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**CROSSING BORDERS,  
BUILDING BRIDGES**

From Culturally Sensitive to Community-Based

A Practical Manual on Effective Models of Participatory  
Community-Based HIV/STI Prevention in Migrants/Ethnic  
Minorities

BORDERNETwork Package 8



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Highly active prevention: scale up HIV/AIDS/STI prevention, diagnostic and therapy across sectors and borders in CEE and SEE

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# Abbreviations

A & M	AIDS & Mobility
AHW	Aids Hilfe Wien
AICS	AIDS Information and Support Centre
AIDS	Acquired Immune-Deficiency Syndrome
ARVT	Antiretroviral Therapy
ASO	AIDS Service Organisation
CAIR	Center for AIDS Intervention Research
CBO	Community-Based Organisation
CBPR	Community-Based Prevention Research
CS	Community Sessions
CSF	Civil Society Forum
CSWs	Commercial Sex Workers
DAH	Deutsche AIDS-Hilfe
ECDC	European Centre of Disease of Control
EMZ	Ethno-Medizinisches Zentrum
EU	European Union
GFATM	Global Fund to fight AIDS, Tuberculosis and Malaria
HESED	Health and Social Development Foundation
HIV	Human Immune-Deficiency Virus
KAB	Knowledge, Attitude, Behaviour
MAP	Migranten AIDS-Projekt
MIMI	Mit Migranten für Migranten
MRM	Minor Roma Men
MSM	Men who have Sex with Men
MSO	Migrant Service Organization
NGO	Non-Government Organization
PaKoMi	Partizipation und Kooperation in der HIV Prävention mit Migrantinnen und Migranten (Participation and Cooperation in HIV Prevention with Migrants)
PARC	Prevention of AIDS with the Resources of Communities
POL	Popular Opinion Leader
SES	Socio-economic Status
STI	Sexual Transmitted Infection
VCT	Voluntary Counselling and Testing
WP	Work Package
WZB	Wissenschaftszentrum Berlin

# From Culturally Sensitive to Community-Based

## A PRACTICAL MANUAL

On Effective Models of Participatory Community-Based  
HIV/STI Prevention in Migrants/Ethnic Minorities



# Introduction

## **Why a Manual on community-based participatory prevention approaches? Background and rationale**

The dissemination of the scientifically and practically proven efficacy of HIV prevention models among ethnic minorities and migrant communities is urgently needed for all countries in Europe.

Community-based participatory prevention approaches prove high relevance in this regard, as they do not merely address affected migrant and ethnic minority groups as stakeholders, but involve them as co-authors and social agents of change throughout the whole process. Hereby participation, empowerment and ownership of the developed models by the communities are vital to success and sustainability of the interventions implemented and of primary concern for both prevention experts and community's representatives. However profound participatory community-based prevention models with migrants/ethnic minority communities remain still a challenge putting more questions than providing answers, e.g.: *Is any kind of participation per se community-based? When does a prevention model become not only community-friendly and culturally sensitive but community-based? How much participation is needed?*

The EU-funded project<sup>1</sup> BORDERNETwork has devoted one of its cooperation areas (WP8)<sup>2</sup> to this challenging task, tackling the improvement of community-based HIV/STIs prevention and sexual health for ethnic minorities as well as migrant groups. For a two-and-a-half-year period an important task of the WP8 activities has been to reinforce the network exchange and capacity building among civil society organizations (NGOs and CBOs) from eight EU and two NON-EU countries (from the Western Balkan Region) in order to translate the good practice experiences of different community-based HIV prevention models for ethnic minorities (in particular the Roma community) and migrant groups.

The main objective of the BORDERNETwork cooperation under WP8 was to participatory study, assess and select HIV/STI prevention models with special focus on levels of participation of the communities involved, community development and quality assurance. The collective outcome of this process is the present good practice manual.

## **Partners**

Participating countries and organizations in WP8:

- Austria – Aids Hilfe Wien (AHW); Vienna, associated partner
- Bosnia and Herzegovina – Association PROI, Sarajevo; NON-EU expert
- Bulgaria –Health and Social Development Foundation (HESED), Sofia; leader of the WP8
- Estonia – AIDS Information and Support Centre (AISC), Tallinn; associated partner
- Germany – Deutsche AIDS-Hilfe (DAH), Berlin, collaborating partner
- Latvia – Papardes Zieds, Riga, associated partner
- Romania - Romanian Association against AIDS (ARAS), Bucharest; associated partner
- Serbia – JAZAS, Belgrade; NON-EU expert
- Slovakia – PRIMA, Bratislava; associated partner
- The Netherlands - CORRELATION II project network; collaborating partner

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<sup>2</sup> WP8 – Work package 8



## Activities

A desk review, an assessment survey and two capacity-building trainings were conducted as the main instruments of WP8 to fulfill the objective.

During the period of March-June 2010 the desk review of relevant actions at EU level was conducted to identify the existing HIV programmes for ethnic minority (especially Roma community) and migrant groups. 167 items (reports, articles, materials, projects, surveys and researches) were examined.

The majority of the reviewed materials were reports and action plans for HIV prevention work among migrants (mostly with African origin) in Europe. The collected data about the Roma in Europe, particularly in Central and Eastern Europe, shows the vulnerability of this community to HIV transmission and the lack of effective and evidence - based interventions in this field.

Based on this desk review several needs in the HIV/AIDS prevention field for ethnic minorities and migrant groups were identified. One of the important findings was the need to develop models of good practice, evaluation and methods of interventions in the field on the basis of an analysis of studies carried out among migrants and ethnic minorities.

This finding resulted in an assessment survey on models of participatory HIV prevention among ethnic/migrant groups with involvement of all WP8 partners. Related to this area, definitions and information about the ethnic/migrant groups represented in the given states and target groups of the NGO's HIV prevention programmes were gathered as well as basic information about the participating NGOs.

The results of the assessment survey showed the variety of methods and approaches in the field of HIV-prevention among ethnic and migrant communities and outlined directions for future improvement in this area.

Some of the most significant conclusions of the assessment survey demonstrated that although there are a lot of similarities between target groups and implemented models, there is no single method or model, adequate for all the situations and target groups mentioned above. All presented interventions are in a process of development and improvement in order to better meet the needs of the target populations. There is a vast range of model's strengths that could be outlined as good practices in the field of HIV/AIDS prevention.

Furthermore, all successful models collected through the survey emphasize several important points that could be implemented regardless of the target population, such as a combination of research of the community features related to the risky behaviour and activities directed to easily change factors in the community and in the individuals; involving representatives of the target population in the programme activities, long-term delivering of HIV prevention services etc.

Exchange and capacity building seminars are crucial elements to reinforce the expert dialogue regarding NGOs' experience in developing, implementing and evaluating models of participatory HIV preventions among ethnic/migrant groups. Thus in a next step a training in the evidence-based participatory model of prevention POL<sup>3</sup> (led by HESED) and a capacity building seminar in three further HIV prevention models (led by Deutsche AIDS-Hilfe Berlin, Aids Hilfe Wien and AICS Tallinn) were conducted by BORDERNETwork. The **POL** model emphasizes the most important features of the participatory approach: the structured gathering of information about the community norms and leadership, involvement of informal community leaders in the innovation process, use of natural communication ways and channels, investment of resources in the community strengths and measurable qualitative and quantitative indicators for the effectiveness of the intervention.

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<sup>3</sup> POL – Popular Opinion Leader

The other three models – **PaKoMi** project of the Deutsche AIDS-Hilfe, Berlin, **PARC** project of AIDS-Hilfe Wien and **AIDS & Mobility** project of AICS, Tallinn are unexceptional examples of HIV prevention interventions with migrants/ethnic minority groups based on the participatory approach.

They are all described in detail in the presented practical manual on effective participatory community-based approaches of HIV prevention for ethnic minorities and migrant groups.

## Definitions of Community, Ethnic Minority and Migrant Group

Seeking for basic and crucial factors to develop effective and adequate HIV prevention programmes, we can learn from the fundamental principles of effective community health education. These principles may be relevant for HIV prevention in ethnic minorities and migrant groups being targeted in Work package 8 of BORDERNETwork.

### Community

Ethnic minorities and migrant groups are not communities per se, nevertheless they can show characteristics of a community. So first of all we have to clarify what is meant by a “community”. Several definitions do exist, but the concept of community in this manual is based on the definition by Glanz et al. (2008), who offers two main distinguishing features:

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

Starting from these two different features, a more detailed definition includes the four following aspects:

Communities are also...

- 1) Functional spatial units meeting basic needs for sustenance
- 2) Units of patterned social interaction
- 3) Symbolic units of collective identity (Hunter 1975)
- 4) Social (virtual) units where people come together politically to make changes (West 1993)

Two conceptual sets are relevant, when explaining the term “community”. *The ecological system perspective* is focusing on population characteristics such as size, density, and heterogeneity, and the physical environment. In contrast the *social systems perspective* focuses primarily on formal organisations that operate within a given community and is exploring the interactions of community subsystems (economic, political etc.).

For the work with communities described in our manual the *social systems perspective* is highly relevant, because it includes a broader approach and is dealing with socioeconomic issues, which have a strong impact on local communities (Minkler, Wallerstein, Wilson 2008). Social change has been pointed out (West 1993) as a specific view to evaluate a community and this can be best achieved when building on pre-existing social networks and structures as well as self-determination and empowerment are being encouraged (Gutierrez and Lewis, 2004).

In the context of optimizing HIV prevention **community organization** and **community building** are crucial factors. Although different models have been developed, older models may be particularly problematic, as organizing increasingly occurs in multicultural context.

The newer **community-building** models emphasize community strengths as a diversity of groups and systems that identify and nurture shared values and goals (Walter 2004; see also aspect 3 above). The community-building approach differs from traditional community organisation practice that is “community-based” but not necessary *of and by* the community (Walter 2004). According to the California-based Prevention Institute (Chávez, Minkler, Wallerstein and Spencer 2007) to approach health and social problems within a broad cultural context both organizing and strength-based community building approaches should be emphasized and “cultural humility” (see below) should be of increasing relevance.

According to Minkler, Wallerstein and Wilson (2008:306) there are six key concepts of **community organization** and **community building**: 1. Empowerment, 2. Critical Consciousness, 3. Community Capacity, 4. Social Capital, 5. Issue Selection, 6. Participation and Relevance. This manual is focusing on the 6<sup>th</sup> concept, which is defined as follows: Community organizing should “start where the people are” and engage community members as equals“. In this definition the “Community members create their own agenda based on felt needs, shared power, and awareness of resources” (ibid.).

As an integral part of an overall health education project community participation or involvement, building leadership skills and increasing community competence belong to the core principles and approaches of community organization and community building practice (Minkler, Wallerstein, Wilson 2008).

While **community organization** stresses the principles of participation and relevance or “starting where the people are”, and the importance of community empowerment to increase their competence, **community building** focuses on community growth and change through increased group identification in order to build a stronger and more caring community (ibid.).

### **Ethnic Minority and Migrant groups**

Community organization and community building are essential for ethnic minorities and migrant groups in order to improve HIV/AIDS prevention. First of all the definitions shared among all WP8 member organizations will be presented:

An **ethnic minority** can be theoretically defined as a group of people within a given national state

- which is numerically smaller than the rest of the population of the state or a part of the state,
- whose members are citizens of the state where they have the status of a minority,
- which is not in a dominant position,
- which has a culture, language, religion, race etc. different from that of the rest of the population,
- whose members want to preserve their identity,
- which has a long-term presence on the territory where it lives,
- whose members are born in this particular state.

A **migrant group** can be theoretically described as a group of people within a given national state

- which is numerically smaller than the rest of the population of the state or a part of the state,
- which is not in a dominant position,
- which has a culture, language, religion, race etc. different from that of the rest of the population,
- whose members want to preserve their identity,
- whose members (and/or their parents) are not born in this particular state.

The term “migration” defines the permanent change of the main residence of an individual or a group. Therefore, it is a special form of mobility. A migrant changes his/her residence over the international borders and moves to another country to stay there. The migrant becomes part of the local people and after generations cannot be called a migrant anymore. The number of generations needed to gain recognition as legal citizens depends on the particular state law.

Several reasons for migration may be noted among migrants in Europe: war and political conflicts, abuse of human rights, poverty and unemployment, continuous demand for cheap labour, family reasons, international traffic and communication reasons in the original state. Thus, different classifications for migrants can be defined:

- Asylum seeker
- Work migrant
- Family or family members
- Highly qualified migrants
- Students etc.

According to an official definition, the United Nations defines a migrant as ‘any person who lives temporarily or permanently in a country where he or she was not born, and has acquired some significant social ties to this country’ (ECDC 2009). However, most definitions are too narrow and static and do not reflect the dynamic and fluctuations in migration flows. Instead of residence and settlement, mobility and “commuting” can be considered as new phenomena (Bhopal 2011).

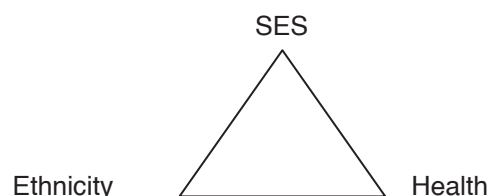
Finally it can be concluded that there is a need for standardization across studies, countries and different migrant populations (recently arrived and/or in transit, established ethnic minority communities).

Irrespective of the status some characteristics are common among many migrant groups and also ethnic minorities.

### **Social Determinants of Health Inequalities and Inequities in Ethnic Minorities and Migrant Groups**

Environment and culture are the main drivers of inequalities and inequities in health (Bhopal 2011). While inequalities are not bad per se, as it means only, that there is a difference, inequity also implies injustice. Therefore interventions should tackle both the inequalities and the inequities (ibid).

Several studies document a co-relation between ethnicity and socio-economic status (SES) of health. In general ethnic minorities have lower SES comparing to the population of the country they live in (Lorant 2011). According to Lorant the relation between SES, Health and Ethnicity is group-specific and country-specific and can be demonstrated by a triangle:



HIV prevention programmes have been implemented and evaluated by WP8 member organizations for and with different ethnic minorities and migrant groups/communities that are the most vulnerable to HIV/AIDS transmission in their countries. The described target groups in WP8 are the following:

- Migrants from sub-Saharan Africa (Austria)
- African migrants (Germany, Austria)
- Roma ethnic minority (Bosnia and Herzegovina, Bulgaria, Romania, Serbia, Slovakia, Latvia)
- Street sex workers whose origin is Roma (Serbia)
- Russian ethnic minority (Estonia)
- MSM (men who have sex with men), MSM with migration background (Latvia, Germany)
- Commercial sex workers (Germany, Latvia)
- Female sex workers with migration background (Germany)
- IDUs (injecting drug users) (Latvia)

Commonly the SES among ethnic minorities is multi-dimensional and it is not only matter of lack of education. This phenomenon can also be observed in the target groups mentioned above. Although they live in different conditions and have different cultural backgrounds, all of them have similar features that are preconditions for their high level of vulnerability, such as:

- Social exclusion - marginalized, discriminated, rejected position in society. For example the Roma communities in Romania, Slovakia and Bulgaria have a similar social and economic status. While part of the Roma ethnic minority group is integrated and has a common lifestyle, another part of the Roma population lives marginalized, discriminated, rejected and poor in quite circumscribed areas in cities and city margins. Another important part of the Roma population lives in rural areas, keeping a traditional way of life, traditional occupations, and maintains an internal organization/hierarchy (including its internal procedure of making decisions and making judgments in various internal community problems – the traditional Romani *court*).

The level of social integration of migrant groups in the participating countries is often lower and mostly they are disadvantaged at the labour market.

- Poverty - poor or extremely poor living conditions usually exist in segregated parts of the particular settlements (for example in Romania: The risk of poverty in Roma community is three times higher than the average risk at national level. For different reasons as lack of skills and skills, members of African migrant communities are often unemployed. Due to poverty these groups have no or less access to health services and are more likely to be vulnerable to HIV/AIDS.
- Patriarchal culture - in some of the described ethnic minority groups women are underprivileged, early marriages are a cultural norm and domestic violence against women is a common right of men.
- Lack of education and/or poor knowledge of the official language – regardless of the status (migrant in a foreign country or member of an ethnic minority), one of the prevalent features is the poor knowledge of the official language. This characteristic combined with low level of education and the belief in incorrect and magical myths about the human body and health makes interventions in the field of HIV prevention an extremely difficult challenge.
- Lack of trusted channels of HIV/AIDS prevention information - for all of the described ethnic minorities and migrant groups, the main and most trusted information channels are the media (mostly TV and radio in the mother tongue/first language) and social face-to-face communication with people from the same group.
- Lack of official knowledge about HIV prevalence among the groups – in Serbia, Romania, Slovenia, Bulgaria and Estonia, data regarding HIV is not collected in terms of ethnicity at national level. In all WP8 participatory countries of Eastern Europe there is no source for official data regarding this topic.

- Insufficient involvement of community-based NGOs in HIV prevention programmes for these target groups. All the countries presented in WP8 (with the exception of Bulgaria) do not have community-based and/or ethnic/minority NGOs involved in HIV prevention activities. Some of the NGOs' team members belong to the target population.

In view of the facts described above tackling health inequalities to ethnicity and migration is of great relevance. Therefore principles and methods of **community building** and **community organizing** can be used for ethnic minorities and migrant groups/communities in order to develop and implement programmes and interventions for HIV/AIDS prevention. Likewise the concept of **community building** and **organizing** can be adapted for other vulnerable groups as young people. In inviting the community members to identify their own issues of greatest relevance the essential community ownership of the project undertaken can be achieved.

## The Participative Approach - A Theoretical Background

One of the biggest challenges in health policy is the reduction/alleviation of inequality and inequity in access to health. Ethnic minorities and migrant communities in particular are often socially disadvantaged and access to prevention and health services is mostly problematic. Against this background it has been proven that without the active involvement of the target group a significant change in the field of prevention, health promotion and health behaviour cannot be achieved.

In this context the question which should be addressed is how the participation of the communities can be defined?

### The nine stages participation model

Wright, Block and Unger (2010) provide the following participation model based on practice: an approach can be described as participative when all the partners are involved in the programmes' activities work on equal bases. Participation starts when all participants have the same right in the decision-making process. They describe nine stages of participation:

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

How could these stages be described?

- 1) *Instrumentalization*: the "**community**" concerns, needs and members do not play any role in the decision making process. The community members are some kind of "decoration" for the decision-makers' activities. Usually the feeling evoked in the community members is "to feel misused, exploited".

- 2) *Directive*: The community situation is recognized but the problem is defined from the decision-makers' point of view. The communication style is directive and one-directional. Usually, the community members perceive the process at this stage as patronizing and depreciatory.
- 3) *Information*: The decision-makers share which kinds of problems are defined with the community members. They explain and give reasons for their definitions and suggest different possibilities for problem solving. The community point of view is considered. This stage has an important role in the HIV-prevention programmes (for example as educational materials).
- 4) *Hearing*: The decision-makers are interested in the community's opinion. Community members are questioned (using different methods – questionnaires, interviews etc.). This stage is also widespread among HIV prevention programmes (adequate intervention suggestions consider the community's point of view and needs).
- 5) *Inclusion*: The decision-makers are advised by selected community members who are invited as experts. The difference between this and the previous stage is that some community members are questioned intentionally for advice. Although these people (for example key informants), can give suggestions even not foreseen by the decision-makers, they do not have influence on the final decision.
- 6) *Co-determination*: This stage presents a participatory approach. The process of decision-making is a process of negotiating with community representatives who can give feedback about the quality of stages of the decision-making process.
- 7) *Partial decision-making power*: At this stage the community representatives have the right to independently make some parts of the whole decision.
- 8) *Decision-making power*: Community members have the right and expertise to take an independent decision on all essential aspects. There is a partnership between all participants in the decision-making process.
- 9) *Self-organization*: This stage is a form of community functioning which lies beyond participation. Here we speak about the responsibility of the taken decision. This responsibility (of the chosen project activities and measures) is completely in the hands of the community.

The participative approach describes interventions which develop strategies and activities for community participation with decision-making rights (stages 5-9).

The participative approach is increasingly recognized in the field of health promotion and prevention. The nine-stage model of participation can be considered as a key concept for the development of prevention projects. However it should serve as an instrument for the project workers to reflect about participation and is not a rating instrument. Finally participation is depending on numerous factors that are not under control of the human being. But by applying methods and concepts of the participative approach participative practice can be strengthened.

