PaKoMi Handbook

HIV Prevention for & with Migrants

WZB
Social Science Research Center
Berlin

Deutsche
AIDS-Hilfe

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PaKoMi Handbook: HIV Prevention for and with Migrants

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Foreword

Dear Reader,

This handbook introduces you to a successful project and invites you to experience the increasing levels of participation and cooperation in HIV prevention activities with migrants in four German cities. You will learn about creative methods and new developments, hear the vivid voices of the participants and get an impression of this unique project.

The PaKoMi project has shown us that participation and cooperation can work – in varying forms and intensity – even if the beginnings are sometimes rocky. Hurdles had to be overcome, trust had to be built and understanding had to be sought. This kind of project works when people openly approach each other, when they are willing to ask questions and listen to the responses, when the projects open their doors and invite people to participate, when room is created for new paths and perspectives, when needs are taken seriously and demands are ascertained, and when services are developed by partners working together on equal footing.

The result of such cooperation is creativity, fun, curiosity and interest, knowledge, mutual experience and reflection, communication and understanding, liveliness and solidarity. Then there is laughter and tears, awakening and departure. Through this process, some differences are better tolerated, a sense of belonging is found and conflicts can be resolved.

It was not possible for the cooperation to succeed everywhere in the way we would have wished: competition is often the greatest obstacle and tends to increase rather than decrease in times of budget cuts in municipalities and states. Yet particularly in work together with migrants, the participation of all stakeholders is needed. No service is too much and no partner is dispensable. Just as we have a great diversity of people with a migration background in Germany, we also require a great diversity of available services in HIV prevention, so that we can come ever closer to fulfilling our goal of making HIV prevention accessible for everyone.

The project is also an example of successful cooperation between service providers in the municipalities, Deutsche AIDS-Hilfe e.V. (DAH) and the scientific project support from the Social Science Research Center Berlin (WZB). HIV prevention was developed, tested, researched and evaluated in a participatory way.

I give my heartfelt thanks to all of the participants of the PaKoMi project. They have performed tremendous work with a great deal of commitment and sacrifice. They have grown from their experiences and have made so much progress possible. I also wish to thank the authors. They have made the project come alive for all of us, allowed us to participate in their experiences and invited us to join them on the path to more participation and cooperation.

I wish you much reading enjoyment, many ensuing benefits and much patience in trying out these ideas!

Silke Klumb
Executive Director, Deutsche AIDS-Hilfe e.V. (DAH)

Introduction

Immigrants are not necessarily less healthy than Germans – in fact, sometimes the opposite is the case. Yet migrants are at an increased risk under certain circumstances and often do not have the same access to the health system, good information, counselling and health-care services as Germans do. These circumstances also apply to HIV/AIDS. Yet it is important to take a closer look at this situation, for there are various migrant groups in Germany with situations that differ greatly from each other and that are affected by HIV/AIDS to varying degrees. The risks of becoming infected with HIV also differ greatly. This handbook is intended to help develop appropriate HIV prevention services for and with migrants.

Why HIV Prevention for and with Migrants?

Health is a human right, independent of whether people live in the country where they were born.[1]

Equality of treatment: All people who live in Germany, independent of their cultural background, should have equal access to information, prevention, counselling and health care. This goal is stated explicitly in the action plan for the German government's strategy for combating HIV/AIDS.[2]

In reality, for various reasons HIV prevention information and services frequently do not reach migrants as successfully as they do the overall population.[3] There is a need to take action.

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.[4]

Immigration and cultural diversity are an enrichment for Germany.

How can HIV prevention be adapted to the needs of migrants? Our suggestions are to include 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 – and that is what this handbook is about.

All people have a right to health – no matter what their migration background.

Only by working together with migrants is it possible to offer good HIV prevention services to them – which is why we talk about HIV prevention **for** and **with** migrants.

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[1] UNAIDS 2001

[2] BMG 2007

[3] ECDC 2009

[4] Robert Koch Institute 2010

Snares in the Dialogue: What Should We Be Aware Of?

When we speak about HIV/AIDS and migrants, we can – even without meaning to – contribute to migrants being perceived as the carriers of the virus and as a threat. Against the background of existing xenophobia, this way of speaking can lead to even more racism, discrimination and exclusion. In the past, this fear has contributed to even committed people taking a very careful approach to the topic of migrants and HIV/AIDS or HIV prevention for migrants.[5]
We think that it is important to talk about it – but with an awareness of the possible pitfalls in the discussion.

