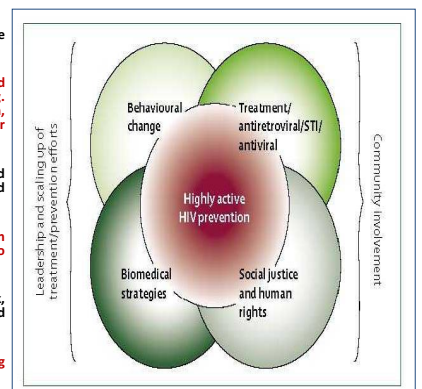
I.BORDERNETwork in focus: brief overview



I.BORDERNETwork in focus: brief overview

Highly active prevention: cornerstone of the project's philosophy!

- > Address both direct disease causes and underlying social determinants of health (e.g. low social economic status, stigmatization, recent migration, frequent mobility) for behavioural change;
- > Enhance links between epidemiological and behavioural research and evidence-based interventions;
- > Integrating stand-alone measures in prevention, diagnostic, therapy and care into holistic approach;
- > Focus on affected and groups at risk, promoting equity, human rights and participation;
- > Mobilisation of civil society as major driving force of local response



Source: *Highly Active Prevention* (Coates, Richter et al.), 2008

I. BORDERNETwork in focus: brief overview

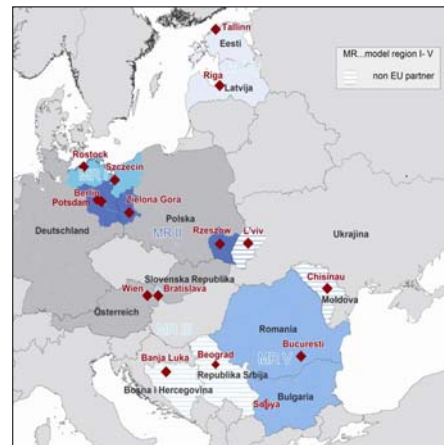
Partner Network

- **13 Partners from 8 EU countries, 6 of them CEE countries:**
Main partner/Co-ordinator: SPI Forschung, Berlin (DE)
- 12 Associated Partners:
 - 3 GOs: RKI, Berlin (DE), NIHD, Tallinn, (EE), SPWSZ, Stettin(PL)
 - 9 NGOs: AHW, Vienna (AT), HESED, Sofia (BG), AISC, Tallinn (EE), Papardes Zieds, Riga (LV); MAT, Rostock (DE), AHP, Potsdam (DE), POMOST, Rzeszow (PL), ARAS, Bucharest (RO), PRIMA, Bratislava (SK)
- **18 Collaborating partners from 8 EU and 3 NON-EU countries**
- **Fact Finding Missions (subcontracts) in 4 ENP countries: Moldova, Serbia, Bosnia and Herzegovina and Ukraine**

I. BORDERNETwork in focus: brief overview

The 5 Cross-border Model Regions:

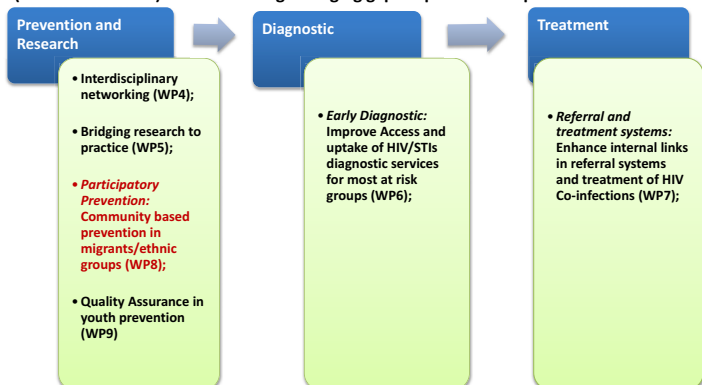
- MR I: Germany-Poland**
- MR II: Germany-Poland**
- MR III: Austria-Slovak Republic**
- MR IV: Latvia – Estonia**
- MR V: Bulgaria and Romania**