### **Learning from Community-Based Participatory Research (CBPR)**

Concerning successful community approach the educator Paulo Freire in the 1970s brought into discussion issues of having communities identify their own problems and solutions in order to achieve social change.

In many countries tools as *participatory action research*, *community-based participatory research*, *community-driven research* have been established in the field of prevention and health promotion for a long time.

Evidence is mounting that participative models are effective in bridging the gap that for example often exists between research and public health practice. Community-Based Participatory Research (CBPR) serves as an innovative approach for improving health. One of the multiple definitions of CBPR is:

“A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings ...” (WK Kellogg Foundation – funded postdoctoral fellowship programme in CBPR - Community Health Scholars Programme).

In opposite to “traditional” research approaches which have failed to solve complex health disparities, a significant community involvement is crucial to identify the local needs. Community involvement can also help to develop interventions which are culturally appropriate and community specific. Furthermore, trust is likely to build if community members are engaged in the development of interventions in an equitable manner.

More key principles are identified for developing successful community-based partnerships (Israel et al. 1994), such as:

- Recognizes community as a unit of identity
- Builds on strengths and resources within the community
- Integrates knowledge and action for mutual benefit of all partners
- Promotes a co-learning and empowering process that attends to social inequalities
- Involves a cyclical and iterative process

### **Ethics**

As ethical issues may affect community participation in research, ethics has also to be discussed in the context of any community-based participation approach. Common problems experienced by communities when working with professionals is “Insensitivity to community concerns or issues” (Hartwig, Calleson, Williams 2006). Therefore any participative community approach should be based on the core ethical principles: respect for persons, beneficence and justice.

A more comprehensive list of ethical principles includes:

- Respect for human dignity
- Respect for free and informed consent
- Respect for vulnerable persons
- Respect for privacy and confidentiality
- Respect for justice and inclusiveness
- Balancing harms and benefits
- Minimizing harms
- Maximizing benefits (ibid.)

If the community concerned is an ethnic minority or migrant community the ethical practice requires also cultural competences.



# Cultural Sensitivity, Cultural Competence, Cultural Humility

Various terms and notions related to the approaches mentioned are being used when dealing with people of different cultures. For the purpose of this manual we will concentrate on some key terms.

## Cultural competence

In general it is said, that “cultural competence” is a complex of personal skills which is essential to make possible and facilitate the communication between people with different cultural background. But what does “cultural competence” mean?

There is no single definition of cultural competence. Definitions of cultural competence have evolved from diverse perspectives, interests and needs and are incorporated in state legislation, federal statutes and programmes, private sector organizations and academic settings. It is a big challenge to synchronize the abundance and tangle of terms, notions and approaches, e.g. cultural awareness, culturally-sensitive, culturally-appropriate, culturally-tailored, cultural integrity, cultural humility etc.

Before we deal with the definitions of cultural competence we have to clarify what cultural competence is **not**:

- Cultural competence is not about memorizing cultural "facts".

Here it is not the aim to present all the definitions around cultural competence, but to highlight some which have a significant impact on the field of health, HIV/AIDS prevention and human services.

One of these definitions is offered by the seminal work of Cross et al. (1989). This definition of cultural competence has established a solid foundation for the field and has been widely adapted and modified during the past 15 years. However, the core concepts and principles espoused in this framework have remained constant as they have been viewed as universally applicable across multiple systems.

Based on Cross et al. (1989) cultural competence is a set of congruent behaviour, attitudes and policies that come together in a system or among professionals enabling effective work in cross-cultural settings and situations. The word **culture** is used because it implies the integrated pattern of human behaviour that includes thoughts, communications, actions, customs, beliefs, values and institutions of a racial, ethnic, religious or social group. The word **competence** is used because it implies having the capacity to function effectively.

Five essential elements contribute to a system's, institution's or agency's ability to become more culturally competent which includes:

- 1) Valuing diversity
- 2) Having the capacity for cultural self-assessment
- 3) Being conscious of the dynamics inherent when cultures interact
- 4) Having institutionalized culture knowledge
- 5) Having developed adaptations to service delivery reflecting an understanding of cultural diversity

Other authors as Denboba (1993) stress the specific comprehensive plan at organisational or programme level, which include interventions at levels of:

- 1) Policy making
- 2) Infra-structure building
- 3) Programme administration and evaluation
- 4) The delivery of services and enabling supports
- 5) The individual

Most authors emphasize that achieving culture competence is a *dynamic, ongoing, developmental process* and that individuals and organizations are at various levels of awareness, knowledge and skills along the *cultural competence continuum* (Cross et al. 1989).

The concept of cultural competence assumes that individual knowledge and self-confidence are sufficient for change. This implies a risk to oversimplify both culture and competence. In this concept culture is perceived predominantly as a matter of ethnicity and does not encompass gender, age, socio-economic status, education, sexual orientation and faith.

In the ethnocentric standpoint of „the white, western, middle-class, high-educated majority” culture is seen ONLY as the domain of the OTHER (the ethnically different). This means, the OTHER is/has a problem (Kumas-Tan, Z. et al. 2007).

As this concept does not reflect the existing imbalance, power inequalities and oppressive social relations across cultures, communities and social groups, it can hamper true openness, participation and decision power of the culturally different communities.

The definition of culture competence (Cross et al. 1989) has been translated into practise of service provision. However, providing the staff with cultural knowledge and adapting the service delivery to ethnic minorities’ needs and characteristics, as cultural competence is initially understood, is seen as very reductionistic understanding. This concept has been further developed, redefined and interpreted more as **cultural humility** rather than competence, meaning that this is more awareness, attitude, sensitivity and self-reflection than just skills.

### **Cultural Humility**

The term cultural humility was first coined by Tervalon and Murray Garcia (1998) who point out the openness to other’s cultures and the ability to listen to our own internal dialogue. In this context Papadopoulos (et al. 2002) offers the designation of the `conscious incompetence`, while Levi (2009) emphasises the acknowledgement of the gaps in one’s knowledge and own barriers to true intercultural understanding.

A more detailed explanation stresses the need for a lifelong commitment to self-reflection, evaluation and self-critique, to redressing of the power imbalances in the encounter of different cultures in social and professional settings (Tervalon, Murray-Garcia 1998).

Humility is crucial in global health settings. It helps to redress the imbalance of power inherent in relationships between health care providers/researchers and those they serve. As professionals they must acknowledge the limitations of their cultural perspective and work toward overcoming this perspective in order to provide better health care for those they serve.

The concept of cultural humility involves that it is not sufficient to acknowledge differences between cultures or to know everything about a culture. As the California Health Advocates (2007) points out humility is a kind of “reflexive attentiveness that requires a great deal of self-awareness” and goes far beyond “knowledge of the details of any given cultural orientation”. To be aware of that differences will still/always exist between one’s own perspective and the perspective of the members of the other cultures is essential.

Trans-cultural competence is a third term that is often used in global health settings. This term emphasizes the flexibility and dynamism of cultures in the process of their mixing and mutual influence and therefore is not focusing on competence of a specific culture.

BORDERNETworks’ practical manual presents four “good practice” models from the perspective of community-based participatory prevention.

# How were the Four Models Selected: Participation, Exchange, Capacity Building

The final question of this introduction to the philosophy of the present manual is why and how were the three models applied by AHW, AISC and DAH (collaborating partner) chosen to be shared as the best practices in the field. How relevant was their expertise to be transferred as methodological competence with regard to implementation of the models in different contexts and migrant/ethnic minority communities?

The most important selection criteria during the assessment survey and peer review of the models were:

- How does the model understand and support the respective community?
- How was a participatory approach integrated in the interventions reaching migrants/ethnic minorities for HIV prevention?
- How does the intervention/model involve and rely on the strengths of the respective community?
- How does the intervention model bring together/unite the goals of HIV prevention and the needs of the community?
- How does the intervention/model support the development of the community?

Based on these criteria all four models were suggested by HESED as the leading partner to the partner circle of WP8 and approved by them to be presented in detail in the final product of the WP8: Manual of effective practice-driven participatory models for community-based prevention among migrants/ethnic minorities.

The POL-model, introduced to BORDERNETwork by HESED, based on their experience with Roma communities was part of the project working plan and was not an object of the assessment study. In March 2011 a training seminar was conducted to build competence in order to work with this model. The other three models were outlined thanks to the active participants in WP8 and the practices described by them in the assessment study questionnaire.

Thus, the four models presented in the manual are (in alphabetical order by country):

- 1) PARC model, developed and presented by AIDS Hilfe Wien (Vienna, Austria);
- 2) POL model, co-developed and presented in BORDERNETwork project by HESED (Sofia, Bulgaria);
- 3) AIDS & Mobility model, co-developed and presented in BORDERNETwork project by the Estonian A&M partner, the AIDS Information and Support Centre (Tallinn, Estonia);
- 4) PaKoMi model, developed by DAH and WZB (supported by the German Ministry of Health) and presented in BORDERNETwork project by DAH (Berlin, Germany)

# PARC Project:

## Prevention of AIDS with the Resources of Communities

Sabine Lex

The PARC project is a participatory HIV and Hepatitis prevention project with and for migrants originating from sub-Saharan African countries. It was conducted from June to the end of August 2011 as a pilot project.

PARC stands for “Prevention of AIDS with the Resources of Communities” which already indicates that effective HIV prevention requires the involvement of the targeted community. Cooperating with peer educators from different African countries who are trained by Aids Hilfe Wien helps to provide information that is accepted by the target group culture. The peer educators also have access to different settings of the community and can overcome language as well as other barriers. Moreover, the project tried to build a network of as many key persons in the African community as possible.

Besides participation and peer education, the project uses the approach of outreach in order to be able to reach the communities at settings where they spend their leisure time. This approach is allowing the peer educators to communicate in a relaxed atmosphere. “Go where the people are!” probably describes this approach best.

### **1. Name, author and agency**

Name: PARC project - Prevention of AIDS with the Resources of Communities

Author: Sabine Lex

Agency: Aids Hilfe Wien, Mariahilfer Gürtel 4, A-1060 Vienna, [www.aids.at](http://www.aids.at)

The PARC project was a short term pilot project funded by the city of Vienna (MA 17 - Department for Integration and Diversity). It was implemented by Aids Hilfe Wien (AHW) as a participatory project, using the approaches of peer education and outreach. The targeted communities are people originating from sub-Saharan Africa.

### **2. On which grounds is the community selected?**

#### **a. What kinds of methods are used in the process of selection (community assessment, mapping, research, and official statistics)?**

Based on available epidemiological data on HIV, Aids Hilfe Wien saw the need to focus prevention activities among migrants from sub-Saharan African countries. Data on HIV prevalence came from the Austrian HIV Cohort Study; information on how many sub-Saharan Africans are living in Austria and in Vienna was taken from official population statistics. The available information showed that sub-Saharan African migrants are the most affected population in Austria, presenting 12 percent of all positive people living in Austria but not even one percent of the whole population in Austria.

Moreover, there is a high proportion of late presenters among them, persons who get to know their HIV status at a most advanced stage of the infection (e.g. number of patients from sub-Saharan Africa in the Austrian HIV-Cohort study) were analysed. More information was also gained by discussions with professionals in the field of HIV prevention and treatment as well as from representatives of the sub-Saharan migrant groups.

## **b. Description of migrant communities in Austria**

In Austria, 16 percent of all inhabitants have another citizenship than Austrian (730,261). The biggest migrant groups are from Serbia/Montenegro, followed by Bosnia/Herzegovina, Turkey and then Croatia. Only 0.27% of the whole Austrian population has an African origin (no official data is available on Africans with Austrian citizenship).

There are several Austrian NGOs that provide different services for diverse migrant communities (among them also for the African communities) such as the Diakonie (housing, counseling), Peregrina (works exclusively with women, counseling), Ute Bock (housing, counseling), Suara (counseling), Caritas (housing, counseling) etc. These organizations are also frequented by migrants from sub-Saharan Africa.

### *The sub-Saharan African community in Vienna*

In Austria, 40,744 Africans are registered (Asylum seekers not included); Africans from Egypt being the largest and from Nigeria the second biggest group. More than half of them live in Vienna (22,430 people).

There are many African organizations, mostly based on their country of origin, and also a lot of churches exist. Furthermore, there is a radio and TV station named "Radio Afrika TV".

Nevertheless, the public perception of Africa in Austria is not always positive and connected with poverty and famine. Many people believe Africans living in Austria to be drug dealers. Furthermore, it seems that Africans are rather disadvantaged on the job market.

### *Inner self-organization of the sub-Saharan African community in Austria (Vienna)*

Although this migrant group is heterogeneous, it is still very well organized. Countries of origin build the basement for their organization as well as religion. Festivities like various national independence days and national holidays are celebrated regularly and are important occasions for gathering; not only for people from the specific countries but also for others. The churches are an essential focal point for social life of the community. They build a central network for the community not only during worship services but also due to the events they are organizing. Once being able to enter a clerical community, reaching people with prevention messages is substantial.

In addition there are also other locations that are considered as important for the communities' social life like restaurants, clubs, hair salons, and African shops where people meet, discuss, and celebrate.

Regarding the most important communication channels in the community, the informal face-to-face channels are the most trusted ones. Cell phone communication is very important to the African communities and works very well as internet access is not always guaranteed. Information channels like the Radio Afrika TV, are focusing on African life and culture in Austria; internet platforms such as afrikanet.info or especially Vienna also need to be considered as influential

### *HIV/AIDS and the sub-Saharan African communities in Austria (Vienna)*

The vulnerability of the sub-Saharan African migrants towards HIV/AIDS and STI is high. More than a third of all patients in the Austrian HIV Cohort Study are born outside of Austria. Among them the biggest group are people originating from countries in sub-Saharan Africa, representing twelve percent of all participants in the Cohort Study (including Austrians). A high number of them only gets to know about their HIV positive status at a late stage of the HIV infection.

HIV/AIDS is a taboo in the community due to different reasons and/or an issue that people rather not talk about. There is fear of being doubly discriminated - 1) because of the already difficult situation of Africans in Austria and 2) because of HIV/AIDS. This can be demonstrated very well by the example of the World Soccer Championship during which the Ke Nako Afrika network was founded with the goal to represent the colourful picture of Africa. During the Championship many events were organized in order to create and popularize a positive image of the African communities. But unfortunately it was impossible to launch HIV information over Ke Nako Afrika and the Championship. The organizers were afraid that the image of Africans would be depreciated.

Due to the fear of discrimination, cultural differences and long-lasting myths, there have never been real attempts to work with the African communities on the issue of HIV/AIDS. In order to overcome those barriers, AHW started a participatory assessment of the situation in Vienna.

**c. What kind of target groups is this method “tailored” for?**

This model is tailored for a vast range of “hard-to-reach target groups” that is vulnerable to HIV/AIDS and STI. The target groups can have different levels of self-organization and geographical density. It is not necessary that a big part of the group live together, but it is inevitable to have places for social life and clear social norms. Recommendable is to have community members with medium and/or high educational level, who demonstrate a high motivation and readiness for commitment to a cause and community work.

**3. Description of the method**

**a. Theoretical background**

Peer education is an approach, where community members are supported to promote health-enhancing knowledge and skills among their peers. Rather than health professionals educating members of the public, the idea behind peer education is that people of the communities are in the best position to encourage healthy behaviour to each other. This approach has been applied successfully in HIV prevention since it is known that various groups have different social, cultural and educational backgrounds.

Usually peer education projects are implemented by health organizations that recruit peer educators and train them on the relevant methods and information. With these acquired skills, the peer educators are able to approach their peers at places where they frequently gather and can engage them in conversations about the issue of concern. The intention is that familiar people, who can give meaningful suggestions in an appropriate language and taking account of the local context, will be most likely able to promote health-enhancing behaviour change.

The project is also based on the model of “Participatory Quality Improvement” (Michael T. Wright 2010). Participation not only means to partake but to involve the communities in a way that they have the opportunity to have a say at all project levels. Within the research phase it was soon obvious that the greater involvement of the community is necessary in order to really “reach” them. However, on the one hand one has to realize that not all people like to be involved at the same level. On the other hand, for coordinators it can be too stressful to involve communities in all decision-making stages.

**b. How is the community involved?**

The community (represented by its members) is involved in all project stages:

*Preparatory stage*

The preparatory phase of the PARC project was dedicated to obtaining information related to the sub-Saharan African migrants in Vienna: their origin, differences, languages, cultures, and ways of reaching the members of the community/communities.

In 2010 a series of meetings and exchanges were conducted. In a first meeting, experts, medical doctors, counselors and one representative of the community came together. Soon it was obvious that the involvement of more representatives of the sub-Saharan African communities would have a better effect than just talking about them; since they are the experts when it comes to their own environment.

For that reason six meetings with eleven representatives of eight different countries (Rwanda, Ghana, DR Congo, Ethiopia, Guinea-Bissau, Kenya, Cameroon, Ivory Coast) in the region sub-Saharan Africa were held. Main issues discussed during the meetings:

- Background information on how the African communities live in Austria;
- What challenges do they face?
- How do Africans deal with HIV/AIDS?
- What myths related to HIV/AIDS does exist?
- How could prevention messages look like and how can they be transferred?
- Where do Africans spend their leisure time?
- How could a HIV prevention project look like etc.?

The first findings showed that migrants from sub-Sahara-Africa in Austria are considerably heterogenic and have different backgrounds (e.g. legal status, languages, duration of living in Austria and respective traditions). At the meetings a problem and needs assessment of the migrant group was conducted and the main settings where the communities could be reached with the help of trained peer educators were outlined.

In 2011 a three-month pilot project was initially planned and conducted together with community members and later on mainly with nine trained peer educators who were recruited through information channels of the communities. As an additional part of the project a small-scale research was carried out. .

#### *Research*

In the course of a master thesis, one peer educator conducted three focus group discussions on “Barriers hindering sub-Saharan African migrants living in Vienna to access HIV testing and treatment services” in cooperation with Aids Hilfe Wien. Sub-Saharan Africans were invited to discuss and received remuneration for their time. The peer educator was mentored by a colleague from Aids Hilfe Wien through the whole process.

#### *Training stage*

During the outreach work the peer educators were regularly trained and supervised. The elements of the theoretical training were based on the findings of meetings in 2010 and the focus group discussions in 2011.

The peer educators constitute the active factor of the intervention among the community since the project should be conducted by peer educators, approaching their peers in diverse settings. Africans were also involved in the process of finding peer educators.

#### *Constant communication*

Throughout the whole project preparation and conduction period a constant communication between the project manager, the peer educators and the communities (one-to-one, feedback rounds, working groups) took place.

### **c. Programme management**

The programme is has been coordinated by AHW. The coordinator (Sabine Lex, Prevention Department, referent for migrants and vulnerable groups) has administrative and team coordinating responsibilities and is also in charge of networking. The willingness to get to know the communities by getting to know the key persons is required. This is only possible by being introduced to them by other community members since relevant information is rarely found on the internet.

The outreach workers carry out regular outreach work among the community and feedback their experiences to the coordinator, as well as collecting their documentation forms.

**d. What kinds of resources are needed?**

This intervention needs financial resources but also - especially in the beginning - time and endurance. The coordination of the project is rather time-consuming if one really wants to put effort in building networks. Peer educators in this project were paid and also other community members were reimbursed for their effort.

In case if voluntary counseling and testing is also being provided, costs for staff have to be taken into account.

**e. How is the training of staff and mediators organized (content, structure, methods, duration)?**

The recruited peer educators received a comprehensive training whose topics covered the most important areas related to HIV and Hepatitis prevention and the professional role of the outreach worker. Prior to the implementation a series of five training sessions of four hours each took place (total of 20 hours) for introduction to the project and coverage of diverse thematic topics:

- Introduction of the project, getting to know each other, key messages of the project
- Information on HIV/AIDS
- Information on Hepatitis A, B, and C
- Information on Aids Hilfe Wien
- Does and Don'ts of Peer Educators
- Communication, role plays
- Where to work, how to work, establishing a work plan
- Introduction of documentation and information material
- Continuous revision of key messages

Prior to the training five key messages were formulated, which were based on the findings of the previous assessments and focus group discussions. The messages played a basic role in the field of counselling provided by the trained peer educators. They were perceived as the minimum standard of the outreach prevention contacts, in order to bring across clear-cut, correct and coherent information that can reach the target community.