Which snares should we be aware of?

Migrants should not be portrayed as a "risk group" or threat.

Generalisations are not helpful: migrants are not a homogeneous group; they are different from each other in many respects (e.g. age, gender, country of origin, language, sexuality, education, occupation, residence status). This diversity should always be taken into consideration.

Multiple stigmatisations can occur when various prejudices interact. On the one hand, HIV/AIDS is stigmatised, which is why people associated with HIV/AIDS are sometimes devalued and avoided.
On the other hand, migrants are often the target of prejudices and discrimination. When these prejudices are combined, they can become very harmful for the individuals concerned. For example, when we speak about Africans and HIV/AIDS, then racism and the HIV stigma interact. If we speak about the Roma involved in sex work and HIV/AIDS, then we already have several delicate topics on the table at the same time: the prejudices and discrimination against the Roma (also called "anti-ziganism"), the prejudices against sex work and prostitutes, and the cliché of sexually liberal Gypsies. All of this combined with the stigma of HIV becomes a volatile mixture that makes conversation about HIV more difficult.

A stigma is a mark of social disgrace. A stigmatised characteristic or illness can harm one's reputation and lead to exclusion. Multiple stigmatisation means that a person has several traits that could give rise to prejudices and exclusion (e.g. HIV positive *and* migrant *and* sex worker).

In order to facilitate the introduction to the topic and the discussion, we would like to present an overview of the various players in HIV prevention in Germany.

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[5] von Unger 2010

Who Are the Main Actors in HIV Prevention in Germany?

There are various organisations in Germany that develop and provide HIV prevention services. The best known are the campaigns by the Federal Centre for Health Education (BZgA). Among other things, they use mass media such as posters, brochures and cinema/TV spots to inform the general public, to promote solidarity with affected people and to encourage safer sex (e.g. "Don't Give AIDS a Chance"). Deutsche AIDS-Hilfe e.V. (DAH) is responsible for HIV prevention among groups that are particularly affected, such as men who have sex with men (MSM) and certain migrant groups.

> **"There is a successful division of work in HIV prevention in Germany: the governmental Federal Centre for Health Education (BZgA) directs its measures (TV/cinema/radio spots, posters, booklets, campaigns in the print media and on the Internet, etc.) at the general public. The non-governmental organisation Deutsche AIDS-Hilfe e.V. (DAH) develops programmes and services for those most affected by HIV/AIDS, hepatitis and other sexually transmitted infections. These particularly vulnerable groups include men who have sex with men, intravenous drug-users, sex workers, and migrants from countries in which HIV is widespread. The BZgA and the DAH have received state funding since 1985 for this division of responsibilities. The BZgA and the DAH cooperate in HIV prevention with many different professional organisations, professional institutions and groups. Professional counsellors at the public health departments, local AIDS service organisations (ASOs) and other local counselling centres, as well as doctors, play an especially important role in HIV prevention."**

Tanja

The BZgA and the DAH are responsible on the national level – they produce most of the brochures, media and information materials. In the 16 federal German states, there are also various organisations that coordinate and implement HIV prevention strategies and services.

Deutsche AIDS-Hilfe e.V. (DAH) is the umbrella association of 130 organisations in Germany, including ASOs, prevention projects, drug help centres, residential and health-care projects, and self-help networks. The DAH is a professional organisation for prevention and simultaneously represents the interests of people with HIV and AIDS.

In many cities, the ASOs and prevention projects assume the tasks of personally communicating HIV prevention by offering private individual consultation, taking their work directly to the streets and distributing information and condoms. German ASOs arose from self-help projects and offer support and counselling for people with HIV/AIDS. In many places, they are also active in efforts to reduce the number of transmissions and HIV infections (which means they offer primary HIV prevention within the scope of **structural prevention**; see box).

There are three levels of prevention: primary prevention aims at protection from disease, which involves reducing the risk of transmission/infection. Secondary prevention is early detection of the disease. For example, it is possible to determine when a person is infected with the help of an HIV test. Tertiary prevention attempts to prevent any worsening of a sick person's state of health.