I. BORDERNETwork in focus: brief overview

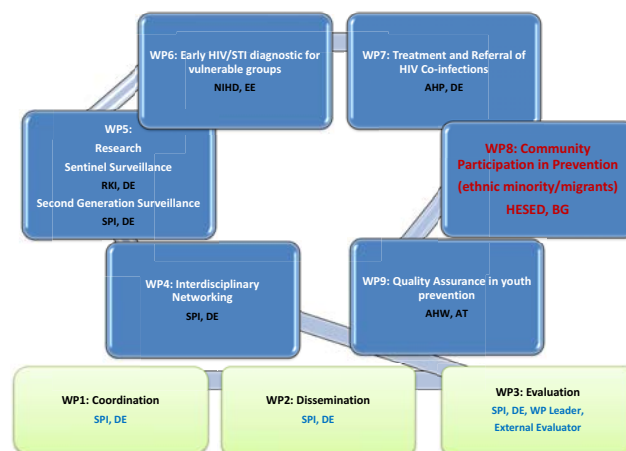
Goal and Objectives:

To improve the nexus between prevention, diagnostic and treatment of HIV/AIDS (incl. co-infections) and STIs through bridging gaps in practice and policies



I. BORDERNETwork in focus: brief overview

Action plan: **Horizontal** and **Core** Work Packages





II. WP8 in focus : Participatory community-based prevention in migrants/ethnic minorities

Objective

To improve HIV/STIs in two-and-a half-years period community based prevention and sexual health for ethnic minorities (e.g. ROMA) and migrant groups through capacity building in participatory prevention models

Process indicators:

- I. Different models of community based HIV prevention for ethnic minorities/ migrants are peer reviewed by other experts and assessed by BORDERNETwork partners.
- II. Relevant ethnic community members and migrant groups are involved in needs assessment, planning, implementation and evaluation of interventions on ongoing basis in the partner countries.

Output indicator:

20 multipliers are trained (2 training seminars) in 3 good practice models of participatory HIV prevention among ethnic minority/migrant groups.

Outcome Indicator:

Training programmes in community HIV prevention among ethnic minority and migrant groups are available, developed by 70% of partners participating in WP8 based on the published manual in 2012.



II. WP8 in focus : Participatory community-based prevention in migrants/ethnic minorities Methods , results and expected outcomes

Assessment Survey on Participatory HIV/AIDS/STI prevention measures for ethnic minorities and migrant groups with participation of 8 NGOs from 6 EU and 2 NON-EU countries: *Assessment Report (Point V. Results and at Social Dialogue Market)*

Review and Outline of 4 good practice models of effective HIV/STI prevention with migrants/ethnic minority communities:

Parc Project/Austria; POL Model /Bulgaria; Aids&Mobility Project/Piloted in Estonia; PaKoMi Project/Germany

2 Competence Building Seminars (based on 3 models) for participatory community-based HIV/STI prevention with participation of 37 prevention workers and community members (7 EU and 2 Non-EU countries): *Deliverable (at Social Dialogue Market)*

Good-practice manual in participatory community-based HIV/STI prevention for ethnic minority/migrant communities - *to come by mid 2012*

III. Definitions in focus: Migrants, Ethnic minorities, Diversity, Complexity

Background

- Europe wide: lack of uniformity in the applied definitions
- Latest ECDC Report (2011): no universally accepted definition of **MIGRANTS** and **ETHNIC MINORITIES** exists
- Different meanings in different countries: challenge to comparability and transfer of practice models/results

Definitions (selected)

• Migrant/regularised/'legal' migrant

„Any person who changes his/her country of usual residence“ (UN, 1998)

• Irregular/undocumented/'illegal' migrant

„...someone who, owing to illegal entry or the expiry of his/her visa lacks legal status in transit or host country“ (IOM,2004)

• Long-term migrant

„A person who movers to a country other than of his/her usual residence for a period of at least a year (12 months)“ (UNDESA, 1998)



Source: European Centre for Disease Prevention and Control. Improving HIV data comparability in migrant populations and ethnic minorities in EU/EEA/EFTA countries: findings from a literature review and expert panel. Stockholm: ECDC; 2011.