The five Key Messages (each of them brought down to more specific sub-messages):

1) HIV/AIDS is not a death sentence!

- Someone who is HIV+ can still live a long and healthy life.
- Although there is no cure, HIV is treatable.
- In Austria, all people with health insurance have access to individual treatment.
- Aids Hilfe Wien provides social work and care services as well as anonymous counselling.

2) Know your status - get tested!

- Knowing your status protects you, your partner, and your unborn/newborns.
- The earlier you know about your HIV+ diagnosis the better it is.
- You are able to access treatment as far as this is necessary.
- It keeps you healthy.
- It maintains a good quality of life.
- Free and anonymous HIV-antibody tests and Hepatitis B+C - screenings can be carried out at the Aids Hilfe House.



3) Using a condom prevents you from getting HIV!

- Unsafe sex is the main mode of transmission.
- Within marriage or partnership, where both partners have not undertaken a test, the use of condoms is the only way of protection!
- Condoms should be used with casual partners.
- Condoms are available at Aids Hilfe House for free.

4) Social contacts with HIV+ don't put you at any risk!

- HIV is not transmitted by kissing, using the same objects like cutlery, tumblers, etc., sharing bathrooms, mosquito bites, etc.
- Discrimination deeply affects the psychosocial health.

5) Hepatitis B is a viral infection of the liver - get vaccinated!

- We distinguish mainly between type A, B, and C.
- There is a vaccination for types A and B.
- Hepatitis B is mainly transmitted sexually.
- Hepatitis C is 10 times more infectious than HIV.
- Hepatitis B is 100 times more infectious than HIV.
- After infection you can get seriously ill OR have no symptoms at all.
- Developing a chronic inflammation of the liver causes increasing destruction of the organ and its functions.
- There are treatment options for Hepatitis B and C but it may be laborious and even ineffective.

**f. What other resources are needed (finances, materials, time, space, etc.)?**

On the one hand there is a need for trainings, feedback and working group meetings. An essential part of the project is also the opportunity to provide a low-threshold VCT service that is located directly at Aids Hilfe Wien.

On the other hand all common prevention materials like condoms, female condoms, community-specific information material, etc. are needed. In case of participation in events like "Afrika Tage Wien", additional costs will be raised and have to be taken into account (e.g. for stand rental or electricity).

Moreover, experience of Aids Hilfe Wien showed that some African organizations may ask for contributions to their special national events. How to deal with such request should be decided on a case-by-case-basis.

**g. How are the peers identified, selected and recruited?**

The announcement of the recruitment of peer educators was planned together with community members. It was distributed to important contacts in the community mainly via e-mail and they further spread the information. An application had to be sent and eligible applicants were invited to an interview which was led by the project coordinator and a colleague of the VCT department. It was mainly looked for their prior experience in outreach or prevention work, their motivation, their involvement in their communities, and their ability to talk openly about issues like sex or HIV/AIDS. Eleven candidates were selected to participate in the training; nine persons had completed it.

**h. What kinds of intervention methods, instruments, tools and techniques are used?**

- i. What is the main intervention instrument(s) in this model? How is this main instrument(s) implemented?

The model applies a participatory approach in a “learning-by-doing” manner. There are two main intervention methods in this model – the peer education training (including the on-going training and supervision) and the regular outreach work that is carried out by trained community members.

The main instrument of the small-scale research is organizing, conducting and analyzing focus group discussions.

- ii. In which settings was it implemented?

The peer educators were trained for their role and received coaching during the implementation on a regular basis. After the training nine peer educators (four women and five men) conducted outreach visits in pairs (English and French speaking). Setting-based outreach to preliminary identified places of community encounters (hair dressers, afro shops, restaurants, parks, churches) and especially organized events (music festivals, pick-nicks organized by churches, soccer games, African days, etc.) was conducted.

**i. Important rules for successful implementation**

The trained peer educators from the African community took on a leading role in the project. This role (project position) has clearly defined rules, and for the success of the project it is crucial to keep up with them. These rules are summarized by the AHW team as follows:

<b>A Peer Educator Does:</b>	<b>A Peer Educator Does Not:</b>
Facilitate trust, openness, comfort, empathy	Dominate, preach, tell people what to do
Accept people as they are	Judge people, try to change them
Listen, clarify, give information	Give advice, offer solutions
Respect confidentiality	Gossip about what was said in a group or about others
Give support and encouragement to take positive action	“Rescue” – do for a person what he/she should do independently
Realize that not all problems can be solved and not all people want to be helped	Expect all problems to be resolved quickly and easily
Refer persons to AHW	Attempt to provide services beyond what he/she is qualified for

**j. What kind of professional supervision is needed?**

The trained peer educators received regular supervision during the whole three-month period of outreach work among the target group. Each month a feedback meeting took place where challenges but also ideas for improvement were discussed.

Furthermore, individual talks with the project coordinator take place on a regular basis in the office.

#### **4. Monitoring and evaluation**

##### **a. What documentation is needed?**

For reporting purposes the following documented (protocol) information is needed:

- Number of people approached?
- How many people were approached for the first time, how many for the second (third etc.) time?
- Places – where were these people approached?
- Origin - from which community?
- Age
- Gender
- Duration of the contact - How long did you talk to them?
- Content of the conversation/consultation - What were your discussions about?
- Other observations/comments - Have there been any particularities?

##### **b. Which assessment methods/tools are used?**

On the one hand, all discussions within the feedback meetings regarding the project were documented. On the other hand, peer educators were given an evaluation questionnaire at the last meeting. Here it was also discussed what should have been done differently, what worked fine and what should be mostly focused on by the project in the future.

##### **c. What are the main indicators for effective implementation?**

The following indicators are the most important for measuring the effectiveness of the implementation:

- The adequacy and completeness of the gathered information related to the community
- The contact with and involvement of the community – difficulties met, people involved
- Scope of the intervention – places where the intervention took place, number of people who were consulted, tested and received their results

##### **d. How is the feedback of the community gathered?**

The feedback of the community is regularly gathered during the on-going training and supervision of the peer educators who are community representatives. They are in constant contact with the community members and receive their feedback during the regular outreach work and in their everyday life as well.

#### **5. Results achieved**

##### **a. Quantitative**

The scope of the three-month long intervention is impressive:

- 5,195 people reached: 3,099 men; 2,096 women

A big variety of settings was identified and visited:

- Shops
- Restaurants, bars, night clubs
- Barbers & hair dressers
- Events, parties
- Churches
- Parks
- Pick-nicks

## **b. Qualitative**

### *Results obtained through documentation forms*

Peer educators should take notes on particularities during their outreach work. The obtained new knowledge regarding the African community and the HIV prevention topic is being summarized by qualitative results. Findings about the existing stereotypes and observed specific behaviours can be summarized as follows:

- For African people an HIV positive result means death without any other possibilities (HIV = AIDS = DEATH). Hence they did not see any reason to get tested for HIV.
- There was a lack of knowledge regarding the availability of treatment in Austria.
- Except for HIV testing the community members are highly interested in getting tested, especially for Hepatitis. Costs and anonymity are of primary importance. Nevertheless some people were afraid that test results might be manipulated.
- Demand for condoms was high; also condoms for female.
- An actual discussion topic (sex before marriage) is related to a community norm and the conflict with the religious norms. One example is the discussion on whether young people should be given condoms, because they might be encouraged to have sex.

## **c. Findings of the focus group discussion**

### **i. Attitudes, norms (citations)**

As part of the research three focus groups (10-15 participants in each) were carried out (*see above*). For participating the attendants received 15 € for participation as an incentive. The results reveal some of the most important internal barriers for the community to HIV prevention services. They are summarized as follows:

#### *Information*

"It is not that African people are not aware of HIV/ AIDS...., the secrecy that surrounds it, they hardly talk about it. It's African attitude towards AIDS and their health; many do not care about their health.... With the work situation in this country, you have to work in the morning and come back (in the) late, they really don't have the time to take care of their health (or talk about HIV/AIDS)".

"Not enough (time and place) to inform ourselves and to discuss about such issues (HIV/AIDS). The only place we meet is churches and clubs. We don't meet at the universities or elsewhere.... We don't discuss at home that kids should use condoms, to have safe sex".

#### *Testing*

"Most people are afraid of the test, because it is better not to know your status. What you don't know, does not kill you; I know I don't have HIV".

„When dying, its better you just die and do not to know that today I have AIDS and in 5 years-time I would die..“

### *Treatment*

"I think the treatment is only for the rich people, I think if you have the money you can get the treatment".

"They are some people that is here that do not have insurance to go to hospital, so how would they start thinking of going to take the test (in the first place) when they even don't have insurance (for the treatment)".

"If you want to convince me to make the test, you have to convince me that you can provide medication and also convince me that I can still live a normal life, then I will take the test".

### *Dealing with HIV positive people*

Many agreed that HIV positive persons should be cared for and treated like any other person without discrimination and stigmatization. However, the majority was saying that people would stay at hands length from those that are infected with the virus if known; others argued that (thought of) individuals would go as far as not even sitting beside an infected person, but he would be a close friend to advise him to seek medical advice .

"People look at HIV/AIDS persons as a devil and do not want to have anything to do with them, they neglect them, they don't want to even talk to them talk less or even moving closer to them".

### *Suggestions to AHW*

"... Aids Hilfe, should go out and meet people where they are. You cannot wait for the people to come here (Aids Hilfe House) and express themselves, this is not the way we used to back home. We have a lot of institutions and they are coming to us in schools and everywhere to tell us about (HIV/AIDS). So it should be done the same here, maybe branches should be also opened because when you take U6 and you drop at Gumpendorfer Strasse the whole people will look at you (suspiciously) and they will think that maybe this guy is dropping at Aids Hilfe. So it is difficult for us to come here to get informed, and the secondly it should be a way to teach all the (Africans) communities“

### *Feedback from the community*

The general feedback from the community regarding the PARC project activities was very positive. Moreover, people suggested implementing the project in Africa. However, there still exists a scepticism that the virus and the illness were brought to Africa by Europeans.

## **6. Lessons learned**

### **a. What are the strengths of this model?**

One of the biggest strengths of this model is that for a short period of time (three months) a vast number of people is possible to be reached. The described intervention is specifically tailored for the sub-Saharan Africa migrant groups in Vienna. The model is easily applicable for most of the “hard-to-reach” migrant groups and ethnic communities in different social environments and state contexts.

The model strengthens the already existing resources (mostly human) with adequate knowledge and skills for HIV prevention among peers. Using the everyday “communication experts” of the community, the model “speaks” the targeted community language and the relevant messages are easily and rapidly spread among the community.

Moreover, the project results offer the community (to its interested members) a well-structured feedback, knowledge related to the existing norms as well as their positive and negative influence on the individual health.

And last but not least, this project has clearly defined rules for the peer educators' position and minimum standards for good practice in outreach work.

- Peer educators are experts in their communities
- Peer educators can bring in their experiences and are a communication channel
- Peer educators can act as role models
- Organizations get to know communities better
- The project/model might also bridge the gap between the organization and the communities

Last but not least, this project has clearly defined rules for the peer educators' position and minimum standards for good practice in outreach work. When the project implementation involves representatives of the targeted community with non-professional background, it is essential that they are trained and have clear standards (qualitative and quantitative) on how to perform the project activities. Additionally, these standards combined with regular professional supervision prevent burn-out syndromes of the outreach workers.

#### **b. What are the limitations of this model?**

The main limitation of the model is that the depth of the behavioural change and sustainability of the results achieved are questionable. This is a common weakness of short-term projects.

#### **c. What kind of obstacles were met and what are the possible solutions (plan B)?**

In the beginning it was assumed that Aids Hilfe has sufficient means for co-sponsoring African events. After some requests clear standards were defined in which cases funds for activities of the communities could be allocate.

#### **d. Measures of sustainability**

After the three months-project period, contact was held to the peer educators. Aids Hilfe Wien also participated in some events which seemed to be very important. Moreover, a subsequent project that started four months later was already planned during the project.

#### **e. Findings about the group/community**

The following findings are important to be taken into account by further implementation of the model:

- African communities are not so hard to be reached as often supposed.
- The right people are needed to access the communities.
- The project needs a lot of personal and financial resources.
- A lot of time for project management is needed if you really want to "listen" to your peer educators and get to know the communities and their leaders.
- Some settings are harder to approach than others.
- Remuneration is essential for the peer educators' long-term commitment.
- Scepticism still exists in African communities.

**7. Accessibility and materials: handbooks, reports, media produced, resources available for implementing the model**

All materials and documents of the PARC project are available for institutions, services and professionals in the HIV prevention field. For more details the contact person is the coordinator Sabine Lex: (lex@aids.at, +43 (0) 1 599 37 93).

**8. What further development and implementation of the model could be possible in the future?**

The project period of three months was always considered as a pilot project leading to a longer term project. This started three months after the pilot project was completed in December 2011. In the frame of this new project (PARC Project = Prevention of AIDS among Africans with the Resources of Communities) a research project will be conducted, including community mappings and a survey among Africans. Furthermore, Aids Hilfe Wien will organize parties (like a sports event) and try to further improve contacts with the African communities.

# The Popular Opinion Leader (POL) Programme

Radostina Antonova and Sylvia Vassileva

## **1. Name, author and implementation agency**

The Popular Opinion Leader (POL) model is a HIV prevention model developed by CAIR (Center for AIDS Intervention Research), Medical College of Wisconsin, USA in the 80's of the past century. Since 2001 the team of Health and Social Development Foundation (Sofia, Bulgaria) in cooperation with CAIR has adapted and implemented the POL model for Roma and MSM (men who have sex with men) communities in Bulgaria.

Popular Opinion Leader (POL) is a scientifically-proven, community-level HIV prevention intervention. During the past 15 years, POL has been used with diverse populations worldwide including men who have sex with men, women, general youth, male and female commercial sex workers (CSWs), and heterosexual adults. The model has been proven to be effective and cost effective.

## **2. On which grounds is the community selected?**

### **a. What kinds of methods are used in the process of selection (community assessment, mapping, research, and official statistics)?**

Since 1999 the Roma community in Sofia's Fakulteta neighborhood is HESED's main target group for HIV prevention and community development interventions. Official data (statistic and research) shows that Roma community is the most vulnerable group in Bulgaria regarding spread of socially significant diseases (such as tuberculosis, STIs, HIV/AIDS etc.).

According to the POL requirements the target group of the POL intervention should be a quantitatively measurable part of the whole community. Based on official statistics, qualitative ethnographic and quantitative KAB<sup>4</sup> surveys (tailored and conducted especially for the POL implementation purposes), and HESED's previous experience with this community, young Roma men (aged 16 – 25) appeared to be the most vulnerable. The majority of them has a mobile life style and highly risky sexual behaviour and are therefore the most suitable group (young men are the power "holders") for the intervention based on the POL model.

The social networks of young Roma men directly involved in the intervention's activities are selected during field observations in spots where this group is socializing (squares, pubs, discos, parks etc.).

### **b. Description of the community**

The district of Krasna poliana in Sofia has a total population of 63,792. The number of children from 0 -18 years is 10,710. Fakulteta neighbourhood, according to official statistics, has approximately 15,000 residents, the largest majority of whom belong to the Roma minority. It is the largest Roma neighbourhood in Sofia and the second largest in Bulgaria. On the other hand, data from NGOs operating on the territory of the Roma neighbourhood estimate about 30,000 people. Discrepancies in the official and unofficial numbers are attributed largely to the influx of newcomers because of internal social migration where people from the countryside come to the capital city in search for better employment opportunities. According to information

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<sup>4</sup> KAB: Knowledge, Attitudes and Behaviour



from the district administration, the number of children aged 0-18 in Fakulteta neighbourhood amounts to approximately 4, 000 and the number of children aged 0-3 amounts to approximately 600. In Fakulteta, the old communist system of housing, employment and schooling-for-all has been replaced with dilapidated and illegal housing, 90 percent unemployment rate, and the worst schooling facilities in the capital. Illiteracy rates are high (over 25 percent) and life expectancy is considerably lower than that of other Bulgarians (only 5 percent reach retirement age compared to 35 percent for non-Roma).

No municipal housing or infrastructure upgrading of any significance has taken place in the Fakulteta during the post-communist era. Consequently, illegal housing and illegal service connections are the norm. It is estimated that some 90 percent of the properties are illegally constructed. There are very few municipal buildings in the entire district. By far, the largest and most important is the '75th School'. This dilapidated and run-down establishment attempts to cater for the educational needs of 6-16 year olds. It has around 1,300 pupils, which represents less than a fifth of the school-age children. Neither nursery nor kindergarten or any other kind of pre-primary education is provided in Fakulteta district.

For the children from disadvantaged families the low standard of life and the inferior social-psychological climate in the families is a specific problem. Almost without exception the concentrated Roma population in Fakulteta neighborhood is living under extremely bad conditions. In most of the cases the only source of income for the families are the state social benefits. The lack of financial means limits the access of children to health and educational services.

#### *The Roma population and HIV*

The Roma population in Bulgaria is particularly vulnerable to HIV/AIDS due to lack of access to health services, cultural barriers, lower educational level, poverty, migration and different values. All governmental institutions and NGOs working in this field believe that Roma are at highest risk of HIV/AIDS transmission of all ethnic groups in the country. Qualitative research shows that men have greater sexual freedom before and during marriage, engage in various risky sexual practices with regular and multiple partners outside of the marriage, and have much more power and control in relationships. In contrast, women are expected to maintain virginity before marriage and then be faithful to their husbands. Misperceptions about how HIV is spread are quite common; especially women have very little knowledge concerning transmission of STIs and HIV. Participants in this qualitative research said they rarely or never talk to their partners about sex and prefer to discuss sexual matters with someone of the same gender. These traditional rules restrict the ability of Roma women to discuss and negotiate the family planning and protection from HIV/AIDS. They do not mention issues related to sexual activity, "especially if both sexes are present", as it is shameful - not even indirectly. Girls and boys do not receive any form of sexual education.

A study conducted among Roma men from the "Fakulteta" neighborhood in Sofia shows that the majority of participants have not used a condom during their last vaginal intercourse; most of them have anal sex with women and a considerable part anal sex with partners from the same sex during the last three months. A significant number of the Roma population is involved in paid sex practices in the country and abroad. A surveillance conducted within the framework of the national AIDS prevention programme (funded by the Global Fund to fight AIDS, Tuberculosis and Malaria) found additional information related to the risks of young Roma men (MRM) (aged 15-25) living in the Roma neighborhoods. In this study, 34% of MRM were MSM, and a significant part of them are commercial sex workers. 47.7% of MSM sex workers have used a condom during their last sexual contact.

The existing information indicates that Roma communities are most vulnerable to health and social problems in Bulgaria due to several factors: 1) the rapid destruction of the patriarchal model of society which is not balanced with new supportive models for social development; 2) gradually increasing social isolation caused by the economic environment; 3) lower general and economic education of the group. The lack of social skills and motivation explains the increase of destructive (individual and group) social behaviour such as leaving school (which further reduces the chances of finding work in the future), abuse of drugs and other substances, crime and sex work. Studies show that there is a continuous process of disintegration of the relationship between major social institutions (health, education and social services, police) on the one hand and Roma communities on the other hand. Unfortunately, the processes of isolation and self-isolation of Roma groups

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are growing and the mistrust and lack of cooperativeness among the representatives of the institutions is visibly increasing. Moreover, Roma communities are highly segregated, which results in vivid differences and stigmatization within the communities themselves. Individuals and families in this "double marginalized" position are particularly vulnerable to all kinds of social and health problems. Most often these people are the poorest groups of the community.

**c. What kind of target groups is this method "tailored" for?**

The POL model is "tailored" for human groups whose members have the awareness that they belong to a common community, have a clearly defined social life, a group structure (the leaders, outsiders and other structure roles are easily recognizable), socializing places and shared community norms of behaviour.

**3. Description of the method**

**a. Theoretical background**

POL is a participatory community-based HIV/AIDS prevention model. It focuses on identifying the most trusted, respected, and popular people within a community and having them personally endorse risk-reduction behaviours to their friends and acquaintances. POL is based on ideas that new behavioural trends can be established if enough popular people – whose opinions are valued by others – are actively seen and heard endorsing a new value.