The concept of structural prevention developed by the DAH combines the three levels of prevention. The goal is to influence individual behaviour *and* social circumstances (structures) in order to reduce HIV risks, as well as strengthen and involve the target groups and communities – including people with HIV/AIDS.

The practical prevention work of ASOs and prevention projects is often performed by teams consisting of voluntary and paid staff. Increasingly, people with a migration background are also part of these teams. The following example describes the situation at the ASO in Hamburg (AIDS-Hilfe Hamburg e.V.):

"In Hamburg we have trained Africans to be health ambassadors (peer educators). Equipped with fundamental knowledge about HIV and AIDS, condoms, multilingual brochures and flyers, they go into their communities to talk with people about HIV. These may be meetings at cultural associations, family celebrations or even football tournaments. For events at the cultural associations, the health ambassadors use a variety of methods (e.g. the Traffic Signal Game) to communicate knowledge and help people learn by means of pictures how to assess risky behaviour. After their field work, the health ambassadors meet to evaluate the campaign. They also meet for advanced training and supervision."

Mara and Omer

Another important organisation in the states and municipalities is the Public Health Service (ÖGD) with its local health authorities, information services and the possibility of anonymous HIV testing.

"The structure and division of duties for the Public Health Services [ÖGD] are regulated at the level of the states in Germany, which means that there are different structures in the individual German states. In Berlin, the Senate Administration for Health and the projects of private organisations prepared a conceptual framework that establishes who is responsible for the various target groups in the HIV prevention projects and services. [6] **The target group of the sexual health and family planning centres (the facilities of the ÖGD in Berlin) is the general public and, in particular, people who are not safeguarded socially and/or integrated in terms of the language. The centres also provide services to special target groups such as women in sex work and teenagers. Although migrants are not explicitly mentioned as a target group by the ÖGD, the portion of the general population that is not integrated in terms of the language has a high share of migrants. The share of migrants is also high among women in sex work. This is why the centres for sexual health and family planning are also responsible for HIV prevention for migrants. The individual centres adapt their work to the population structure of the district in which they are they located. All of the centres present their services on flyers in various languages and – whenever necessary – provide community translators for various languages. For example, prevention events with translators are conducted at shelters for asylum-seekers, women's crisis centres, residential facilities for unaccompanied underage refugees and prostitution facilities. At these events, HIV prevention can be embedded as one topic in the general promotion of health, but it may also be the sole topic of the event. The ÖGD'S HIV prevention work with and for migrants is not limited to the work at the centres, which involves HIV test counselling, the examination for sexually transmitted infections [STIs] and, within the scope of care for pregnant women, various means of contraception. It should be clear to all of us that working with the general public also always means working with migrants!"**

Gerd

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[6] "Conceptual Framework for the Prevention of HIV/AIDS, Hepatitis and Sexually Transmittable Infections, as well as the Care of People with HIV/AIDS and/or Chronic Hepatitis Infections in Berlin" by the Senate Administration for Health, Environment and Consumer Protection of Berlin of October 2010.

In addition to the BZgA, the DAH, the facilities at the state level, the local AIDS service organisations and the ÖGD, many cities have counselling centres, non-profit organisations and facilities of the Arbeiterwohlfahrt (Worker's Welfare Organisation) or church organisations (e.g. Caritas and Malteser) which also offer services for health promotion and HIV prevention. The cooperation of the local organisations on the communal level is different in each of the respective cities and states. Here is an example from Berlin:

> **"In providing assistance and support for migrants with HIV/AIDS, the projects of the non-profit organisations – in addition to the public health authorities – play a big role in Berlin. There are currently twelve projects in Berlin that provide services to vulnerable target groups and people with HIV and AIDS. They receive funding from the senate administration. For the most part, the projects were created as self-help groups and are organised in LABAHS [previously called LABAS, the State Organisation of Berlin AIDS Self-Help Groups], which is both the advocacy group and the professional association. The target groups include men who have sex with men [MSM], women in sex work, people from high-prevalence countries [countries in which HIV is widespread], intravenous drug-users and people in prison. The projects offer primary prevention and testing, as well as counselling, care and support for people with HIV and AIDS. They have a good network with each other and with the public health authorities and complement each other well. One project is oriented especially to people from high-prevalence countries, while the other projects offer services to all people in the respective target group irrespective of their origin. In this process, the services have different intercultural orientations, depending on how high the proportion of migrants is among the clientele. A working group with projects and facilities – including public health authorities – has worked in Berlin since 2005 on the topic of migration in order to do justice to the special situations of the migrants across all of the target groups."**