III. Definitions in focus: Migrants, Ethnic minorities, Diversity, Complexity

Definitions (selected)

Ethnic Minority/ethnic origin

Refers to both citizens (nationals) of Member States and non-citizens (non-nationals) who consider themselves as having, or are considered by others to have, identifiable group characteristics with respect to, e.g. shared language, religion and cultural practices (RAXEN, EU Agency for Fundamental Rights (FRA))

Long-standing minority of nationals

„Being born in the country of residence and having ever been part of the country's population (Roma ethnic minority)“

Long-standing minority of non-nationals:

„Socially, culturally, ethnically distinct group of residents who are non-nationals, but who are also non-migrants („black British“, „Turkish German“)“

Complexity

- How long does it take before a group ceases to be defined as a migrant?
- Emerging patterns of globalisation and mobility: tourists, frequent travellers or migrants?



Source: European Centre for Disease Prevention and Control. Improving HIV data comparability in migrant populations and ethnic minorities in EU/EEA/EFTA countries: findings from a literature review and expert panel. Stockholm: ECDC; 2011.

III. Definitions in focus: Ethnic group and Community

Ethnic (minority) Group (Harding et al, 1968)

„Collection of people considered both by themselves and by other people to have in common one or more of the following characteristics:

- 1) religion
- 2) racial origin
- 3) national origin
- 4) language
- 5) cultural tradition”



III. Definitions in focus: Ethnic group and Community

The concept of Community (Glanz et al, 2008)

- Typically defined in geographical terms...
- May be based on shared interests or characteristics as ethnic background, sexual orientation, occupation

Communities are also...

- (1) Functional spatial units meeting basic needs for sustenance
- (2) Units of patterned social interaction
- (3) Symbolic units of collective identity
- (4) Social (virtual) units where people come together politically to make changes



- **Most important attribute:** self-defined as pertaining to one and a same community and not defined from outside (target group)
- **Trigger point for community-based participation:** self-determination and decision power

Source: Health Behaviour and Health Education: Theory, Research and Practice (4th Edition, 2008)

IV. Key Terms

Abundance and tangle of notions, terms and approaches:
challenge to synchronization

CuLTural aWareness
 CultuRal huNger; **Culturally-seNsitive**
cuLtural competence; cUltUrally- apPropRiate
CULTURAL INTEGRITY;
comMuniTy-orieNted;
Culturally-tailored, Migrant-friendly;
communiTy-Based
cUltural Humility
CoMmunity ParticiPation

LOST in TRANSLATION?

IV. Key Terms

• Cultural Competence (Cross et al, 1989)

- Set of congruent behaviours, attitudes and policies that come together in a system enabling effective work in cross-cultural settings.

- Ability to interact effectively with people from different cultures

- Five essential elements:

1. **Valuing** diversity;
2. **Conducting** cultural self-assessment
3. **Managing** the dynamics of difference
4. **Acquiring** and institutionalizing cultural knowledge
5. **Adapting** to diversity and the cultural context of the community

- This is a generally accepted and adapted (90ies, 2000) definition, based on the awareness-knowledge-skills models



Does it suffice?

IV. Key Terms

The difference between intellectually knowing another culture and being able truly to relate to it

Cultural Competence

vs.

Cultural Humility

- Assumes that individual knowledge and self-confidence are sufficient for change - risk to oversimplify both culture and competence:
 - Culture is perceived predominantly as matter of ethnicity, does not encompass gender, age, socio-economic status, education, sexual orientation, faith
 - Culture is seen ONLY as the domain of the OTHER (the ethnically different) - Other is/has a problem - ethnocentric standpoint of „the white, western, middle-class, high-educated majority“ (Kumas-Tan, Z. et al, 2007)
- Does not reflect the imbalance, power inequalities and oppressive social relations across cultures, communities, and social groups - can hamper true openness, participation and decision power of the culturally different communities



- The 'conscious incompetence' (Papadopoulos et al, 2003)
- The acknowledgement of the gaps in one's knowledge and own barriers to true intercultural understanding (Levi, A., 2009)
- The need to a lifelong commitment to self-reflection, evaluation and self-critique, to redressing the power imbalances in the encounter of different cultures in social and professional settings (Tervalon M, Murray-Garcia J., 1998)

V. Results

BORDERNetwork Assessment Survey aimed to:

- study HIV/STIs prevention interventions among:
 - Roma communities (Bulgaria, Romania, Serbia, Slovak republic, Latvia)
 - Russian minority (Estonia)
 - Sub-Saharan African communities (Austria, Germany)
 - MSM, female and male SWs with migrant/minority background (Germany, Bulgaria, Serbia, Bosnia and Herzegovina)
 - IDUs (Latvia, Slovakia, Romania)
- assess and select prevention models with special focus on levels of participation, community-development and quality assurance of the interventions;
- reinforce the construction and exchange in an expert network among NGOs from 7 EU and 2 ENP countries

V. Results: Background Context

- Shared understanding of social inequity as one of the major drivers of HIV vulnerability of migrants/ethnic minorities;
- Similar features of social context and community structure in all studied countries underlie high level of vulnerability of the respective communities:

- Social exclusion
- Poverty
- Patriarchal/traditional culture and/or cultural taboos and barriers
- Insufficient education and/or poor knowledge of the official language
- Lack of trusted channels for HIV/AIDS prevention
- Lack of knowledge about HIV prevalence among the groups
- Lack/insufficient involvement of community-based (CBO) organisations/migrant-self- organisations (MSO) in HIV prevention

„People in our community are not vulnerable, they are faithful to each other; condoms are needless and HIV testing is so, too“ (experience from Romanian project ARAS).

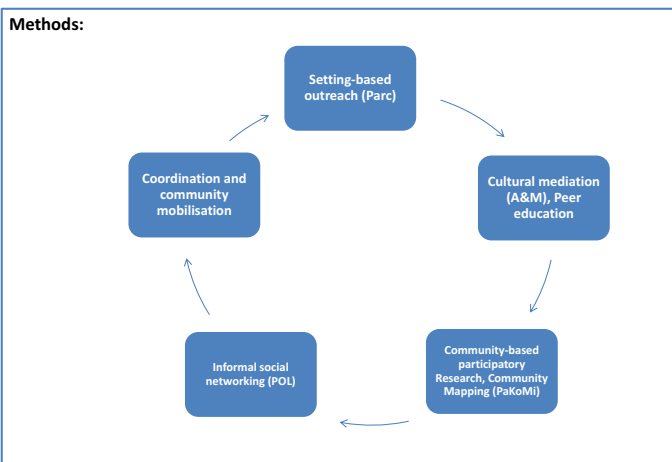
V. Results: Concepts and approaches

- Apparent similarities in conceptual notions of cultural competence:
 - Addressing similar communities (to great extend) in a "culturally-competent" manner through:
 - specialty tailored services;
 - (active) involvement of the target communities in the teams
 - reflection of language, culture and tradition
- ...but great divergences along the line of community involvement and level of participation:
 - Do translation and test pilot of migrant-specific information materials alone suffice?
 - Does one community representative stand for the "Community"?
 - Is any kind of involvement of the migrant community a "participatory" and "community-based" per se?
 - Single-off contacts during community outreach work or education session vs. social networking and self-help group of community representatives?

"We work with them and not for them" (Experience of JAZAS, Serbia)



V. Results: Methods



V. Results: Methods

Teams:

- Multi-cultural and multi-disciplinary teams: basic prerequisite for success

Experts: health professionals, psychologists, social workers, researchers

Community Leaders: are to be consulted not only as "gate keepers/openers"

Community members: peers, outreach workers, mediators, health assistance, community researchers etc.

Concepts of training and sustainability:

- training programmes – not always consulted and tailored up to needs of target communities;
- volume of training – from low- to high-threshold (50 hours training curriculum)
- Profoundness and sustainability of measures - single-off "event" type of community sessions or continuous gradually deepening involvement of community through series of events: "mapping", individual talks, group sessions, contacts and attendance of health care service

V. Results: Quality Assurance

- Often used indicators: quantitative measurement of intervention's scope of reach**
 - Number of people reached;
 - Number of mediators/peers trained;
 - Mediators certified;
 - Community sessions held;
 - Hours referees worked;
 - Number of settings (e.g. parks, clubs, events) covered;
 - Number of brochures and number of condoms disseminated;
 - Average duration of intervention
 - Seldom/not used indicators: although applied not valued as a quality indicator for community-based participation**
 - Proportion of the community's participation – diverse roles and decision-making practiced by the community
 - Feedback (level of satisfaction) of community and evaluation of interventions.
- Do not involve community representatives for the sake of their representation, rather identify the appropriate ones first: what are their resources, their strengths, their motivation, why should they engage with?**

VI. Challenges : Community-based participation

Community-based participation (Israel, 2003)
 "facilitates collaborative, equitable partnerships in all phases..."