In all social groups, certain people are more influential than others. These are the people who are well-liked and have opinions that are trusted by their peers. If opinion leaders advocate certain behaviour, the group will know this is an accepted norm among the people who are popular. The POL model identifies and trains these naturally popular and well-liked people to function as AIDS educators.

During the late 1980s Prof. Jeff Kelly developed the POL model in the Medical Institute of Wisconsin in Milwaukee, Wisconsin, USA as an HIV prevention intervention based on field observation among gay community and the Diffusion of Innovations Theory of Everett Rogers created during the 1950s in USA.

According to this theory **diffusion** is the process by which an **innovation** is communicated through certain **channels** over **time** among the members of a **social system**. Diffusion is a special type of communication concerned with the spread of messages that are perceived as new ideas.

Innovation could be defined as "an idea perceived as new by the individual". An innovation is an idea, practice, or object that is perceived as new by an individual or other unit of adoption. The characteristics of an innovation, as perceived by the members of a social system, determine its rate of adoption.

According to this theoretical concept **the four main elements** in the diffusion of new ideas are:

- 1) The innovation
- 2) Communication channels
- 3) Time
- 4) The social system (context)

If the intervention is planned based on this concept, these four elements should be the cornerstones in the planning process.

*1) The innovation*

Some new ideas are spread and adopted easier and more quickly than others. How could this phenomenon be explained and used? The characteristics which determine an innovation's rate of adoption are:

- Relative advantage

**Relative advantage** is the degree to which an innovation is perceived as better than the idea it supersedes. The degree of relative advantage may be measured in economic terms, but social prestige, convenience, and satisfaction are also important factors. It does not matter so much if an innovation has a great deal of objective advantage. What does matter is whether an individual perceives the innovation as advantageous. The greater the perceived relative advantage of an innovation, the more rapid its rate of adoption will be.

- Compatibility

**Compatibility** is the degree to which an innovation is perceived as being consistent with the existing values, past experiences, and needs of potential adopters. An idea that is incompatible with the values and norms of a social system will not be adopted as rapidly as an innovation that is compatible. The adoption of an incompatible innovation often requires the prior adoption of a new value system, which is a relatively slow process.

- Complexity

**Complexity** is the degree to which an innovation is perceived as difficult to understand and use. Some innovations are readily understood by most members of a social system; others are more complicated and will be adopted more slowly. New ideas that are simpler to understand are adopted more rapidly than innovations that require the adopter to develop new skills and understandings.

- Trialability

**Trialability** is the degree to which an innovation may be experimented with on a limited basis. New ideas that can be tried on the instalment plan will generally be adopted more quickly than innovations that are not divisible. An innovation that is trialable represents less uncertainty to the individual who is considering it for adoption, who can learn by doing.

- Observability to those people within the social system

**Observability** is the degree to which the results of an innovation are visible to others. The easier it is for individuals to see the results of an innovation, the more likely they are to adopt it. Such visibility stimulates peer discussion of a new idea, as friends and neighbours of an adopter often need more information about and more time for the evaluation of the new idea.

Within the frames of the POL model the new ideas are spread as simple messages created by the leaders of the community. The above mentioned five characteristics of the innovation are important cornerstones in the messages' creation process.

## 2) *Communication channels*

**Communication** is the process by which participants create and share information with each other in order to reach a mutual understanding. A **communication channel** is the means by which messages get from one individual to another. Mass media channels are more effective in creating knowledge of innovations, whereas interpersonal channels are more effective in forming and changing attitudes toward a new idea, and thus in influencing the decision to adopt or reject a new idea. Most individuals evaluate an innovation, not on the basis of scientific research by experts, but through the subjective evaluations of near-peers who have adopted the innovation.

## 3) *Time*

The time dimension is involved in diffusion in three ways:

On the first place, time is involved in the **innovation-decision** process. The **innovation-decision** process is the mental process through which an individual (or other decision-making unit) passes from first knowledge of

an innovation to developing an attitude towards the innovation. This process includes the decision to adopt or reject the new idea, to implement the new idea, and the confirmation of this decision. An individual seeks information at various stages in the innovation-decision process in order to decrease uncertainty about an innovation's expected consequences.

According to this theory the innovation-decision process has five stages which require their own time period. These five stages/steps are:

**Knowledge** - person becomes aware of an innovation and has some idea of how it functions.

**Persuasion** - person forms a favourable or unfavourable attitude toward the innovation.

**Decision** - person engages in activities that lead to a choice to adopt or reject the innovation.

**Implementation** - person puts an innovation into use.

**Confirmation** - person evaluates the results of an innovation-decision already made.

Furthermore, the second way in which time is involved in diffusion refers to the **innovativeness** of an individual or other unit of adoption. **Innovativeness** is the degree to which an individual or other unit of adoption is relatively earlier in adopting new ideas than other members of a social system. On the basis of innovativeness **five adopter categories** or classifications of members of a social system are defined:

- **Innovators** - the first 2.5 per cent of the individuals in a system to adopt an innovation

Venturesomeness is almost an obsession of innovators. This interest in new ideas leads them out of a local circle of peer networks into more cosmopolitan social relationships. Communication patterns and friendships among a clique of innovators are common, even though the geographical distance between the innovators may be considerable. Being an innovator has several prerequisites. Control of substantial financial resources is helpful to absorb the possible loss from an unprofitable innovation. The ability to understand and apply complex technical knowledge is also needed. The innovator must be able to cope with a high degree of uncertainty about an innovation at the time of adoption. While an innovator may not be respected by the other members of a social system, the innovator plays an important role in the diffusion process: That of launching the new idea in the system by importing the innovation from outside of the system's boundaries. Thus, the innovator plays a gate-keeping role in the flow of new ideas into a system.

- **Early adopters** - the next 13.5 per cent of the individuals in a system to adopt an innovation.

Early adopters are a more integrated part of the local system than are innovators. Whereas innovators are cosmopolites, early adopters are localities. This adopter category, more than any other, has the greatest degree of opinion leadership in most systems. Potential adopters look to early adopters for advice and information about the innovation. This adopter category is generally sought by change agents as a local missionary for speeding the diffusion process. Because early adopters are not too far ahead of the average individual in innovativeness, they serve as a role-model for many other members of a social system. The early adopter is respected by his or her peers, and is the embodiment of successful, discrete use of new ideas. The early adopter knows that to continue to earn this esteem of colleagues and to maintain a central position in the communication networks of the system, he or she must make judicious innovation-decisions. The early adopter decreases uncertainty about a new idea by adopting it, and then conveying a subjective evaluation of the innovation to near-peers through interpersonal networks.

- **Early majority** - the next 34 per cent of the individuals in a system to adopt an innovation.

The early majority adopts new ideas just before the average member of a system. The early majority interact frequently with their peers, but seldom holds positions of opinion leadership in a system. The early majority's unique position between the very early and the relatively late adopters makes them an important link in the diffusion process. They provide interconnectedness in the system's interpersonal networks. The early majority are one of the two most numerous adopter categories, making up one-third of the members of a system. The "early majority" may deliberate for some time before completely adopting a new idea. "Be not the first by which

the new is tried, nor the last to lay the old aside," fits to the thinking of the "early majority". They follow with deliberate willingness in adopting innovations, but seldom lead.

- **Late majority** - the next 34 per cent of the individuals in a system to adopt an innovation.

The "late majority" adopt new ideas just after the average member of a system. Like the "early majority", the late majority makes up one-third of the members of a system. Adoption may be the result of increasing network pressures from peers. Innovations are approached with a sceptical and cautious air, and the late majority does not adopt until most others in their system have done so. The weight of system norms must definitely favour an innovation before the "late majority" is convinced. The pressure of peers is necessary to motivate adoption. Their relatively scarce resources mean that most of the uncertainty about a new idea must be removed before the "late majority" feel that it is safe to adopt.

- **Laggards** - the last 16 per cent of the individuals in a system to adopt an innovation

They almost possess no opinion leadership. Laggards are the most locality in their outlook of all adopter categories; many are nearly isolated in the social networks of their system. The point of reference for the "laggard" is the past. Decisions are often made in terms of what has been done previously. "Laggards" tend to be suspicious of innovations and change agents. Resistance to innovations on the part of "laggards" may be entirely rational from the "laggard's" viewpoint, as their resources are limited and they must be certain that a new idea will not fail before they can adopt.

The third way in which time is involved in diffusion is in **rate of adoption**. The **rate of adoption** is the relative speed with which an innovation is adopted by members of a social system. The rate of adoption is usually measured as the number of members of the system that adopt the innovation in a given time period. As shown previously, an innovation's rate of adoption is influenced by the five perceived attributes of an innovation.

#### 4) *The social system*

The fourth main element in the diffusion of new ideas is the social system. A social system is defined as a set of interrelated units that are engaged in joint problem-solving to accomplish a common goal. The members or units of a social system may be individuals, informal groups, organizations, and/or subsystems. The social system constitutes a boundary within which an innovation diffuses. It has been studied how the system's social structure affects diffusion. A second area of research involved how norms affect diffusion. Norms are the established behaviour patterns for the members of a social system. A third area of research had to do with opinion leadership, the degree to which an individual is able to influence informally other individuals' attitudes or overt behaviour in a desired way with relative frequency. A change agent is an individual who attempts to influence clients' innovation-decisions in a direction that is deemed desirable by a change agency.

The "social system" is a fundamental element of the POL methodology. In order to find out who is functioning as a POL in a given community it is necessary to study their structure, their needs, their norms and as a main aspect their leadership system. The crucial question is: "What makes people leaders in this community"? Therefore it has been recommended to start with a need assessment and a sociometric approach to identify the leaders.

A final crucial concept in understanding the nature of the diffusion process is the critical mass, which occurs at the point at which enough individuals have adopted an innovation that the innovation's further rate of adoption becomes self-sustaining. The concept of the critical mass implies that outreach activities should be concentrated on getting the use of the innovation to the point of critical mass. These efforts should be focused on the early adopters; the 13.5 percent of the individuals in the system to adopt an innovation after the innovators have introduced the new idea into the system. **Early adopters are often opinion leaders, and serve as role-models for many other members of the social system. Early adopters are an instrument in getting an innovation to the point of critical mass, and hence, in the successful diffusion of an innovation.**

### **b. How is the community involved?**

Community members are involved at any stage of the intervention planning, implementation and evaluation. At the beginning innovators/gate-keepers are invited to become a part of the implementing staff. They are an essential part of the staff – mostly as outreach workers, who introduce the researchers in the community, help them to observe and understand the community's structure and behaviour, and to establish contact with the opinion leaders.

The young Roma men are invited to participate in the model's activities as opinion leaders. Their agreement and motivation are crucial to be approved by the researchers. The sociometrically selected leaders of the individual friends' networks are involved as creators and communicators of HIV prevention messages.

### **c. Programme management**

The management of the model's implementation is simple. The principal researcher coordinates the administrative, financial and research (ethical and scientific issues) activities. A coordinator is responsible for the outreach team and the research/trainer team. A supervisor is responsible for the professional standards of the training process.

### **d. What kind of human resources are needed?**

The model's implementation requires the following human resources: a principal researcher with professional background in psychology, sociology, social psychology and with administrative experience; a coordinator of the "field" team - with professional background in psychology, sociology, social psychology and with administrative experience; the "field" team – researchers (with professional background in psychology, sociology, social psychology), outreach workers (members of the community); trainers (with professional background in psychology, psychiatry, clinical social work and additional education in group training methods); a supervisor of the trainers (with professional background in psychology, psychiatry, clinical social work and additional education in group training methods and supervision); an accountant. A VCT service/team is recommendable to be included in the resources and activities.

### **e. How is the training of staff and mediators organized (content, structure, methods, duration)?**

Despite the professional education and training of the researchers and trainers, the whole team (professionals and outreach workers from the community) needs a specialized training in outreach work, team work, and scientific bases and implementation planning. The training of the staff combines both – three-day long residential team- building and on-going training in the learning-by-doing manner (form of team meetings and supervision).

### **f. What other resources are needed (finances, materials, time, space, etc.)?**

#### *Premises*

The sociometric survey, the KAB survey should be conducted in a confidential environment; the POLs' training needs a big room. HESED has established a health and social centre in the Fakulteta neighbourhood. Since 2003 this centre has been the only place in this neighbourhood where medical services, HIV/AIDS and STI prevention, and personal and community development activities have been provided.

#### *Time*

The POL intervention is time consuming. One year is an appropriate period for its implementation and evaluation. Three to five months are needed for the preparation – choosing the target group, observing the social life and structure of the community, recruiting gate keepers, baseline with KAB questionnaire, and first

contacts with the POLs. The next step – recruiting and training of the POLs – depends on the size of the target group. If the group consists of 100 people approximately, according to the model 15% should be trained, i.e. there will be 15 POLs at least. If the group is heterogeneous and different sub-groups cannot be trained together (due to existing norms and/or inner-group conflicts, different levels of motivation to participate in the training), two training groups have to be conducted. The duration of the whole training of one group is three months. The evaluation stage needs several months as well – follow up with the KAB questionnaire, processing and analyzing the data, and finally, evaluation of the whole implementation process and results.

#### *Financial resources*

Finances are needed for staff's remuneration, office expenses and utility costs, incentives for the interviewed members of the community and for the trained POLs, research costs (hard- and software, stationary, transport, room rental etc.), training costs (room rental, stationary, educational materials, catering etc.), HIV/AIDS and STI testing (consumables, tests, laboratory equipment etc.).

#### **g. How are the participants identified, selected and recruited?**

As HESED has experience in implementing the POL method, the team is also familiar with identifying the target population, the channels of informal contacts as well as the informal and formal leaders. HESED's team is experienced in identifying the places where these people usually socialize with each other (see 2.a.). HESED has been working among the biggest Roma Communities in Bulgaria (Roma neighborhoods in Sofia – 30 000 people and Plovdiv – 50 000 people). All big Roma communities can be divided in sub-groups according to distinction marks like religion, social status, language, economical status etc.

The size of the target population determines how many POLs need to be trained. As was mentioned above (see 3.f.) 15% of a population has to be trained as POL in order to have an optimal effect. It is further recommended to start the implementation of POLs with one of the subgroups of the community and then to implement the method gradually in other subgroups and not simultaneously.

#### *Some specifics of the POL implementation in Bulgaria*

With exception of female sex worker networks, in many cases it seemed difficult and ineffective to recruit women for POL training. In case of HESEDs experiences of work with Roma communities', women are often ashamed. Men are often embarrassed and feel uncomfortable due to fact that normally they want to make the decision of using a condom or not. But this experience is not automatically transferrable to other communities of migrants or ethnic minorities.

During the recruitment process it is important to identify the social norms of the community. For example in a MSM community girls are very often close friends of the gay men. This knowledge can be used for the POL recruitment. As women are just female friends and no sexual partner of the men, they function very well as channels of information, e.g. in bars.

#### *Preliminary work/ preparation stage*

##### Mapping of the community

As a first step of the intervention a "mapping of the community" has to be undertaken in order to identify the POLs. The preliminary work includes the following important steps:

- 1) Identifying the group
- 2) Identifying the places, where people of the group meet
- 3) Identifying the values of the group
- 4) Identifying the friendship group
- 5) Who of them are visiting this particular places?
- 6) Who of them has characteristics of a POL?

- 7) Identifying who has the power - Identifying who are the people who “pull the strings”? (Usually these people are trying to keep the status of the group.)

The type of leaders who are needed for the POL intervention should have the following characteristics:

- Popular in the informal context
- Trusted by their friends
- Contacted for advice and support
- Listened to by their peers
- Popular among their friends
- In the venue they are more often contacted than other people.

The leaders may also have risky behaviour – this depends on the group’s norms. According to the POL methodology it is not intended to correct the behaviour of the POLs, but to prevent them from HIV/AIDS. The behaviour of POLs is not necessarily “good”, but they are persons who are well-liked in the community. In order to get their support the trainer team needs their trust.

There are five main approaches for identifying the “right people” known also as the sampling of the POL-group.

In practice usually the five approaches are applied in combination. Each approach has its own data collection form (questionnaire, which is used during the needs assessment in the community). These instruments have been applied in the work of HESED and can be easily adopted and modified to other work situations.

#### First approach: Recommendation of community leaders or gatekeepers

When the gatekeepers have been identified it is necessary to meet them several times and to clearly explain to them the POL methodology in order to encourage them to participate in the programme. Even if the POLs were nominated by the gatekeepers, the staff has to check first whether these persons meet the criteria of a POL.

#### Second approach: Observation of the venues / places by the agency’s staff

The used method is the direct observation, i.e. the staff goes to the venues of informal contact to identify informal leaders. The main goal of the observation is to understand and define the specific circles of friends (social networks). These first observations are supported by gate-keepers and some of them are hired as outreach workers.

If there are indoor venues the permission of formal leaders is needed. The task of the programme staff is to explain the objectives / activities to the owners of the bars (venues). It is very useful to provide the owners with flyers or brochures of the ongoing intervention.

Another method is the “cold observation” – when entering the venue the observer should spend some time before getting in direct contact to the target group in order to allow the group to get used to the observers.

Third approach: Based on information/experience of previous programmes/projects the team has conducted (such as prevention programmes, social support programmes, educational programmes etc.). The contacts with community members can be used as a trigger point for the recruitment of POLs.



#### Fourth approach: Survey of the community to find out who is most popular (sociometric approach)

This approach is time consumable but the results are most detailed and informative. The selection of the POLs is evidence-based and objective. The survey should be conducted in different social networks. The applied instruments are sociometric questionnaires. Each member of the social networks needs to be interviewed. The collected data should be processed with sociometric methods and to be analyzed. This approach provides a “map” of the relationships of the surveyed social networks.

#### Fifth approach: Asking for POLs / nomination (volunteers for POLs)

Very often people say that they like to participate in the programme and are very interested, but in fact they are not the appropriate person. This is a quite sensitive issue. On the one hand, the programme staff likes to support the community, but on the other hand the rules of selection have to be respected. In order to find the right POL the group dynamic has to be observed and understood.

According to the experience of HESED the first contact is initiated by the leaders of the target population. Normally the leaders are very curious and like to learn, although they are also doubtful concerning the intention of the programme staff. After they have been convinced of the purpose of the intervention, the leaders are cooperative.

#### Empowering of the identified POLs

After having identified the POLs of a community the staff has to present themselves. In a next step their task is to convince the person to participate in the training as a POL. In the context of empowering the person aspects such as personal profit and helping the community can be underlined. It is highly important to make the person aware of his/her strengths that:

- s/he is pointed out by the community as a leader
- s/he is able to support his friends
- s/he is very important for the HIV prevention work
- In the end the agreement of the POL to participate in the training is needed.

Leaders recruit leaders: At a later stage when the right persons have been identified as leaders they are asked to nominate persons who have similar characteristics for POL. This has mostly a positive impact.

#### **h. What kinds of intervention methods (instruments, tools and techniques) are used?**

- i. What is the main intervention instrument(s) in this model?

The main intervention methods are: (1) selection and recruitment of popular opinion leaders and (2) the training of the selected leaders. The first one was described thoroughly in the previous point. The second one will be described in the next point.

- ii. How is this main instrument(s) implemented?

The implementation of the POL model has several steps:

- 1) Preparing for POL intervention: The first step is to identify an appropriate population to be targeted and to identify the places (venues) where this population could be reached. Programme logos have also to be prepared.

- 2) Identifying and recruiting POLs: After the population and venues have been identified, the regular visiting and observing of these places should start. The POLs could be identified and recruited by observing the interaction between the population members.
- 3) Training of POLs to become effective risk reduction advocates: The training programme consists of four basic and four maintenance sessions. They are scheduled as follows: the basic sessions should be conducted once per week; the first two maintenance sessions – once every two weeks, and the last two maintenance (reunion) sessions – once per month. The POL model relies on opinion leaders to deliver risk-reduction messages in their everyday conversations with friends and acquaintances. This approach is supposed to change the existing norms in the targeted population. This is why this new behaviour (new conversation's topics and content) needs time to be accepted. During the acceptance period it is recommendable that the POLs are being supported by the implementation team. This role can be taken over by the maintenance sessions.

The training is based on the following programme:

Session 1:

- Explain that all members of the group are special people, popular with others.
- Explain that members will be taught how to share prevention messages about HIV/AIDS and STIs.
- Provide POLs with accurate HIV and STI information.

Session 2:

- Review risky behaviours prevalent in the community.
- Understand strategies to make risk reduction changes.
- Help POLs develop risk reduction messages.