Nozomi

An extremely important component of HIV prevention for and with migrants is the cooperation and networking of facilities that offer HIV prevention services, on the one hand, and facilities and groups that provide other services to migrants, on the other (e.g. cultural, integration, language courses, education). This cooperation and networking is important because HIV prevention for and with migrants involves the following considerations:

appropriate consideration of ethnic diversity in all groups of the population and target groups of HIV prevention;

appropriate consideration of diversity among migrants with respect to regions of origin, residence status, age, gender, level of education, level of HIV risks, and so on;

involvement of people with a migration background in the development and implementation of HIV prevention services (i.e. participation);

the cooperation of those providing HIV prevention services with persons, groups and facilities that work with migrants on other topics (e.g. migrant self-organisations, counselling centres, refugee aid);

depending on the need, the collaborative development of targeted services for especially vulnerable groups with a migration background.

The AIDS service organisations have made varying degrees of progress in the implementation of these tasks. There are promising developments and successes;[7] but many challenges remain.[8] The aims of the PaKoMi project were to promote the participation of migrants in HIV prevention and to improve the cooperation of providers in the area of HIV prevention for migrants.

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[7] DAH 1998; Wiessner 2010

[8] von Unger, Klumb, Gangarova and Wright 2011

PaKoMi Project

PaKoMi stands for participation (Pa) and cooperation (Ko) in HIV prevention with migrants (Mi).

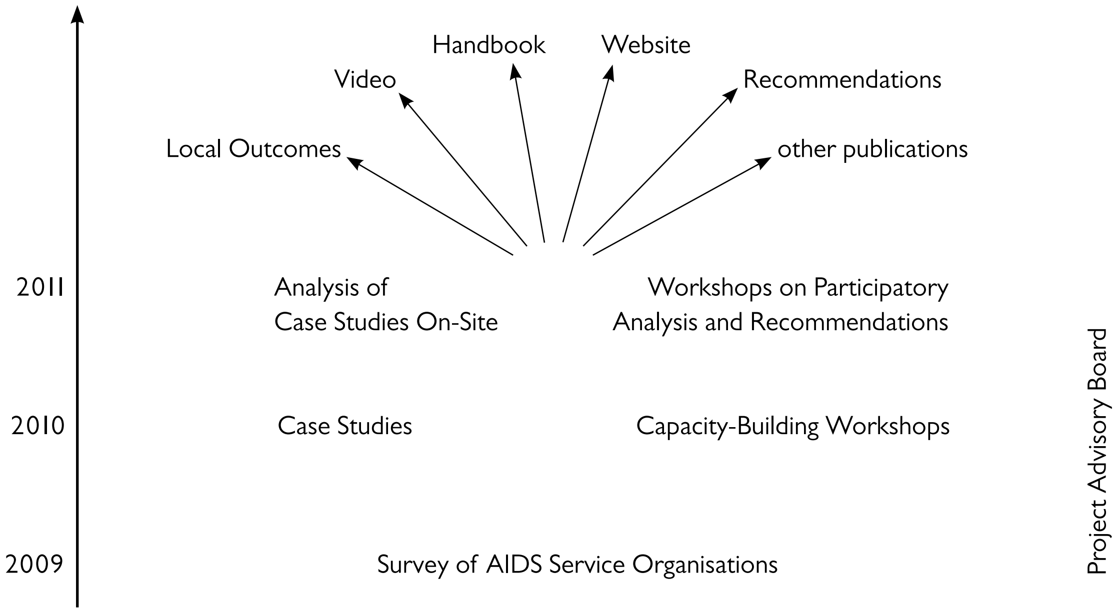
PaKoMi is a project of Deutsche AIDS-Hilfe e.V. (DAH); it received scientific project support and supervision from the Social Science Research Center Berlin (WZB). It is implemented in cooperation with local partners in four German cities: Berlin, Hamburg, Dortmund and Osnabrück. The scientific accompaniment by the Public Health research group at WZB was funded by the Federal Ministry for Health (BMG) over a period of three years (2008-2011).