Proportion of participation/Stage model of participation (Wright, Block, von Unger 2010, WZB)

In all stages of intervention/research: from problem definition and needs assessment to equitable team members and equitable share in decision making about planning interventions, implementation and evaluation of results

Stage	Description	Participation Level
Stage 9	Self-Organization	Goes beyond participation
Stage 8	Decision-making power	Participation
Stage 7	Partial decision-making power	
Stage 6	Co-determination	
Stage 5	Inclusion	Preliminary Stages of Participation
Stage 4	Hearing	
Stage 3	Information	
Stage 2	Directive	Non-Participation
Stage 1	Instrumentalization	

VI. Challenges : Community-based participation

Some necessary prerequisites:

- Available structure and infrastructure of the community: existing, concentrated or dispersed, self-defined/self-organised, closed or open, permeable and accessible or tight and rigid borders?;
- Openness and trust to the available community resources: lived experience expertise ;
- Sitting on the same table and being on the same page with all relevant stakeholders – community, experts, health/social care services, local decision and policy makers
- Mutual respect and readiness for joint working –“co-producing” of the social change

VI. Challenges : Community-based participation

Some limitations:

- Not all interventions can reach high proportion of participation of the community right from the pilot test;
- By strongly marginalized (Roma) communities, integrated stigma and negative community self-image can hamper the trust in own decision-power, participation and change potential;
- In contexts of increased economic/political hardship priorities within the communities are put on survival skills vs. longer-term community participation/development
- Naturally the grade of participation varies back and forth – so the grade of community-involvement, community-centeredness and community-based character of the interventions.
- Some project's touch upon only the community tangents (though community-friendly and culturally competent), others try to cross the entry gates, while third rely for their implementation fully on the internal resources of the community itself (community self-organisation)



What do we learn from that?

VI. Challenges : points of discussion

- **How much participation is enough?**
 - What is a minimum standard (cannot do without)?
 - What is a golden standard (better to target it next time)?
- **What are the difficulties/barriers for migrant/ethnic minority community participation?**
 - from the standpoint of the communities
 - from the standpoint of the experts/projects/NGOs/CBOs
 - from the standpoint of society and politics
- **What are the advantages of migrant/ethnic minority community participation?**
 - from the standpoint of the communities
 - from the standpoint of the experts/projects/NGOs/CBOs
 - from the standpoint of society and politics

THANKS TO:

Team of HESED, lead partner of WP8:

Radostina Antonova
Milena Mihaylova
Silvia Vassielva

All survey participants:

AHW, Vienna
AISC, Tallinn
ARAS, Bucharest
DAH, Berlin
JAZAS, Belgrade
Papardes Zieds, Riga
PRIMA, Bratislava
PROI, Sarajevo

The projects/organisations, having delivered their good practice models:

A&M/AISC
Parc /AHW
PaKoMi/DAH
POL/HESED

Teams and community members from the participating migrant/ethnic minority communities

Co-funded by the European Union, in the framework of the Health Programme.
The sole responsibility of any use that may be made of the information lies with the author SPI Forschung gGmbH

**Thank you very much
for your attention!**

**Tzvetina Arsova Netzelmann
Elfriede Steffan**

SPI Forschung gGmbH, Berlin, Germany
www.bordnet.eu

Co-funded by the European Union, in the framework of the Health Programme.
The sole responsibility of any use that may be made of the
information lies with the author SPI Forschung gGmbH



(1) How much participation is enough?

- Minimum standard (cannot do without)?
- Golden standard (better to target it next time)?

(2) What are the difficulties/barriers for migrant/ethnic minority community participation?

- from the standpoint of the communities
- from the standpoint of the experts/projects/NGOs/CBOs
- from the standpoint of society and politics

(3) What are the advantages of migrant/ethnic minority community participation?

- from the standpoint of the communities
- from the standpoint of the experts/projects/NGOs/CBOs
- from the standpoint of society and politics