Session 3:

- Train POLs to deliver effective prevention messages in conversations to other members of the target population.
- Give POLs the opportunity to role play their HIV/AIDS prevention conversations.

Session 4:

- Provide feedback and coaching to the POLs first conversations as well as discuss barriers to conversations they have encountered.
- Inspire the POLs to continue to have effective prevention messages in conversations.

Reunion sessions:

- Thank POLs for their efforts and continued participation.
- Encourage POLs commitment to disseminate messages.
- Motivate POLs to continue their efforts to make a difference in their community.
- POLs improve their communication skills during the training sessions by watching the trainers` model of effective messages and are trying out these skills with each other. By scheduling training sessions once a week the POLs are given time to practice risk reduction messages with friends and family members between sessions. At the end of each session, the POLs define a goal which they will try to accomplish by the time the group will meet again. This planning exercise is especially necessary for Roma communities as one of the special features of their members is the lack of planning and goal setting skills. On the other hand, thinking about prevention requires exactly these specific life skills (to "think ahead" and manage his/her own behaviour).

- 4) Evaluate the intervention and troubleshooting, if necessary: successful interventions require evaluation. Monitor and measure how the implemented model is meeting the prevention goals. This process is important for reconsideration of possible improvement.

iii. In which settings was it implemented?

All model's activities are recommendable to be realized among the community. The observations, recruitment, first contacts with the Roma youth and the conversations of the POLs with their friends happen in the places where they normally gather to socialize. The individual conversations between the recruited boys and the researchers, and the training of the selected POLs take place in HESEDs premises of the health-and-social centre for community development in the Fakulteta neighbourhood.

#### **i. Important rules for successful implementation**

The POL model is characterized by 16 core elements whose compliance assures the effectiveness of its implementation:

- 1) Intervention is directed to an appropriate and identifiable target population that engages in risky HIV behaviour.
- 2) Target population meets at well-defined meeting places where they naturally gather to socialize (a venue).
- 3) Venue population is of an appropriate size (100 -1000 members) to work with intensively.
- 4) Intervention systematically identifies and recruits individuals from the venues to serve as disseminators of information.
- 5) Individuals are recruited because they are popular, respected, well-liked, influential and trusted.
- 6) Individuals are recruited from the target population.
- 7) At least 15% of the members of the target population in the venues have been trained as POLs.
- 8) Participants attend small group training sessions. (Normally 4 core sessions and 3-4 reunion sessions.)
- 9) Participants attend at least two or more trainings sessions.
- 10) Participants are taught to disseminate risk-reduction messages to others.
- 11) Participants are taught to incorporate risk-reduction messages in everyday conversations with members of the target population.
- 12) Participants are taught how to communicate on effective behaviour change (risk-reduction) in the course of everyday conversations.
- 13) Training includes opportunities for participants to role play delivering HIV risk-reduction messages.
- 14) Participants set goals for engaging in risk-reduction conversation with others.
- 15) In later training sessions participants have the opportunity to discuss how their risk-reduction conversations went, including overcoming barriers encountered.
- 16) Logos, symbols or other devices are used to stimulate conversations between participants and other members of the population.

Furthermore, the composition of the trainer team is very important. The team is composed of both gender (a woman and a man). It is recommendable that both main trainers have a professional background (psychology, psychiatry, social work) and additional education in interactive training/group work. Usually these trainers are "outsiders" for the community. Thus, the trainer team has to be completed with a para-professional (outreach worker) from the community.

It is important to emphasize that this intervention is time-consuming among the Roma communities as to reach the needed POLs and to gain their trust is a long-term process.

Last but not least, the POLs have to be selected precisely. In the Roma communities there usually are community leaders who are extremely powerful within their community due to their economical and formal power. These leaders are not appropriate for the purposes of the POL model. They should be informed prior to the intervention that informal leaders of small friendship/social networks of young Roma are needed.

#### **j. What kind of professional supervision is needed?**

The outreach team needs a regular professional supervision by a psychologist/clinical social worker in order to prevent the burn-out syndrome and to develop the most successful strategy to motivate the selected leaders. Furthermore the trainers' team needs a regular supervision by a specialist in group trainings.

### **4. Monitoring and evaluation**

#### **a. What documentation is needed?**

Besides the administrative and financial documentation, research and training documentation is highly important for the model.

Research documentation includes protocols for the observations (description of the venues and the social networks there – their size, norms, language, active hours, risky behaviour, leaders etc.), sociometric and KAB questionnaires. The training documentation includes lists of participants' attendance, conversation grids for each trained POL (a table with planned and realized conversations with their friends).

#### **b. Which assessment methods/tools are used?**

The evaluation is an essential part of the POL model. A basic evaluation plan should combine quantitative, qualitative and process measures.

Quantitative measures assess the target population's knowledge, attitudes, behaviours, and intentions before and after POL implementation. Moreover, they present numeric responses in easy-to-understand statistics. Adequate for the POL goals is a KAB questionnaire, structured/semi-structured interviews, check-lists etc. Qualitative measures (such as observations, in-depth unstructured interviews, and focus groups) are used to describe, analyse and interpret data. The process methods (e.g. progress notes, meeting minutes, flowcharts etc.) are used to assess programme implementation and congruence.

Before and after the intervention (the POLs training) a KAB questionnaire on the target population should be conducted. The comparison between baseline and follow-up data gives a feedback regarding the effectiveness of the intervention.

During the intervention: Keeping detailed records about the intervention gives the opportunity to replicate the programme in the future. Usually process methods are used which permit to identify potential problems. A simple table can be used to:

- Track the number of POLs attending reunion sessions
- Quickly calculate how many POLs are still having conversations
- Determine whether you need to train additional POLs

The progress can be assessed by using simple qualitative measures (e.g. a focus group with gate keepers). This information will help to continue tailoring the programme to the population.

**c. What are the main indicators for effective implementation?**

Indicators for the positive effect of the intervention on the target population include:

- Decreased rates of risky behaviour
- Increased knowledge of preventive measures
- Increased willingness to engage in preventive measures.

**d. How is the feedback of the community gathered?**

The feedback of the community about the effectiveness of the intervention is gathered with the means of the quantitative KAB research form by one or two follow-ups after the intervention (during the first month and 6<sup>th</sup> months/12<sup>th</sup> months after the intervention). Moreover, the feedback and reactions of the POLs friends are thoroughly discussed during each session of the training. At the end of each training a small party is organized all POLs' friends are invited and are asked for feedback.

**5. Results achieved**

**a. Qualitative and Quantitative**

All results of the implementation of the POL model among Bulgarian Roma community are published in international scientific magazines and journals (see list of publications below). The qualitative results are described in the next point "Findings about the group".

**b. Feedback from the community**

The feedback of the Roma community is positive. The main benefit for the young men is that "now we know how to protect our health – our and the health of our families and children". More shared benefits are: "I feel part of the big world", "I care more for myself", etc. The feedback shows that besides the direct impact on the risky sexual health behaviour the intervention has added value to the inclusion of the Roma youth by involving them in a process causing and developing their social skills.

**6. Lessons learned**

**a. What are the strengths of this model?**

The POL model is an evidence-based, cost-effective and a time-sustainable intervention among different kinds of communities. It is easily adaptable for different group contexts, because it uses the natural human relations and leadership norms in order to decrease the health risks for the single individual and for the whole community. It is a community level intervention which invests resources (knowledge and skills) in powerful community members and thus has an impact on the community development and community self-organization.

**b. What are the limitations of this model?**

The proper implementation of the POL model is time-consuming. Time is needed to understand deeply and correctly the community norms, to select and motivate the real opinion leaders, to support their new behaviour and to change the targeted behavioural norm.

### c. What kind of obstacles were met and what are the possible solutions (plan B)?

The first and most important barrier in the Roma community is to gain the trust of the people and to receive the “permission” of those who hold the inner power of the community. A conversation with the community leaders (pastors, rich people, representatives of old families etc.) is recommendable. Plan B for this possible difficulty is to recruit gate-keepers who will introduce the programme and will introduce the team to the social life of the community. The trust of the Roma community where HESED has worked is gained by long-term (since 1999) and constant programmes adequate to the community needs.

### d. Measures of sustainability

The results presented in the article published in the British Medical Journal (2006) showed that the “prevalence of unprotected intercourse in the intervention group fell more than in the control group (from 81% and 80%, respectively, at baseline to 65% and 75% at three months and 71% and 86% at 12 months second follow up). Changes were more pronounced among men with casual partners.....”. (Kelly, J.A. & co., 2006))

All results of the ten -year long intervention of POL among Bulgarian Roma community have been summarized and published (see list below). They evidence the impressive impact of the intervention on the community and the significant and sustainable change of social networks’ norms, individual knowledge, attitudes as well as behaviour aimed to decreasing the sexual risky behaviour.

### e. Findings about the group/community

#### i. Attitudes, norms

The direct work and the research among the Roma community increased the knowledge of HESED’s staff about its patterns of behaviour and why the people are so deeply rooted in these patterns. Some of the findings are:

**Gaining trust:** The Roma communities are very eager to get attention, because they are usually very isolated. Often they think that the project staff will take care of their needs.

**Testing:** The testing situation of HIV, Hepatitis and Syphilis seems to be a complex situation and it takes a lot of effort to motivate Roma community members to go for a test. Characteristic for them is the perception that they are not ill till they feel pain. As a result of the POL intervention the numbers of those who want to be tested have been increased.

**MSM and Roma:** The question of sexuality is very particular in the Roma community. People who see themselves as gay or homosexuals are in fact often transsexual.

MSM practices are very spread, most often in the way of sex work. About 65% of the men between 14 and 20 have experience with sex with other men. At the same time they regard themselves as heterosexual and sometimes they get even married. There are worrying tendencies among the married men like selling sex for business purpose. Many of them agree to have sex without a condom. This is the reason why we mostly implement POL among this target group.

Other findings are thoroughly described and available in the scientific publications listed below.

#### ii. Use of these findings during the programme implementation and possible future use

All findings were put in practice in order to establish trustful contact with the community members, to develop adequate intervention and to create powerful HIV prevention messages.

## **7. Accessibility and materials: handbooks, reports, media produced, resources available for implementing the model.**

The POL model is accessible by contacting CAIR (Center for AIDS Intervention Research), Medical College of Wisconsin, USA (contact person – Prof. Jeffrey Kelly) and HESED (Health and Social Development Foundation, Bulgaria).

All results of the POL intervention among Roma community in Bulgaria are available in:

- Amirkhanian Y.A., Kelly J.A., Kabakchieva E. et al., *Evaluation of a Social Network HIV Prevention Intervention Programme for Young Men Who Have Sex with Men in Russia and Bulgaria*. In: AIDS Educ. Prev. 2003, 15(3): pp. 205-221.
- Amirkhanian Y.A., Kelly J.A., Kabakchieva E., Kirsanova A.V. et al., *A Randomized Social Network HIV Prevention Trial with Young Men Who Have Sex with Men in Russia and Bulgaria*. In: AIDS. 2005, 19(16): pp. 1897-1905.
- Kabakchieva E, Amirkhanian Y.A., Kelly J.A. et al., *High Levels of Sexual HIV/STD Risk Behaviour among Roma Men in Bulgaria: Patterns and Predictors of Risk in a Representative Community Sample*. In: International Journal of STD & AIDS, 2002, 13(3): pp.184-191.
- Kabakchieva E., Vassileva S., Kelly J.A. et al., *HIV risk behaviour patterns, predictors, and STD prevalence in the social networks of young Roma (Gypsy) men in Sofia, Bulgaria*. In: Sex Transm Dis. 2006; 33(8): pp. 485-490.
- Kelly J.A., Amirkhanian Y.A., Kabakchieva, E. et al., *Prevention of HIV and Sexually Transmitted Diseases in High Risk Social Networks of Young Roma (Gypsy) Men in Bulgaria: Randomized Controlled Trial*. In: British Medical Journal. 2006; 333(7578): pp. 1098-1101.
- Kelly J.A., Amirkhanian Y.A., Kabakchieva E., Csepe P., et al., *Gender Roles and HIV Sexual Risk Vulnerability of Roma (Gypsies) Men and Women in Bulgaria and Hungary: An Ethnographic Study*. In: AIDS Care. 2004; 16(2): pp. 231-245.
- Kelly, J.A., Amirkhanian, Y.A., Jeffrey A., Kabakchieva, E., Antonova, R. & co., *High-risk sexual behaviour, HIV/STI Prevalence, and risk prediction in the social networks of young Roma (Gypsy) men in Bulgaria*. In: Journal Migrant Minority Health, DOI 10.1007/S10903-012-9596-4, Springer Science+Business Media, LLC 2012.

## **8. What further development and implementation of the model could be possible in the future?**

The POL model is easily applicable for a vast range of communities at high HIV/AIDS risk such as youth, migrant groups and ethnic minorities.

Resources:

<http://www.stanford.edu/class/symbys205/Diffusion%20of%20Innovations.htm>

[http://www.tcw.utwente.nl/theorieenoverzicht/Theory%20clusters/Communication%20and%20Information%20Technology/Diffusion\\_of\\_Innovations\\_Theory.doc/](http://www.tcw.utwente.nl/theorieenoverzicht/Theory%20clusters/Communication%20and%20Information%20Technology/Diffusion_of_Innovations_Theory.doc/)

# The AIDS & Mobility Project

Ramazan Salman, Jury Kalikov and Sirle Blumberg

## 1. Name, author and implementation agency

The AIDS & Mobility project is an international project in the field of HIV prevention among ethnic minorities and migrant groups. It was funded by the EU Public Health Programme and coordinated by the Ethno-Medizinisches Zentrum (EMZ) Hannover (Germany) in the period 2007-2010. The main aim of AIDS & Mobility Europe is to reduce HIV vulnerability of migrant and mobile populations in Europe.

The main project's objective was to create a system of mediators training in migrant/minority communities in six countries. The participating countries are: Germany, Italy, UK, Denmark, Turkey, and Estonia. At the beginning seven organizations, had started the project, but two of them discontinued with the AIDS & Mobility project.

In the present manual the Estonian experience is described. The implementing NGO in Estonia was AIDS-i Tugikeskus (AISC - AIDS Information and Support Center). It is a social non-profit non-governmental (NGO) organization which was founded 01.02.1994 by a group of volunteers in Tallinn, Estonia. For the implementation of the AIDS service organization the AIDS-i Tugikeskus team uses the model of the Finnish AIDS Tugikeskus (now Finnish AIDS Council). AIDS Tugikeskus is based in Tallinn and has two departments:

- 1) Kopli 32, 10412, Tallinn. In this department HIV and STIs testing and consultation cabinet is operating, serving the general public and vulnerable groups (sex workers, LGBT, drug addicts etc.);
- 2) Erika 5a, Tallinn. This department was created to serve intravenous drug users: consultations of different specialists, needle exchange, methadone treatment, rehabilitation services including rehabilitation commune etc.

Regarding the working plan of the AIDS & Mobility project, training schedule and piloting models were planned to run on the same principle in each country. These principles include:

- To **develop an innovative health education model** for migrants and ethnic minorities: Literature review, curriculum, guidebook, slide-kit
- To **implement structured transcultural mediator training and to conduct educational group sessions** on HIV/AIDS: Six training platforms in six countries, 120 mediators to be certified, raining quality to be measured, 240 community sessions to be held, 2400 young migrants to be reached.
- To **strengthen the existing network structures of HIV prevention among migrants**: Network, constituency and map of services, partner activity reporting, legal registration
- To **evaluate performance and outcomes**: Common reporting requirements, bilingual questionnaires, evaluation report
- To **disseminate the results** and communicate them broadly: Enhancing awareness among local health and scientific community documentation centre, project website, project newsletter, materials to be distributed, media reports
- To **design adequate strategies to assure continuity of the approach**: Potential partners map, sustainability plan, project briefings, master toolkit
- To **influence European and National policy making**: Policy briefings, technical support, CSF participation, policy summit report, common recommendations, future development report



However, the Estonian model which was adapted and piloted by AISC together with specialists from the NGO “Living for Tomorrow” (Prevention and Sexual Health Training in Youth AIDS Prevention), introduced some changes considering the particularities of the local context.

## **2. On which grounds is the community selected?**

### **a. What kinds of methods are used in the process of selection (community assessment, mapping, research, and official statistics)?**

The target group for the HIV prevention activities of AIDS & Mobility intervention were young people aged 16-25 from Russian speaking national minorities in Tallinn.

This group was selected by the AISC due to NGOs previous experience with their members (during the last five years). The conclusions of this experience showed that the most vulnerable group towards HIV/AIDS and STI was precisely this group (see description below). Moreover, the already established relations between the AISC and members of this national group had been a reliable base for further intervention.

During previous activities of AIDS & Mobility Network a needs assessment was conducted whose results underlined the high vulnerability of this group.

### **b. Description of the community**

#### *Ethnic minorities in Estonia*

Within the framework of the Estonian A&M project the community to be addressed were the Russian speaking citizens, natively Russians, Belarusians, Ukrainians or other nationalities. These community groups can not be considered as "migrants" in Estonia, as the majority of them were born in the country. Thus, they do not identify themselves with the term "migrant".

In Estonia the term “migrant” is not popular due to the specific situation. After becoming part of the European Union there is no significant number of migrants. In 2009 only 40 persons applied for a status of asylum seekers. The labour migration is not significant as well.

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However, in Estonia the demographic situation is quite specific – out of 1.34 million inhabitants 65% are Estonians and the other 35% are representatives of different national minorities. Thus, the ethnic minorities in Estonia are defined as national groups. These are: Russians 28%, Ukrainians 2,5%, Belarusians 1,5%, Finns 1%, and several smaller groups. They are not only defined by nationality, but by the way and purposes of migration (studying, labour migrants, family reunion etc.).

#### *HIV/AIDS among the Russian national minority*

The Russians are the biggest national minority group in Estonia. It is the most vulnerable group towards HIV/AIDS/STIs transmission as well. Official data regarding HIV/AIDS and STI prevalence in the target ethnic minority/ migrant groups is not available as dividing national HIV/STIs statistics by nations was never accepted in Estonia. Only speculations can be made by using HIV regional statistics, research statistics on the number of IDUs in different regions, and HIV prevalence statistic in regions of a compact Russian speaking population.

### *Inner self-organization of the Russian national minority*

The Russian national minority is very well organized, there are several community-based NGOs, working with cultural, political and educational aspects. Some of these NGOs are united under a “roof organization” – the National Network of National Minorities Associations.

In the field of HIV/AIDS prevention there are national minority group based NGOs. The access of the Russian ethnic group to HIV prevention information has been improved during the years of the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM) programme (2004-2007). The most trusted channels of information are: the Russian radio, Russian newspapers, Russian news portals on the Internet and Russian versions of main governmental web pages concerning HIV/AIDS. The access to HIV prevention materials (condoms, lubricants, clean syringes/needles/other injecting equipment etc.) is quite satisfying according to the NGOs working in the field. In all VCTs in Estonia condoms and lubricants are free of charge. There is a network of youth health counselling centres, where young people also have free access to condoms and lubricants, other methods of contraception and some testing possibilities. The main obstacles were the long-time absence of the sexual education component in the school curriculum concerning health education and the conservative frames of sexual education in the families.

#### **c. What kind of target groups is this method “tailored” for?**

The described model is “tailored” for communities whose members have the awareness that they belong to a common community. The community itself should have a high level of self-organization which means that some of the community members should have the educational and socio-economic status to work at official and established institutions for community development (schools, media, NGOs, trusted communication channels etc.).

Moreover, the model is suitable for communities in a high risk situation for HIV/AIDS and STI transmission and where various taboos related to sexuality exist among different generations.

### **3. Description of the method**

#### **a. Theoretical background**

Specifically, the project conducted in 2007-2010 was based on the transcultural health mediator approach “MiMi”<sup>5</sup> developed by migrants at the EMZ in Germany. Since 1992 the Migranten-AIDS Projekt (MAP) and the “Kultursensible AIDS-Mediatoren Ausbildung” in Hamburg (KAMAHH, 2005/6) have recruited, trained and supported transcultural mediators in HIV/AIDS prevention within migrant communities.