PaKoMi is a participatory project, which means that the partners work together on an equal footing – as equals. It is also a participatory *research* project, which means that research is conducted together in order to better understand the living environments and needs of migrants. The goal was to develop HIV prevention for and with migrants while studying and strengthening the participation of migrants and the cooperation of various providers.

The project was divided into multiple components (see ill. 1): a survey of 90 AIDS service organisations, case studies in four German cities (Berlin, Hamburg, Dortmund and Osnabrück), a workshop series for capacity-building, an on-site evaluation of the case studies, evaluation workshops in Berlin (for a cross-case analysis of the overall project) resulting in a series of project results, and a project advisory board that accompanied and advised the project. The project advisory board included community experts on living environments, practitioners and scientists.

In addition to this handbook, the results of the PaKoMi project include an Internet website (www.pakomi.de); recommendations for politics, practice, science and communities (Chapter 7); and a video that was created as a joint endeavour (see Chapter 8). Additional information on the PaKoMi project can be found in the articles and essays that have already been published. Two examples are an article on the findings of the survey by the AIDS service organisations[9] and a description of the research approach and the study design.[10]

Illustration 1: Overview of the PaKoMi Project



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[9] von Unger, Klumb, Gangarova and Wright 2011

[10] von Unger 2012

About the Handbook

The PaKoMi Handbook is intended to help people with and without a migration background work together in HIV prevention. It explains terms, describes methods and reports on experiences from the practice. It is intended to help practitioners in HIV prevention open up both to the topic of migration and to cooperation with migrants. It also is intended to help individuals and communities with a migration background open up both to the topic of HIV/AIDS and to cooperation with professionals in HIV prevention.

We show how people can work and research together in order to better understand the needs of the target groups or communities with a migration background. This approach is essential because good HIV prevention for and with migrants can only be developed on the basis of familiarity with the living environments, the needs and the resources of the migrant communities.

This handbook contains many texts and quotations by people who have collaborated in the PaKoMi project. It was important to us to show the diversity of our perspectives. The handbook presents a mosaic of various perspectives that complement (and sometimes contradict) each other: members and representatives of various migrant communities, professional practitioners (e.g. social workers at AIDS service organisations, staff at counselling centres and public health authorities) and scientific researchers express their views.

The handbook is structured in such a way that we first clarify our understanding of community; Chapter 2 is dedicated to cooperation within the intercultural context; Chapter 3 defines our understanding of participation; Chapter 4 explains how to provide HIV prevention services to migrants; Chapter 5 offers an insight into the life of migrants with HIV/AIDS; Chapter 6 describes how people can do research together by using the example of the PaKoMi case studies; Chapter 7 presents recommendations that we prepared for the further development of HIV prevention for and with migrants in Germany. Chapter 8 gives a brief explanation of how to work with the PaKoMi video in order to strengthen on-site participation and cooperation in HIV prevention for and with migrants. Chapter 9 presents literature sources and an extensive bibliography with links, as well as the names of the facilities that participated in the case studies.

Many of the chapters have a work guide at the end. These are questions that can be used to initiate an on-site discussion or to enrich existing discussions and mutual relationships. We address the readers in an informal tone, in an attempt to express the friendly and personal form of communication that we have cultivated during the PaKoMi project. By using this more personal form of address, we also hope to encourage readers to participate. The quotations in the text are attributed to first names only for the same reason: they reflect personal opinions and experiences. All of the quotations have been translated into English. The terms “migrants” and “people with a migration background” are used interchangeably in this handbook. They denote migrants and immigrants of the first and second generations, which means people who have migrated to Germany (from within or outside Europe) or whose parents have migrated to Germany.

We hope that this handbook proves helpful for reflection and discussion, for renewing strength when things get difficult, for discovering ideas and for serving as a reminder that it is worthwhile to communicate with each other, look for understanding and learn from each other.

We thank all of the people who participated in PaKoMi – particularly those who contributed to this handbook (see below). We warmly thank Chris McBride for his drawings, which make the handbook even livelier; Anja Feldhorst for the helpful and flexible proofreading of the German version; and Bernhard Koppmeyer for the design of the cover and layout. And a huge thank-you to the editorial team, which supported us with its attentive reading and constructive feedback, even when the texts were sent just the evening before: Nozomi Spennemann, Stefan Schröder, Catherine Flohr, Antje Sanogo and Gerhard Peters.

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Vivi-Lore Nzouatcham, 25, student from Cameroon; collaboration in the PaKoMi case study in Hamburg.

Everyone else quoted by their first names in this handbook participated in the PaKoMi project workshops or case studies. In a few cases, pseudonyms (made-up names) have been used in order to protect the person's privacy.

I. From I to We: Communities

Community plays a central role in HIV prevention, in participatory research and in the PaKoMi project.

Who and What Is a Community?

In the German language, there are various translations of the term *community*,[1] but it generally refers to a social group whose members have something in common – they interact with each other and share common values, characteristics or interests.

For example, a shared identity or a sense of belonging can develop when people live in the same town or come from the same region, have the same interests, belong to the same association or some other "mutual cause." Communities are not necessarily organised according to ethnicity. People with a migration background also belong to communities in which occupation, language, religion or another trait or interest is more important. Communities do not form automatically just because people live in the same house or have the same nationality: they form a community only when there are social networks and meeting places and when people feel that they are part of a community. Incidentally, they can also occur on the Internet (online community). A shared identity frequently develops through commitment to a mutual cause, political actions, cultural initiatives or joint celebrations and parties.

A community is a group of people who have something in common and feel connected with each other.

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[1] Loss 2009

Examples of Communities

People with HIV/AIDS can give each other support and form a *community*. Homosexual men who visit the meeting places of the scene or are committed to their human rights can understand themselves as part of a community. Groups of resident migrants are also called communities. However, when we take a closer look it often becomes clear that there is generally not just *one* community such as *the* African community or *the* Turkish community but many sub-groups. For example, there are various African communities in Hamburg and the case study in Osnabrück has shown that the surveyed Africans are not automatically part of an African Community or even feel that they belong to a community (see below). Participants in a PaKoMi workshop mentioned completely different communities to which they feel they belong: a church congregation, a centre for mothers, online community, artist community, LGBT community, student community, community of people with HIV/AIDS, PaKoMi community, dog-owner community, African community, Nigerian/Cameroonian/Vietnamese/Beninese community, and so on.

> **"To me, a community is a group of individuals in which the members have the same interests and needs and pursue goals together. Or, in other words, a community is a social group in which the members cultivate similar cultures or religions. I belong to the Burkinan community in Hamburg and to the Café Africa community."**

Omer

The term community is sometimes criticised for being imprecise, for whitewashing reality and for implying that all members of a community are the same or have the same interest.[2] However, more recent concepts of community clearly say that there is diversity in every community and people (can) belong to a number of communities at the same time.[3] Another point of criticism is that the English-language term can only be applied to the German circumstances to a limited degree. Despite its weaknesses, we find the term helpful since it describes people's living environments and the social nets, identities and groups to which they feel they belong. As a result, it opens a possibility for taking the reality and perspectives of community partners seriously and learning from their knowledge as experts of their lived experience and life-worlds.

> **"My observation as part of a group of migrants who primarily have an African origin is that the members strongly define themselves through their African origin, even though they come from a great variety of African countries. For me as an Afro-Brazilian, this type of identification with the group is not possible, even though I am part of it. My 'entitled membership' in the group has even been more or less doubted at times. On the other hand, there are also common factors that connect me with the group such as a migration background. The goal of this African-characterised community stands for what is called a multidimensional community in the more recent conceptual approaches, meaning a community in which there is a different self-image even if mutual interests exist. But what can a community be for a woman who is heterosexually oriented and a mother, has a migration background and is HIV positive? Is she automatically part of the communities in question? Or must she fight for her various interests in various groups or communities? A person will actually always find himself or herself in various communities of which he or she is a part either simultaneously and parallel or one after the other."**

Kelly

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[2] Labonte 2005

[3] MacQueen et al. 2001; Walter 2007

What Is the Difference between a Community and a Target Group?

A community is not the same as a target group. In HIV prevention, a target group refers to a group of people with specific health risks and needs who are the target of specific measures and services. **Target groups are defined by professional practitioners.** The focus here is often a problem (such as HIV risks or another need). **Communities define themselves.** Although problems may play a role (e.g. the shared experience of discrimination), communities generally also keep an eye on their strengths and resources. Communities have a broader scope than target groups: the former includes the facilities and persons from the life-worlds of the target groups – such as parents, friends and acquaintances who do not necessarily share the same HIV risks as the respective target group (see ill. 2).