In this approach two different social groups are involved:

- 1) Socially integrated, bilingual migrants, legal residents, trained as transcultural mediators
- 2) Migrants (mostly with a lower level of social integration), who participate in community group sessions led by transcultural mediators

EMZ has considerable experience in the development and transfer of transcultural mediator programmes across 24 sites in Germany. The similar dissemination impact of the work in migrant communities is anticipated in AIDS & Mobility 2007-2010 project. Coordinator of the overall project and one of the authors of

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<sup>5</sup> World Health Organization – Regional Office for Europe (2007), Socio-economic Determinants MiMi – Mit Migranten für Migranten - With Migrants for Migrants  
[http://www.euro.who.int/socialdeterminants/socmarketing/20070403\\_2](http://www.euro.who.int/socialdeterminants/socmarketing/20070403_2)

the AIDS & Mobility model is Ramazan Salman, Executive Managing Director of the Ethno-Medizinisches Zentrum e.V. I (Ethno-Medical Center) in Hannover, Germany.

#### **b. How is the community involved?**

The community is involved in the following project levels:

- Project team: One of the trainers of the educational module had an Ukrainian background. The lecturers and specialists involved in the training of mediators were Russians, Ukrainians, Estonians, and Belarusians.
- Intervention: Firstly, all trained mediators were selected to be community (Russian-speaking national groups) members. Secondly, all young people trained by the mediators were representatives of the Russian-speaking national groups.

#### **c. Programme management**

The AIDS & Mobility project was carried out by the following team: a coordinator (who was expected to take over the administrative responsibilities and to play an expert role in the training as well), a team of trainers and medical specialists-lecturers.

#### **d. What kind of human resources are needed?**

The training of mediators was organized and provided by a general team consisting of representatives of the following NGOs:

- 1) AIDS-i Tugikeskus
- 2) AIDS Prevention Centre
- 3) Living for Tomorrow
- 4) Medical Center Tervisekeskus Elulootus

Valuable and important for the project implementation were the contacts with the NGOs Union of Sexual Health and Union of National Minorities organizations, the Unemployment Center of Labour Market Department, the youth counselling centres, the Ministry of Education as well as the Tallinn Social and Health Department.

#### **e. How is the training of staff and mediators organized (content, structure, methods, duration)?**

The trainers had professional background in psychology and medical sciences. The accent was put on the main intervention method the "Training of Trainer (ToT) for the mediators. The Estonian A&M Training of cultural mediators comprised 50 hours of training (evening sessions and weekend training) which were divided in two parts:

Part I: Theory of AIDS and Migration. It consists of eight sessions, four hours each with focus on:

- Introduction / Migration and HIV/AIDS
- Basic knowledge of HIV/AIDS
- Basic knowledge of Hepatitis
- Support system and services
- Living with HIV/AIDS

- Family planning and sexual health
- Why don't we talk about sexuality?
- Basic knowledge of harm reduction (exchange of syringes, safer use, substitution)

Hereby, it should be noticed that the topic of the second last session was suggested by the Estonian trainers and adapted in Russian language for the training materials. This topic "**communication about sexuality**" is an important cornerstone when addressing the issues of HIV/STIs risks and when various gender, cultural norms and stereotypes spread in different communities have to be handled. In this regards, this is a contribution to the European curriculum of AIDS & Mobility which has created added value for the whole project's outcome; moreover if it were considered in the other countries and other language versions.

Part II: Practical Methods. It consists of three weekend sessions six hours each, implemented in between and at the end of the theoretical sessions (Part I). The covered topics are:

- Didactics and the employment of media at A&M information events
- Preparation of an A&M information events
- Exemplary organization of an information events
- Organizational tips for the organization of an information events
- Practical presentation
- Evaluation

The sessions were conducted in an interactive "**learning-by-doing**" manner.

**f. What other resources are needed (finances, materials, time, space, etc.)?**

The preparation for the training took one year, the training process including the certification another six months. Beyond that all trained mediators had the task, stipulated by a contract with the local coordinator, to organize and to conduct two community educational sessions for up to ten participants each within two months. The whole process was preceded by the selection of mediators; a prerequisite for the success of the training was the identification and recruitment of appropriate mediators.

**g. How are the participants identified, selected and recruited?**

One of the most important preconditions for the successful implementation of the intervention is the process of the selection and recruitment of the mediators. This process is characteristic only of the Estonian A&M project.

Initial and crucial questions hereby were: How to identify and attract skilled and interested community representatives? How to assure their participation in the time-consuming high-threshold training (50 hours) and the effective application of the experience gained afterwards? The approach used by the team on the spot was not through establishing contacts with the background communities and their "gate keepers". Several internationally developed advertising media (poster, leaflet) were proposed for the whole project co-ordination. They aimed to announce the call for mediators and to attract interest in the communities in charge. According to the Estonian partner's opinion the channels, which turned most effective, was a spot in the Russian speaking radio channel.

As a result of this recruitment approach a lot of interested community representatives were reached. From the beginning of the selection procedures the A&M team made the threshold for participation explicitly clear: intensive and lengthy training programme over one and a half months (availability during the week for 8

evening sessions and during the weekend for three longer sessions). In addition, the certification was offered only to those who pertained to the training programme and attended at least 40 of the planned 50 hours of training. In such a way, the project team implemented its concept of quality assurance of the training trying to keep the drop-outs as low as possible.

The selection and interviews of candidates took two months. 24 mediators were selected (target was 20). All 24 selected mediators completed the training course.

What was the success clue of the training and how was it (positively) influenced by the specifics of the community selected in Estonia?

The profile of the mediators (some socio-demographic data about them): all of the selected mediators were Russian speaking belonging to Russian-speaking ethnic communities in Tallinn. The age range was 20 to 50 years; there were actually very few "true" peers from the perspective of adolescents and young people, the selected target community of the project. The majority of the selected mediators (21) were women, only three were men. The education background of some of the mediators was assessed as favourable to the training intervention: teachers, social workers, social workers in prisons. Some of the mediators were unemployed. Such profile of the selected mediators suggests that the Estonian A&M team focused more on the "expert" role of the mediators, many of them being multipliers working in institutional contexts (school, youth centre, and prison). The latter enabled an easier access to the targeted group (young people at high risk).

**h. What kinds of intervention methods (instruments, tools and techniques) are used?**

- i. What is the main intervention instrument(s) in this model? How is this main instrument(s) implemented?

The main intervention "instrument" of this model is the selection and training of mediators. These A&M components were already described in the previous points.

The methods applied in the training could be divided in two groups:

- Knowledge-based methods: Communication and acquisition of knowledge, including theoretical knowledge
- Ability-based methods: Communication and acquisition of skills and social competence

Both groups of methods could be implemented by interactive plays and techniques. The selection of the interactive exercises is very important for the successful training of the mediators in a "learning-by-doing" manner. Here are some group exercises used by the Estonian team:

*Exercise 1: The group is divided in two parts. Each small group (three to four members) has a flip-chart paper with a drawn tree with roots, branches and fruits on it. The tasks of the two groups are different: "A 16-years old girl gets pregnant" and "A 16-years old boy gets an STI". These two statements are written down on the tree trunk; the technique which is used is named "the problem tree". The roots of the tree illustrate the causes, the fruits the consequences.*

*The two groups have the task to fill in the causes and consequences areas with suggestions from the perspective of the 16-years old protagonist. Doing that, the group members have their own target person/community/friends in mind.*

*Summing up in a plenary group the facilitator emphasizes the importance of getting a true impression of the problem and the way it is perceived by the target community members. Then the related consequences can be only addressed with specially tailored interventions for behaviour change and risk reduction.*

*Exercise 2 is focused on condoms, condom quality, variety, types. Triggering questions are: "Which condoms brands do you know? Where do you buy condoms, or where would you go if you like to buy one. What do you look at when buying condoms?". Based on the group brainstorming a very informative discussion and exchange should take place of how to "bring across" the condom issue in a playful but serious manner when working with the target communities/friends' networks. Practical exercises, such as "buy a condom for the next session and describe your experience with it" can be easily applied in the frame of each training/skills building workshop with a target community.*

*Exercise 3* presents the "continuum line of condom use" starting from "decision to use condoms", "negotiation of condom use" to "disposal of the used condom". The group receives several A4-sheets of paper, where the various stages of the condom use are written down. The task is to find a group solution for the sequence of the stages of condom use and to arrange it on the floor. The exercise is very effective as a "gate opener" to the topics of partner communication, negotiation skills and assertive decision-making, It is especially important in contexts, where a lot of negative attitudes towards condom use hamper the open talking and the exchange about it.

*Exercise 4* is engaged in prevailing stereotypes of risk and related to that stigmatization of one or another target group (e.g. single male heterosexual sporting star vs. divorced female heterosexual university teacher, or single heterosexual female singer vs. homosexual male working in a bank). The exercise helps the group to explore; to name and address typical myths and stereotypes related to risky behaviour and to promote open sharing, tolerance and non-judgmental attitudes when measuring risks. This exercise can be very effectively applied in the education sessions of the training/group when addressing rigid gender and social roles prevailing in particular communities.

*Exercise 5* is focused on verbal communication skills when addressing topics of sexuality, sexual behaviour and risk. In couples, the participants have to explain in words selected terms, e.g. (oral sex, contraception, safe sex etc.). This can be used as a good icebreaker in a group training process when addressing various terms, and especially the language we chose when talking about sexuality, HIV/AIDS and protection with various community members and groups. A lot of taboos of language and culture can be also addressed through the exercise.

*Exercise 6* aimed to bridge tolerance, acceptance and value of the affected communities, with special focus on PLHIV. All participants receive a set of core human values (areas of personal self-fulfilment such as health, love, relationships, care, career, friends, financial prosperity, rights, diversity, freedom etc.), and have gradually to give up the majority of them until the four most important values for oneself remain. The exercise is focused on the importance of maintaining core values, self-image and sense of life even under severe circumstances of deprivation (illness).

After each exercise the facilitator should initiate feedback and reflection on the technique, so the participants could shift from the role of a "target community member and trainee" to a "prevention professional", exchanging ideas on methodology and its effective application.

ii. In which settings was it implemented?

The training of the mediators was conducted in the premises of the Estonian National Library. All HIV-prevention sessions with the young people (conducted by the trained mediators) were set in different premises (schools, youth centres etc.) where it was convenient for the mediators and for the participants. The expenses were calculated and covered by AISC as part of the small mediators' projects within the framework of the A&M project.

**i. Important rules for successful implementation**

The most important rules for the successful implementation of this model could be summarized as follows:

- The mediators have to be members of the targeted community. It is not obligatory to be at the same age (to be peers), to be part of youth friendship networks or to have the same profession as the target group of the intervention.
- The selected mediators should have already access to the target group of the intervention (young people in this particular case).
- The rules of the mediators' participation should be clear from the very beginning of their participation in the process. By a contract between them and the project management team (project coordinator) the frames of the co-operation could be visualized and made official.
- The topics of the training should be adequate to the target group and the covered topics not only related to HIV/AIDS and STI knowledge but also to existing norms and taboos in the community.

- The intensive educational process for the mediators in time provides the basis of a systematic skill development.
- The mediators have the right and the opportunity to decide (with or without the methodical support of the AISC expert team) the topics and training style of the community sessions. This point makes this model part of the participatory approach.

Upon completion of the training, each of the 24 trained mediators signed a contract and agreed upon the organization of two group education sessions, covering at least two topics of the curriculum (Part 1). Above all it was required that one of the topics should be HIV; the second one was free choice . The application of this rule stands for the openness towards a more participatory way of structuring the community education sessions, as far as the interests, needs and motivation of the mediators are appropriately considered. At this point it would be interesting to gain some insights in the process of selection of the at-choice topics. How many of them have been discussed with the background community, and to what extent have the needs of that community been considered by making this choice? Such a point of departure would have confirmed a higher level of involvement of the communities addressed by the intervention.

The mediators received remuneration for the two conducted sessions; they were responsible for their own planning, design, set up of setting, materials, catering etc. This provided an opportunity for a direct application of their skills, decision power and self-regulation of the implementation of the group sessions.

Given that many of the settings where the mediators conducted sessions were institutional, some of the predefined conditions of their structures reduced the mediators` possibility to apply the skills for autonomous planning. Generally, many of the sessions were conducted in schools, youth centers, prison, but some in leisure-time settings, in the open air and parks.

It was the intention of the project coordinator to provide a short-term "action"-plan for the implementation, only two months after the training. The rationale behind was that with the time, the motivation would decrease, the drop—off chances will increase and the commitment to the content topics would be lower.

#### **j. What kind of professional supervision is needed?**

The trained mediators had the possibility to receive methodological support while preparing, organizing and conducting of the community sessions. The team of the trained Russian speaking mediators was equipped by full range of instruments for providing community-based sessions (guidebook, slide kit, condoms, lubricants, leaflets and booklets).

Even after the official end of project they still have free access to the project team as well as needed training and HIV prevention materials.

#### **4. Monitoring and evaluation**

##### **a. What documentation is needed? (see next point “assessments methods/tools”)**

##### **b. Which assessment methods/tools are used?**

The assessment method used for evaluation of the mediators' and training effectiveness is the structured and semi-structured interview. The expert team conducted the interviews as follows: (1) in-depth interview of mediators before the start of the training and after completion, (2) questioning before and after every training session, questioning before and after community sessions.

Mediators' reporting that is related to the conducted community sessions (i.e. the mediators' reports on their personal small projects in the framework of A & M project) is another applied method. The results confirm the positive effect of this method: 20 out of 24 mediators sent all necessary reports in time; three mediators sent their reports during the next few weeks; only one mediator (due to family reasons) organized the CS and reported them a few months later.

Common evaluation algorithm was applied in the whole project (regardless of the national and ethnic differences of the targeted communities) using very extensive evaluation forms and application of pre- and post-intervention questionnaires for the mediators and post-intervention questionnaires for community sessions' participants. It turned out that this was very time consuming and also too much focused on quantifiable changes, which was seen as a weak point.

##### **c. What are the main indicators for effective implementation?**

The most important quantitative indicators are:

- Number of recruited mediators
- Number of mediators who successfully completed the training
- Number and quality of the mediators' personal small projects for conducting of the community sessions
- Number of successfully organized, conducted and reported community sessions
- Number of participants in the community sessions. (For example, more than 500 young people participated in non/formal interactive HIV education programme.)

The main qualitative indicators are:

- Gained new and correct HIV prevention knowledge
- Level of satisfaction of the mediators and participants in the community sessions – with the intervention
- Changed attitudes towards the risk level of the personal sexual behaviour

##### **d. How is the feedback of the community gathered?**

After completion of the community sessions every mediator was obliged to submit a detailed report to the coordinator, which includes the place of the CS, number of participants, themes chosen additionally to the obligatory HIV, and post-session questionnaires for participants. Reports were supported by photos, articles in school/community wall or web newspapers and blogs.



## **5. Results achieved**

### **a. Qualitative**

The developed training materials (guidebook and toolkit), the piloted training programme and the developed sustainability plan for ensuring the involvement of the mediators after the project's end are seen by the project as main achievements of AIDS & Mobility. The training of cultural mediators is based on preliminary created and compiled good practice materials going back to the experience and traditions of the project coordinator, EMZ. Standardized tools and materials (Guidebook and core training materials) were developed and translated in 16 languages to be used in all the project's countries. The diverse minority/migrant communities addressed in the six countries were among others Turkish, Romanian, Albanian, Russian, Arabic, Spanish, and Portuguese. The originally set targets of the project were to train 120 transcultural mediators (20 per country) and to reach 2400 (400 in each country) young people from migrant/minority communities in group education sessions.

### **b. Quantitative**

- 24 Mediators were trained and completed 50 hours training (planned 20)
- 24 Personal agreements with mediators were signed.
- 44 Community sessions were organized and provided by 23 mediators (planned 40)
- All together 548 young people (planned 400) from national minorities were participated in those CS

### **c. Feedback from the community**

The feedback was positive and the youth was highly motivated to participate and contribute to the project activities.

## **6. Lessons learned**

### **a. What are the strengths of this model?**

The model has demonstrated a vast list of strengths. From the participatory approach's point of view most important of them could be summarized as follows:

- The model uses and stimulates the most motivated and leading members and resources of the community in order to create and develop community strategies and resources to cope with the existing problem.
- The model presents a complete process of recruitment, selection, training and empowerment of community members in the field of HIV prevention.
- Within the project's framework a training programme which is effective and adequate to the community needs has been developed, implemented and evaluated.

### **b. What are the limitations of this model?**

There are some limitations of this model which is recommendable not be underestimated by future implementation. First of all, this model requires a high educational level of the mediators and self-organization of the community. It might be difficult to replicate the model in cultures of poverty with a high level of illiteracy, underdeveloped communication channels (such as radio), and where people are socially excluded (e.g.

without or with a limited number of professionally educated people of the same community origin who are working at the existing institutions).

Secondly, it is questionable whether this model reaches young people who are in a situation of high HIV transmission risk and do not have access to the institutions where the mediators work and organize the community sessions. In addition, the scope of the intervention among the community and the target group (young people at risk) is difficult (even impossible) to be measured.

Another weak point of the model is that the time-consuming selection and robust training of the mediators did not reflect one especially important factor of effectiveness sufficiently - sustainability of participation of the mediators. Such an assumption illustrates somehow that the chosen approach did not rely very much on the natural resources and motivation for participation of the community representatives.

On the other hand the "project" planning frame of the whole intervention left limited space for flexibility. All pilot interventions had to be conducted in each of the partner countries by a certain deadline. (The Estonian mediators conducted 44 sessions, and reached 518 community members.)

It would be interesting to evaluate whether the pilot interventions could have taken another course if more time were provided and more than one group education session were planned with one and the same community sub-group.

### **c. What kind of obstacles were met and what are the possible solutions (plan B)?**

Timing: The preparation stage (disseminating/"advertising" of the training and recruitment of the mediators) is recommendable to be in a period which is active for the targeted group. For example, the training course was originally planned to start in September. Because of several circumstances – difficulties contacting potential mediators and participants during the summertime vacation period, necessity of translating materials to Russian and Estonian languages, lack of interest from the organizations of national minorities - the training course was postponed to the 3<sup>rd</sup> of November till the 12<sup>th</sup> of December. The training phase is recommendable to take place during a period which is less active for the mediators.

Premises: The Estonian NGO had no proper auditorium room and for the purposes of the interactive training it was necessary to find a new site. "Plan B" are halls in official buildings. For example, AIDS-i Tugikeskus made an agreement with the National Library and Portus company (equipped rooms and reasonable prices for seminar organizers).

Lack of interest from national minorities' organizations: It is recommendable to establish good partnership relations with the main minority organization (if there is such an organization) and/or with the community organizations in the field. For example, AIDS-i Tugikeskus contacted the head organization Union of Organization of National minorities in Estonia.

### **d. Measures of sustainability**

As a contribution to sustainability the investment in the community expertise has been the most important outcome of the project: 24 members of the community were trained, financially and methodologically supported for the duration of the project, and methodologically supported by the AIDS-i Tugikeskus team, even after the project end. The Estonian experience with the trained mediators was that they needed coaching and also further support possibilities over a period of time. Some of the most committed mediators were ready to initiate own small projects, however they were lacking skills for proposal writing, budgeting and work plan design. The local coordinator is supposed to be in close contact with all of them. But how many of them will stay active in their role as transcultural mediators remains not sufficiently answered by the sustainability plan of the project.

**e. Findings about the group/community**

i. Attitudes, norms (citations)

This programme had a great impact on the participants. Some of their insights were:

*“How to change our lives to become more safe? I feel that I am in the big risk”. Nikolai, 21*

*“We all the time make choices in our life? What opportunities are open for me? Sometimes “the risky pleasures” are our choice, sometimes that is the choice of our partners”. Julia, 15*

*“It is the first time in my life, when I feel, that somebody who teach me have so much respect for me and it is not important, that I am 17 and she is 42”! Anton, 17*

*“In our school we don’t talk about all those details, teacher gives as just general information”. Vera, 16*

*“We need to know about sex in such informal way, just lectures are boring”. Anna, 21*

ii. Use of these findings during the programme implementation and possible future use.

The Russian speaking minorities and youth in particular have smaller access to HIV/STIs testing and consultation services, sometimes less access to information. A very small number of young people was aware of the network of Youth Counseling cabinets around Estonia and the possibilities to have counseling and HIV/STIs testing services there for free. Teachers at school often talk about sex and HIV issues in a very formal way. Sometimes difficulties in getting information are due to the low level of knowledge of their parents and some obstacles due to religious, social or moral prejudices in families.

**7. Accessibility and materials: handbooks, reports, media produced, resources available for implementation of the model**

Within the framework of the AIDS & Mobility project each country had to summarize the gained experience in different written tools. The Estonian NGO prepared a folder with all materials; a slide kit and all presentations were saved on CDs and shared for all trainers in printed and electronic form. All the prepared and published materials are available on the projects and NGOs’ websites - [www.ethno-medizinisches-zentrum.de](http://www.ethno-medizinisches-zentrum.de) and <http://www.aidsmobility.org>. Important contacts for further information are:

- [office@eatg.org](mailto:office@eatg.org) (EAGT) (for a CD ROM copy of Master Toolkit).
- [www.aidsmobility.org](http://www.aidsmobility.org) or [www.hivaidsclearinghouse.eu](http://www.hivaidsclearinghouse.eu) for downloadable versions of Guidebook and Master Toolkit.
- The contact person for the AIDS&Mobility model is Ramazan Salman - Executive Managing Director, Ethno-Medizinisches Zentrum e.V. | Ethno-Medical Center
- Königstr. 6 | D - 30175 Hannover (Germany)
- Phone: +49 (0511) 16841020 | Fax: +49 (0511) 457215 | Phone: +49 (0170) 7515 429
- Office: [ethno@onlinehome.de](mailto:ethno@onlinehome.de) | private: [ethno@salman.info](mailto:ethno@salman.info)

The contact person for the Estonian model is Jury Kalikov - The Head of the Board, NGO AIDS-i Tugikeskus ([www.tugikeskus.ee](http://www.tugikeskus.ee) and [aids@tugikeskus.ee](mailto:aids@tugikeskus.ee)). Sirle Blumberg and Olena Waldenmaier were the trainers from the NGO “Living for Tomorrow” ([www.lft.ee](http://www.lft.ee) and [sirle@aims.ee](mailto:sirle@aims.ee)).

**8. What further development and implementation of the model could be possible in the future?**

The team of trained moderators has regularly contact with each other and the coordinator by e-mail. Once a month the coordinator sends a letter with the latest news in the field of HIV/STI/sexual education and information about new resources for funding to all moderators. The coordinator has taken responsibility to support them in future actions by free literature/leaflets and condoms/lubricants. In future we hope that this successful model can be used in other communities of national minorities and at least in three NGOs: Living For Tomorrow, AIDS Prevention Centre and AIDS-i Tugikeskus.

# PaKoMi-Project:

## Participation and Cooperation in HIV Prevention with Migrants

Tanja Gangarova and Hella von Unger

### 1. **Name, author and implementation agency**

Participation and cooperation in HIV prevention with migrants (PaKoMi-Project)

The PaKoMi-Project is a three-year (2008-2011) participatory research project funded by the German Ministry of Health and conducted by the National Association of Community-Based AIDS Service Organizations (Deutsche AIDS-Hilfe e.V.) in collaboration with partners from different immigrant communities, AIDS service providers and researchers from the Social Science Research Center Berlin (WZB).

#### Project background

In Germany, some migrant groups are disproportionately affected by HIV/AIDS, including migrants from African, Central and Eastern European countries. To date, these groups and their communities are only marginally involved in HIV prevention and research. Community-Based Participatory Research (CBPR) provides a valuable tool for building capacity and enabling immigrant communities to create knowledge for HIV prevention and health promotion in their communities.

Thus, the PaKoMi-Project is a participatory research project which aims to improve the involvement of immigrant communities in HIV research and prevention services. Furthermore, the PaKoMi project aims to explore different ways in which community participation can be realized. In other words, the project aims are:

- Increase the participation of immigrant communities and the cooperation of service providers in HIV prevention.
- Understand the barriers and facilitating factors.
- Employ participatory research strategies to better understand the needs of vulnerable immigrant communities and develop appropriate HIV prevention measures.

The primary elements of the project are:

- A quantitative survey of the local AIDS service organizations regarding their prevention activities for immigrant communities, including current services and partnerships with other organizations;
- Community-based research projects in four German cities (Berlin, Osnabrück, Dortmund and Hamburg) - community partners decide on the aim and procedures of the local project within the frame of the overall study aims; Participatory needs assessments are carried out to develop new HIV prevention services for migrants; Peer researchers from local migrant communities are collecting and analysing the data supported by academic researchers;
- Capacity Building Workshops - to enable members of immigrant communities and service providers to work together and conduct community-based research for improving HIV prevention;
- Development of participatory research methods which can be used at the local level to maximize the effectiveness of HIV prevention for migrants;
- Recommendations for better involving migrant communities in HIV prevention research and services.

## **2. On which grounds is the community selected?**

The statistics show that in Germany about every third new HIV diagnosis is given to a person who has immigrated to Germany. Because the infections are not just brought from the countries of origin but also occur in Germany, HIV prevention services must be better tailored to the needs of migrants (RKI 2010). How can HIV prevention be adapted to the needs of migrants? Our suggestions are to involve them, to work with them to determine existing needs, and to work together with them to develop the HIV prevention measures and services that meet their respective needs. This approach requires developing prevention strategies in a participatory way.

Based on this, people with a migrant background and of different national and ethnic origin – mostly migrants from African, Central and Eastern European countries - were selected for the presented HIV prevention project.

### **a. What kinds of methods are used in the process of selection (community assessment, mapping, research, and official statistics)?**

The target communities were selected based on official statistics and scientific studies related to HIV/AIDS transmission; epidemiological data (Robert Koch Institute) and on the experience of regular HIV prevention work of DAH and other German ASO.

In the case studies, the first months were used for the identification and invitation of possible community partners (key persons) and the creation of working groups. This worked best when people from the communities invited other community members. In order to better understand the community needs, a variety of research methods were used by the educated peer researchers (key persons from the communities): interviews, focus groups, story dialogue, community mapping and photo-voice.

### **b. Description of the community**

Following migrant communities were involved in the CBPR projects:

- urban African migrants (Hamburg)
- rural African migrants (Osnabrück)
- men who have sex with men (MSM) – Turkish- and Russian-speaking MSM (Berlin)
- Turkish- and Russian-speaking community leaders (Berlin)
- Bulgarian MSM sex workers (Dortmund)
- female sex workers from Bulgaria (Dortmund)

### **c. What kind of target groups is this method “tailored” for?**

Community-Based Participatory Research (CBPR) provides a valuable tool for building capacity and enabling target groups to create knowledge for HIV prevention and health promotion in their communities.

In participatory research, various partners work together as equals. They start with a research topic that is important to the community itself (needs based). The goal is to acquire information, develop competences and capacities and take action in order to improve the situation of the community.

### **3. Description of the method**

#### **a. Theoretical background**

The theoretical background of each part of the project is described below.

#### **b. How is the community involved?**

This research project has a mixed-method design, using both qualitative and quantitative methods, and is being implemented according to principles of community-based participatory research. Community members, service providers and scientists are involved at each stage of the project. An advisory committee has also been formed for the project as a whole, composed of community members, researchers and other experts in the field. The whole project was implemented in collaboration with scientists from the Social Science Research Center Berlin (WZB).

At the local level, community-based research projects are taking place in four cities. The community partners decide on the aim and procedures of the local project within the frame of the overall study aims. Participatory needs assessments are carried out to develop new HIV prevention services for/with migrants. Key Persons from local immigrant communities are trained as Peer Researcher in workshops in order to collect and analyze the data with support from academic researchers. Peer researchers are financially reimbursed.

#### **c. Programme management**

The PaKoMi team consists of: Two project coordinators – one service provider (DAH) with a migration background and one academic researcher (WZB) without migration background.

- service providers in four cities (Hamburg, Berlin, Osnabrück and Dortmund) - ASO and other service providers
- Peer researchers - key persons from the communities are involved in the four local studies – 10 to 15 in each case. All of them are financially reimbursed.
- Social Science Research Center Berlin (WZB)
- Advisory board that accompanies and advises the project. The project advisory board includes community experts on living environments, practitioners and scientists

#### **d. What kind of human resources are needed?**

For the purposes of the participatory research community experts on living environments (key persons), practitioners and scientists are needed.

#### **e. How is the training of staff and mediators organized (content, structure, methods, duration)?**

In the PaKoMi case studies we trained various people with a migration background to be peer researchers. Formalized training (six modules /20h) included introduction to participatory research, study aims and design, research ethics, methods of data collection, interviewer- and moderator-training, data management and analysis. Then we planned and conducted the research projects together.

Moreover workshop series for capacity-building were offered at the national level in order to enable members of migrant communities and service providers to work together and conduct community-based research (see detailed description in point 3. h.)

**f. What other resources are needed (finances, materials, time, space, etc.)?**

The needed resources could be divided in:

- Resources for the research implementation and administrative resources. This kind of research is a cost-effective one:
- Time: two to three years is the optimal time in order to realize all stages of the research;
- Space: premises for team meetings and workshops are needed. In the community geographical area small separated rooms for interview conducting are needed;
- Materials: record devices, computer hard and software for qualitative and quantitative data processing; all materials for pencil-paper research and interactive workshops;
- Staff costs (project-coordination and scientific monitoring)
- Reimbursements for community involvement
- Project-Dissemination (Project-Handbook, Web-Site [www.pakomi.de](http://www.pakomi.de), Project-Video etc.)

**g. How are the participants identified, selected and recruited?**

Key persons from the migrant communities have been identified with the help of our cooperation partners (ASOs and other local organizations) and offered to participate in the project. The selected participants in the research belong to the selected migrant communities.

**h. What kinds of intervention methods (instruments, tools and techniques) are used?**

The main intervention methods are: 1) the quantitative survey of the local AIDS service organizations; 2) Participatory Approach, 3) Peer Researcher Training, 4) community-building and community-organizing and 5) the capacity building workshops for the research teams. Used instruments are questionnaires (qualitative and quantitative with closed and open-ended questions), focus groups and other interactive participatory methods: Story dialogue, community mapping, photo-voice etc.

Quantitative survey of the local AIDS service organizations regarding their prevention activities for immigrant communities, including current services and partnerships with other organizations and migrant communities

The first stage of the project was an Internet quantitative survey of the local AIDS service organizations. The aim of this survey was to identify the existing practices, their strengths and weaknesses related to the prevention activities for migrant communities.

*Background*

The quantitative survey of the local AIDS service organizations

HIV prevention services need to be better tailored to immigrant communities. AIDS service organizations (ASO, "Aidshilfen") provide community-based HIV prevention services in many German cities. They may play an important role in developing and providing HIV prevention services to immigrant communities, in particular in cooperation with immigrant communities, health authorities and other social and health service providers. To assess the experiences and perspectives of German ASO on HIV prevention services for immigrants, a survey was conducted as first part of the three-year participatory research project on HIV prevention with immigrant communities (PaKoMi).

*Methods*

A survey of the 118 members of the national association of ASO (Deutsche AIDS-Hilfe e.V.) was conducted to assess their experiences in providing HIV prevention services to immigrants. The survey is part of a participatory research project (PaKoMi). The questionnaire included closed and open-ended questions on HIV prevention services, the involvement of immigrants, lessons learned and partnerships with other providers.



Data analysis was conducted with SPSS. The qualitative data was analyzed following the procedures of qualitative content analysis using the software Atlas.ti.

### *Main results*

90 AIDS service organizations (ASO) participated in the survey (return rate 76%). The great majority (89%) provide HIV services to immigrants. The question whether immigrants should be targeted as a separate group is a contested issue. 35% offer HIV prevention services specially tailored to vulnerable immigrant groups, such as refugees. ASO describe good and bad experiences as well as special challenges entailed in providing HIV prevention services to immigrants. Major challenges in providing HIV prevention services to immigrants include:

- Intercultural challenges, “cultural differences” and “taboos”
- Lack of resources
- Limited access of ASOs to immigrant communities
- Language barriers
- HIV-related stigmatization
- Practical and conceptual challenges resulting from the complex needs and multi-layered problems of those immigrant groups who are most at risk for HIV/AIDS

87% state it would be desirable to increase the participation of immigrants in the development and provision of HIV prevention services. Only 10% of ASO are satisfied with the local cooperation of service providers, NGOs and health authorities in providing HIV prevention services to immigrant communities.

Some of the extracted needs for further training and education are:

- Gaining access to migrant communities
- Developing culturally sensitive and migration-specific approaches to HIV prevention
- Improving the cooperation with migrants by developing intercultural competence and trans-cultural communication; involvement of migrants in developing of HIV prevention services
- Conducting need assessment, health prevention intervention and evaluation with migrants

### Capacity building workshops for the research teams

The seminars aim: (1) to foster mutual learning and exchange; (2) to create inter-/trans-cultural competence; (3) to build skills and capacity for participation and cooperation; (4) to enable participants to conduct HIV prevention in participatory way.

### *Curriculum*

To build skills and capacity for participatory forms of HIV prevention and research with migrant communities, a workshop series was developed for community-members and service providers. There are five modules (see below). Each module contains a two-day workshop designed for 20-25 participants. The workshops apply a range of tools for participatory learning and action: e.g. storytelling, small group work, role plays, simulations, presentations, group discussions, open space, etc.

### Workshops-Modules:

- 1) “*Multi-cultural, inter-cultural, trans-cultural?!*” Approaches and good practice examples for participatory HIV prevention and research with immigrant communities
- 2) Working with communities: Using “community mapping” as a participatory method to analyse the situation, needs and assets of immigrant communities

- 3) Participatory intervention planning: Clarifying partners, aims and resources for HIV prevention with immigrant communities
- 4) “Building bridges”: Tools for intercultural communication and cooperation in community-based HIV prevention
- 5) “Peer research”, “photo-voice” and other participatory research methods

### Peer Researcher Training

Peer Researchers are members of a research project’s target population who are trained to participate as co-researchers. We implemented the “Partner Model” of Peer Research - Peers are partners or leaders in all aspects of the research. They received:

- Formalized training (six modules) (20h)
- „On the job“ – training in the case studies, tailored to project and person (varied hours)

The trainings included introduction to participatory research, study aims and design, research ethics, methods of data collection, interviewer- and moderator-training, data management and analysis.

### *Community building and community-organizing*

Communities are dynamic: they respond to external influences, structure themselves in order to achieve something and can be built, organized and mobilized, which means that they are created (community-building and community-organizing). In the Osnabrück case study, it became clear that a community hardly existed. As a result, we set ourselves the goal of developing measures for community building: an African community should be built and strengthened which is a precondition for developing HIV prevention in a participatory way – for and with Africans. Thus we conducted a “Love Health” campaign within the scope of the case study with about 15 African community partners. In addition, a plan was developed (with the help of a logic model) for founding a migrant self-organization (Afro-Info). This new MSO (Migrant Service Organisation) was intended to provide information and support from Africans to Africans in order to facilitate access to the health-care system, bring Africans together, promote health and inform them about certain topics. Afro-Info still exists and grows very fast.

#### i. What is the main intervention instrument(s) in this model?

The main intervention instrument in the PaKoMi model is the Community-Based Participatory Research (CBPR) which means equal partnership between community members, traditionally trained "experts" and scientists. It aims to (1) collect more information und understand community needs; (2) to strengthen community resources and to develop solutions of the existing HIV prevention problems which are found by the community members themselves; (3) to evoke in the community a readiness for action for change, (4) brings different perspectives together.

CBPR was implemented in all four sites (Berlin, Hamburg, Dortmund and Osnabrück) among different migrant groups. Within the frames of the next point of the present manual two examples will be given. They were chosen because they present a quantitative research among Hamburg African community and a qualitative research among male sex workers from Bulgaria in Dortmund.

One of the most important preconditions for a successful implementation of the instrument is the co-operation with migrants, migrant self-organizations, with professional ASOs which provide HIV-prevention, low threshold and outreach services among these communities and with other service providers as well as Centres for Sexual Health. Various people and facilities bring different knowledge and abilities with them: for example, people with a migration background are experts on their life-worlds and have local knowledge and language competences. Social workers are familiar with social services and the social system. AIDS service organization employees know much about HIV/AIDS and the German health-care system. Facilities from the

migration area are familiar with legal and political issues, and so forth. When working together, we can use and combine respective strengths.

All different projects within the work frame of PaKoMi are implemented:

- a community-based survey of HIV-related knowledge, attitudes and behaviour among urban African migrants (Hamburg)
- a qualitative study on community building and health in a more rural African immigrant community (Osnabrück)
- internet-based research with immigrant men who have sex with men (MSM) – Turkish- and Russian-speaking MSM (Berlin)
- expert interviews with Turkish- and Russian-speaking community leaders (Berlin)
- Community mapping with Bulgarian MSM sex workers (Dortmund)
- Cooking and interviews with female sex workers from Bulgaria (Dortmund)

ii. How is this main instrument(s) implemented?

Africans survey Africans on HIV/AIDS (PaKoMi Hamburg)

Peer researchers are people who are familiar with the communities and life-worlds that the study is about since they are a part of them. They have practical experience, social contacts, language skills, (inter-)cultural competences and much more, which enriches the research. Peer researchers can do research on an equal basis. They have a better access to the communities and can frequently better understand the community members compared to outside researchers. Peer researchers are not scientists but life-world experts. In order to be able to research, they need training and support. In the PaKoMi-Hamburg-Case and workshops people from the African community were trained to be peer researchers.

The first couple of months were used to invite service providers and community partners. A working group was formed, which jointly assessed the situation. Various areas of expertise were brought together in this process: the experiences of the practitioners, the knowledge of the community representatives, statistics and scientific findings. The community partners reported on their communities – how the people live and work, where they meet (community mapping) and which groups exist. They showed pictures (photo-voice), told stories with examples and conducted research.

After the initial research in the case study of Hamburg, the community partners wanted to collect additional data systematically in order to precisely assess the needs of African migrants in Hamburg with respect to HIV prevention. They conducted a questionnaire-based survey and focus groups.

Twelve persons – six women and six men – from the African associations and organizations – who were mostly trained health ambassadors of the AIDS service organization – completed the training to become peer researchers. This training was designed and conducted by the scientific partner and coordinated by two salaried employees of the AIDS Service organization. They received formalized Peer Researcher Training as mentioned above:

Together, these 15 persons planned and conducted a survey in Hamburg. The first step was to determine the topic and ask: What do we want to find out? The community partners decided to research specifically on the topic of HIV/AIDS within the scope of the PaKoMi case study. Among other things, the reasons for this were that HIV/AIDS is an important topic for many Africans in Hamburg. There is a need for action and the chances are high that the partners involved can actually translate the results into action (for example, with respect to HIV prevention services and overcoming HIV stigma in the communities). The following research questions were asked: How well are Africans in Hamburg informed about HIV/AIDS? What do they think about people with HIV/AIDS? How do they behave? The goals of the survey were:

- Better understanding of the situation, perspectives and needs of Africans
- Improving HIV prevention
- “Effecting change in our communities“
- Supporting HIV-positive people and reduce stigma

Interviews within the African community in Hamburg:

A questionnaire was developed and translated into three languages (French, English and German). We used a British study as a template for formulating the questions. The questions on knowledge were phrased in such a way that they did not cause insecurity but provided or confirmed information. This means it was stated that statements such as “You cannot tell from someone’s appearance whether he or she has HIV or not” are true and the person was then asked if he or she already knew this. The answer options were (a) I knew this already; (b) I didn’t know this; (c) I wasn’t sure if this was true or not; (d) I don’t understand this. The questionnaires are available at [www.pakomi.de](http://www.pakomi.de).

Then the questionnaires and flyers were tested: a pilot phase was designed to determine whether everything could be understood. After the last revisions, the data recording began: the peer researchers talked to Africans informed them and asked whether they would like to participate in the survey (recruiting). They spoke with their friends and acquaintances, but also with people who they did not know, in the communities, at Afro shops, at street festivals, in betting studios and on the street – wherever Africans can be found in Hamburg. Then the participants were able to decide whether they wanted to fill out the questionnaire on their own or together with the peer researcher (which was a good option for people who spoke but could not read and write very well French, English or German).

The data were processed and jointly analysed. The peer researchers used a software programme for this purpose (Grafstat 2). In addition to the survey, three focus groups were conducted in order to elaborate on individual topics: a focus group with French-speaking African women on the topic of pregnancy and HIV, a group with French-speaking Muslim men, and a third mixed-gender,-English-speaking group with members of a Christian community.

### *Findings*

A total of 263 Africans participated in the survey. Two-thirds (67%) of the respondents were male, one-third (32%) was female and one person was transgender. The respondents were relatively young (81% were between 20 and 40 years old). Religion: 59% were Christian, 28% Muslim and 10% did not belong to any religion.

The participants showed a high level of basic HIV/AIDS related knowledge – over 90% of them is well informed about the sexual way of transmission and the window period. They were less informed about the possibilities of HIV treatment and ARVT, about the symptoms, ways of transmission and risk related behaviour. There was a lack of knowledge about the HIV related health services such as services for testing, VCTs etc. The question about stigma towards PLHIV showed that about 50% of the participants do not perceive the existence of stigma and will support HIV positive people from the African community.

The findings provide many indications for the improvement of HIV prevention services in Hamburg. For example, they show that the surveyed Africans are well informed about many things. But there are information gaps with regard to other paths of transmission and the possibilities of medical treatment for HIV/AIDS. More information is required on test services.

A closing event took place at the Hamburg Health and Consumer Protection Agency in June 2011. The agency had invited us to present the results of the case study. The peer researchers presented their work and were very involved and full of ideas and energy for continuing to work on the issue of HIV/AIDS and broader topics (education, health promotion, cooperation with the countries of origin, etc.). The agency expressed its appreciation, as well as its willingness to provide longer-term financial support for the community work of the AIDS service organization, health ambassadors and peer researchers.

### Community Mapping with Male Sex Workers from Bulgaria (PaKoMi Dortmund)

The implemented method was Community Mapping. The method of Community Mapping is a participatory process by which the characteristics, resources and problems of a community can be expressed visually: a map of a community is drawn. Community mapping is also suitable for groups that have limited reading and writing skills.

The PaKoMi case study in Dortmund addressed Bulgarian men who are involved in sex work. The case study was coordinated by the AIDS Service Organization of Dortmund e.V. (Neonlicht project). About 70% of the male sex workers in Dortmund had a migration background. The majority of these men was between 18 and 25 years old and came from Central Europe, particularly Bulgaria. They were primarily men from a Turkish-speaking Bulgarian minority, some of whom had a Roma background. This group presented major challenges for the prevention project: there were language and cultural barriers, as well as the presumption that the boys were socially severely disadvantaged and probably exposed to a high HIV risk due to the sex work.

The participatory situation analysis involved research on the internet, informal interviews and group conversations with the sex workers. As a result, it was decided that setting-appropriate, target group-specific measures of structural HIV prevention must be developed for the respective group (male Bulgarian sex workers). Within the scope of the case study, a sub-project was carried out: a community mapping with Bulgarian male sex workers ("boys").

The project staff member first made contact with two male Bulgarian peers who are also engaged in prostitution. They had informal conversations in bars frequented by male sex workers and their clients in order to build trust and get to know each other. The employee spent time with the boys and accompanied the peers for a day (shadowing). Then focus group conversations were conducted in order to illuminate the needs and wishes of the Bulgarian male sex workers in Dortmund. This step brought the following results: Most of the boys have a poor geographical orientation in Dortmund and rarely know the names of the streets. Some of the Bulgarians who had already lived in Dortmund for a longer period of time accompany new boys to the residents' registration office and receive a small fee for these services. There are hardly any or no links with the social care and health-care assistance facilities in Dortmund. They have very little knowledge about HIV and other sexually transmitted diseases. There is little talk about the risks and dangers within the context of prostitution.

#### Community mapping – meeting

Based on these findings, the decision was made to conduct a community mapping project with the Bulgarian boys in order to support the young men in their orientation in Dortmund, help them better understand their living environment and working world and create a foundation for better tailoring HIV prevention services to their needs.

In the time period from June to December 2010, community mapping on the theme of "Dortmund, this is where I live" was planned and implemented. The boys illustrated their world of living and working in Dortmund and helped each other to become more familiar with the city and the places where they can get help. Two peers from the Bulgarian male sex workers scene were recruited for conducting the community mapping. A flyer was designed with the help of drawings that explained what the mapping involved. (see [www.pakomi.de](http://www.pakomi.de)).

The community mapping method requires a number of meetings and work steps. The peers were trained and prepared everything together with the Neonlicht employee. They took over the recruiting – informing the boys and inviting them to participate in the first mapping meetings.

The first meeting lasted almost one and half hours. The boys drew a map of the city Dortmund with the places that were important for them. ("Which places do we know? When someone is new, which places should he get to know?") and a legend that explained the drawing. One peer (Azis) assumed the moderation, and the other (Nikolai) was in charge of the documentation. During the meetings, the statements and discussions by the

boys were recorded and the process was documented with the help of photos. At request by the boys, their faces on the photos were made unrecognizable. After the meeting, there was an extra meeting of the two peers with the project staff member. At this extra meeting, the map that had been drawn and its legend were discussed and drawn cleanly. They reflected on the first meeting, discussing what went well and not so well. They planned to provide food and beverages for the next meeting.

The second meeting for mapping in a large group took place shortly thereafter. The objective was to discuss the map again and add further points to it. The participants also included two new men who had just arrived in Dortmund a few weeks before. Some of the boys offered to help giving them information on Dortmund. A total of nine boys participated, that was one more compared to the first meeting. The second meeting was more relaxed and motivated than the first: the boys already knew the process, collaborated attentively, participated actively in drawing and expressed constructive criticism. An example of this was when they did not agree on the signs to be used or where something was located. This meeting also lasted approximately one and half hours. In the end, all of the boys agreed and were as well a bit proud that they knew much more as a group than they thought they knew. But it was also clear to them that they wanted to know more about the Dortmund town centre, as they were familiar only with a barber, the Western Union and a few shops where they occasionally bought clothing. In conclusion, a follow-up meeting of the two peers with the project staff member was held. They discussed the process and the results and supplemented the notes.

### *Findings*

The community mapping gave the boys an opportunity to exchange information and become oriented in the city. The method was well accepted and put into action. It was clear that they moved only in a very limited manner (in specific areas and on certain paths) and did not yet know many places and facilities in Dortmund (such as the town centre, providers of social services, the public health authorities). The mapping sparked their interest in getting to know more of the city. At the same time, that they already knew some of the places such as the bars for male prostitutes, cinemas, parks, the community-based gay health centre “Pudelwohl” (where the meetings took place), Internet cafés, Western Union, pharmacies, the Klinikum Nord hospital and some other locations was felt as a success. In this respect, their self-confidence was reinforced.

For the project staff member, the mapping was a valuable insight into the life-worlds of the boys in Dortmund. He gained a precise understanding of which places they were familiar or not familiar with. This enabled him to give them specific information about places that could increase their room to manoeuvre and take action (e.g. offers of information and help, practical information, healthcare services, cultural services). At the same time, the process of cooperation “got the ball rolling”: trust was developed and the boys now come to him with their questions.

#### iii. In which settings was it implemented?

The project was implemented in community-related settings, in places where they naturally gather to socialize and in the NGOs premises.

#### **i. Important rules for successful implementation**

The most important rules are the requirement of the participatory approach – involvement and equal decision making right for the community representatives at each project stage. Cooperation plays also a central role.

## **4. Monitoring and evaluation**

### **a. What documentation is needed?**

For the research purposes the following documentation is needed: developed questionnaires, protocols and transcriptions of the conducted interviews.

### **b. Which assessment methods/tools are used?**

Every step of the project is evaluated by educated community members and scientists (integrated knowledge translation). Moreover evaluation workshops took place in Hamburg, Dortmund, Berlin and Osnabrück and in Berlin (for a cross-case analysis of the overall project).

### **c. How is the feedback of the community gathered?**

Community representatives are involved at any project stage. The participation can be realized in different ways according to the practical conditions in the project and the living conditions of the community. The objective is to find the appropriate stage of participation that corresponds with the conditions and the participation persons. The „Combined Participation“ is particularly advantageous – involvement of key persons (peer researcher) on higher levels of participation (with Decision-Making-Power). The broader part of the communities is asked for consultation (in terms of focus groups, surveys etc.).

## **5. Results achieved**

The main benefits of the PaKoMi project could be summarized as:

- For those involved: their resources were activated and their skills were strengthened;
- For the communities: communities and their self-organization were strengthened and further developed;
- For the employees in NGOs or other projects: improved cooperation;
- For the prevention: better understanding of the needs and capabilities of immigrants, development of appropriate HIV prevention services, tools for supporting participation.

## **6. Lessons learned**

- Different migrant groups have different needs;
- HIV-prevention as part of a broader concept of health promotion that pays attention to legal, social and cultural factors (Structural Prevention);
- Participation works if the preconditions are given (the right persons, decision-making power and resources);
- „Combined Participation“ is particularly advantageous.

### **a. What are the strengths of this model?**

- The cooperation of various partners from the communities, service provision and science on an equal basis;
- The cooperation with different migrant groups in four cities of different states;
- The customized, needs-oriented method: at the beginning of each case study, the local need for action and research was determined; on this basis, the local goal of the cooperation was mutually determined;
- Participation from A to Z: in many projects, target groups and community representatives are included at some point in one way or another. But very few projects succeed in incorporating practice and community partners so consistently into all phases of the research and development processes (from goal-setting to the distribution and utilization of the results).

**b. What are the limitations of this model?**

The participation is time consuming and very expensive.

**c. What kinds of obstacles were met and what are the possible solutions (plan B)?**

As a result we have found obstacles at four levels:

- **Society:**
  - The participation of people with a migration background is hindered by legal structures and discrimination, xenophobia, racism and social inequality;
  - Facilities of the public health system, such as AIDS service organizations, prevention projects;
- **Public health authorities:**
  - The lack of resources hinders the participation of migrants;
  - Another problem is the limited degree of the “Interkulturelle Öffnung“ (intercultural opening) of the service providers;
- **Migrant communities:**
  - Obstacles include HIV stigma and taboos, limited resources, lack of trust;
  - Other priorities (such as family and work), bad experiences, partially underdeveloped community;
  - Structures, insufficient self-confidence and fear of exclusion from one’s own community;
- **Contact and cooperation:**
  - The biggest problems occur at the level of cooperation. Above all, sham participation (when migrants only participate but are not allowed to be involved in decision-making) inhibits the development of a genuine participation; however, problems are also caused by communication difficulties, mistrust and mutual reservations, too little appreciation and recognition, as well as the resulting conflicts.

**d. Measures of sustainability**

From the beginning, long-term sustainability has been the foremost premise of the PaKoMi project and was taken into consideration in the design of the project. On-site we made efforts to ensure that the findings of the case studies can be and are being implemented, for example through the development and stabilization of structures (MSOs, associations, cooperation, etc.). For example this has been very successful in Hamburg. In other case studies – such as Dortmund – sustained long-term use has become very difficult due to events that are beyond our control. At the national level, we have worked to translate the results into action and continue the participatory process by developing recommendations. Deutsche AIDS-Hilfe e.V. also contributes to the further development of the PaKoMi idea with its seminar offers and follow-up projects. We plan to train community and practice partners so that they can further spread the ideas, findings and recommendations of PaKoMi as multipliers.

**e. Findings about the group/community**

- i. Attitudes, norms (citations)

See detailed description in point PaKoMi Hamburg and PaKoMi Dortmund.

- ii. Use of these findings during the programme implementation and possible future use



From each case study important conclusions could be drawn for future interventions. - See detailed description in point PaKoMi Hamburg and PaKoMi Dortmund (more information [www.pakomi.de](http://www.pakomi.de) )

**7. Accessibility and materials: handbooks, reports, media produced, resources available for implementing the model**

The model has been described in a manual: "PaKoMi Handbook – HIV-Prevention for & with Migrants". In addition to this handbook, the results of the PaKoMi project include an Internet website ([www.pakomi.de](http://www.pakomi.de)); recommendations for politics, practice, science and communities (Chapter 7); and a video that was created as a joint endeavor. Additional information on the PaKoMi project can be found in the articles and essays that have already been published. For further information the contact person for DAH is Tanja Gangarova ([tanja.gangarova@dah.aidshilfe.de](mailto:tanja.gangarova@dah.aidshilfe.de) ) and Dr. Hella von Unger for WZB ([unger@wzb.eu](mailto:unger@wzb.eu) ).

**8. What further development and implementation of the model could be possible in the future?**

The presented model and the results of PaKoMi project have provided the policy makers, ASO, migrants and the scientists with valuable and adequate knowledge, method and intervention tools for more effective HIV prevention and strategies at community, local and national level. Furthermore, it strengthens the community inner capacity and resources coping with the HIV rapid spread and self-organization.

# Discussion and Implications for Future Transfer

The presented models in this manual were selected based on their innovative HIV/AIDS and STI prevention approaches for migrants and ethnic minorities in order to decrease the health risks and sexual risky behavior at individual and community level. They are all practice-driven participatory models for community-based prevention among migrants/ethnic minorities. However, they are very heterogeneous and differ in level and stage of participation of the communities involved. Here some spotlights of the models` strengths will be summed up.

## **Community-Based – Community Involvement - Community Development**

In how far a model is community-based and/or involves the community varies. Essential is that a higher level of involvement of the communities is necessary in order to mobilize their inner resources and to trigger the process of change. Crucial for community development, including community self organization, is to strengthen these resources and enable the community to develop strategies to cope with the HIV/AIDS problem.

For example the POL Model is a community-level intervention, which invests resources (knowledge and skills) in influential community members, and thus has an impact on the community development and community self-organization. This model is easily adaptable for different group contexts, because it uses the natural human relations and leadership norms in order to decrease the health risks for the single individual as well as for the whole community.

The PaKoMi Model is applicable for a vast range of “hard-to-reach” target groups and communities and also involves and reinforces the natural resources of the community.

Considering the PARC Model the target groups can have different levels of self-organization and geographical density. It is not necessary that a big part of the group lives together, but it is inevitable to have places for social life and clear social norms. Recommendable is to address community members with medium and/or high educational level, who demonstrate a high motivation and readiness for commitment to a cause and community work.

Whether or in how far the models focus also to the single individual also differs. The PARC and PaKoMi Models are strongly focused on HIV/AIDS prevention at community level, while the AIDS & Mobility Model is strongly focusing on sexual risky behaviour of individuals.

## **Community-needs driven**

Another central aspect is, that every model/intervention is constructed in such a way that it is adequate to the community needs in order to be effective in HIV prevention.

It does not matter which community or group is addressed and which model is applied, but it is always important to understand thoroughly and correctly the community norms before starting the intervention.

Whatever is offered, a training program or a community-based research programme, the needs of the community have to be identified and met. Concerning this aspect the PaKoMi Model seems to be the best example and can therefore be considered as highly customized and needs-oriented. At the beginning of each case study the community needs for research and action is mutually determined, and on this basis also the local goal and aim of cooperation. Comparing to the PaKoMi Model the preliminary assessment of community needs is rather lower in the AIDS & Mobility Model.

## **Participation**

Similar to the aspect of community-based work, the level of participation varies in all the models presented.

According to the Participatory Model by Michael T. Wright (2010), there are nine stages of participation. The PaKoMi Model presents a high level participation of target groups and community representatives. However, one has to discuss how much participation is possible and useful for the particular community. First of all, participation can only work if the preconditions are given (the right persons, decision-making power and resources). Moreover, on the one hand one has to realize that *not all people like to be involved at the same level*. On the other hand, for prevention experts it can be too stressful to involve communities in all decision-making stages.

To find the appropriate stage of participation that corresponds with the living conditions of the community and other social context factors as well as the participating persons is crucial.

## **Methods of participation**

The aspect of participation is fulfilled through the members of the community who not only get trained comprehensively for HIV prevention work, but are involved in the planning and implementation of the intervention and have therefore a role as co-agents. These members are not merely interested and motivated community members, but rather “experts” of their community and the life circumstances. They function as peer educators (PARC Model), Popular Opinion Leader (POL Model), mediators (AIDS & Mobility Model) and peer researchers (PaKoMi Model).

The PARC Model presents a strong point of the method *peer educators*, who apply *setting-based outreach*. Their role is clearly defined:

- *Peer educators* are experts in their communities
- *Peer educators* can bring in their experiences and are a communication channel
- *Peer educators* can act as role models

The AIDS & Mobility Model uses and stimulates the most motivated and leading members and resources of the community in order to create and develop community strategies and resources to cope with the existing problem. The method of participation is reflected in a completed process of recruitment, selection, training and empowerment of *cultural mediators* who are engaged as *peer educators* in the field of HIV prevention.

The process of participation from A to Z is presented by the PaKoMi Model, where natural resources of the community are used and reinforced by a research programme. The *Community-Based Participatory Research* incorporates the community partners in one way or another into all phases of the research and the development process (from goal-setting to distribution and utilization of the results).

The „Combined Participation“, introduced by the PaKoMi Model might be advantageous. There is the involvement of key persons (peer researcher) on higher levels of participation (with Decision-Making-Power) and a broader part of the communities who is asked for consultation (in terms of focus groups, surveys etc.). Hence, this method includes a combination of higher and lower level of participation.

As it has been very well demonstrated by the POL Model HIV/AIDS and STI prevention can also be effective, because it applies *Informal social networking and Behaviour Change Communication Methods*.

From the perspective of community-based participatory prevention all the models have in common that they address structural (health) inequalities by coordination and community mobilisation.

## **Obstacles and difficulties to implement the models**

One of the most important aspects for implementing a model in any community is to gain the trust. That in many migrant communities obstacles include HIV stigma and taboos has been clearly demonstrated by the PARC Model and the POL Model applied within the Roma Community. Related to the HIV taboo is the fear of many people to get tested and their bad experiences with health services. Often internal barriers like the socio-economic situation of the families in the community hinder the implementation as they really don't have the time to take care of their health and have other priorities.

Finally limited resources of the community and/or a less developed community (e.g. high level of illiteracy, poor communication channels) are obstacles for implementation of any model and especially for a model, which is rather tailored for highly organized and further developed communities (AIDS & Mobility Model). The AIDS & Mobility Model even requires mediators with a high educational level.

Regarding difficulties to implement the models two aspects are central. Firstly, it is crucial for the long-term planning to be aware that all the models are more or less time-consuming and time-intensive. Secondly, funds are a further important factor and therefore the available budget should be checked properly before starting the project. The PaKoMi Model presents a high level of participation and enables the cooperation of various partners from the communities, service provision and science on an equal basis. However the implementation is very expensive compared to the more cost-effective POL Model.

## **Sustainability**

The question of effective application of the experience gained after the training in HIV/AIDS and STI prevention should be central, as sustainability of the results achieved is often a common weakness of short-term projects. Sustainability of the participation of peer educators, community leaders and mediators has to be assured.

The POL Model has been used for diverse population worldwide (e.g. CSWs, MSM, youth, heterosexual adults) during the past 15 years. It is an evidence-based intervention at community-level that has been scientifically-proven to be effective and cost-effective in risk reduction of HIV/AIDS and STI infection.

Sustainability is further related to the suitability of the model selected. In order to find the most suitable model, it is recommended to study and consider the particularities of the local context with an anthropological and sociological approach.

Whether the model is applicable for "hard-to-reach" and vulnerable target groups and communities (PARC Model, PaKoMi Model) or highly organized communities (AIDS & Mobility Model), any model can be more effective and sustainable if HIV/AIDS and STI prevention is part of a broader concept of health promotion that pays attention to legal, social and cultural factors which are the corner stones of the Structural Prevention approach.

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Some useful information:

[www.jiscmail.ac.uk](http://www.jiscmail.ac.uk) – 'join' the discussion list: minority ethnic-health

Diversity in Health & Care – Quarterly Journal:

[www.radcliffe-oxford.com/dhc](http://www.radcliffe-oxford.com/dhc)

NHS Evidence: [www.library.nhs.uk/ethnicity](http://www.library.nhs.uk/ethnicity)

[www.ethnic-health.org.uk](http://www.ethnic-health.org.uk) or e-mail: [mr dj@dmu.ac.uk](mailto:mr dj@dmu.ac.uk)



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PAPARDES  
ZIEDS  
Papardes Zieds (Latvia)



SPWSZ  
SPWSZ (Poland)



**POMOST**  
POMOST (Poland)



ASOCIATIA ROMANA ANTI-SIDA  
ARAS (Romania)



PRIMA  
PRIMA (Slovak Republic)