> **"In health promotion and prevention, we learn to think of target groups. This is intended to help us develop measures for those people who are most likely to be affected by health problems. Entire support programmes are based on the definition of target groups such as single mothers or preschool children. PaKoMi makes it clear that the participation of people from the target groups is possible when we perceive them as members of self-defined communities and work together with these communities. Epidemiological categories show us where we should look. However, health promotion and prevention only have a meaning when they have a direct relationship to the living environments of the people. Communities make this possible."**

Michael

In the Berlin PaKoMi case study, the difference between the target group and the community became very clear: the target group defined by the participating practitioners (men who have sex with men but who do not consider themselves "homosexual") did not form a community – the opposite was true. These men do not belong to a "homosexual community" and even the term MSM (men who have sex with men) is an attribution (by professional practitioners) that has no identity-creating function for the men themselves. In this case – similar to people who have experienced sexual violence – there may be a demand for action and research, but no community in this sense.[4] The question arises here as to what extent these persons may have other community relationships that can be used. On the one hand, the following illustrations show that target groups can be part of a more broadly defined community (ill. 2) and, on the other hand, that persons from a target group (e.g. MSM) can belong to various communities (ill. 3).

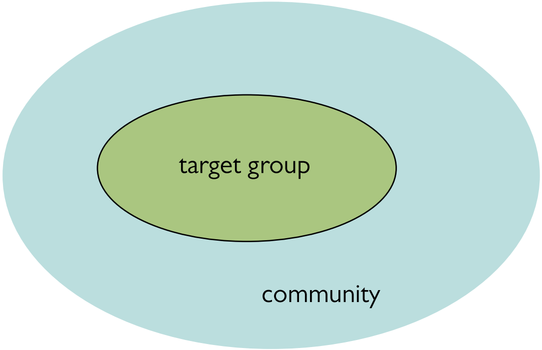

Illustration 2:
Target group as part of a more widely defined community

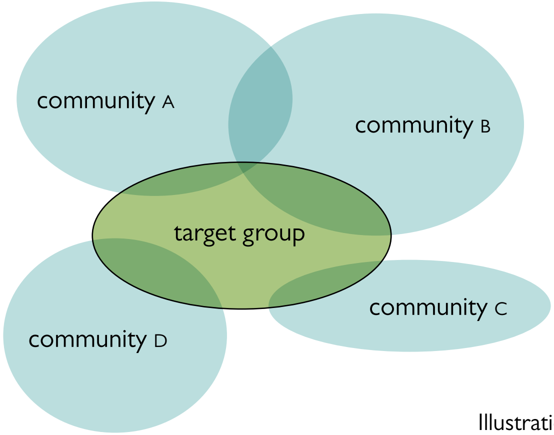

Illustration 3:
Target group belongs to various communities

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[4] Campbell et al. 2004

What Do I Do When There Is No Community?

"We were faced with precisely this question in the Berlin case study because the target group of our study ('MSM with a migration background who are difficult to reach') had no community of 'men who do not openly live as homosexuals'. It is clear that if a community of these men existed, they perhaps would not be so difficult to reach. So the Berlin case study was primarily concerned with finding out how to get access to these men. On the one hand, we were able to gain insights about the MSM with a migration background through innovative methods (chat survey, narrative interview with male prostitutes). On the other hand, we researched access to our 'target group' by including the migrant self-organisations (MSOs). So even if certain MSM are not organised into a community of homosexual men, each of them are integrated into one or more communities. There actually is no origin-oriented community, such as the Turkish community or Russian community as it is perceived by the outside world. The presumed community is too heterogeneous for this to be true. Yet there is no doubt that the MSO serves as the first contact point for many migrants; as a result, a good deal of information can be communicated and distributed through them. The Berlin case study also showed that the MSO is very willing to deal with topics such as HIV and AIDS. Conclusion: There are always communities of people in which they are integrated, even if they are not always identical with the 'target group'. Especially for target groups that are difficult to reach, the success of HIV prevention depends upon how this community or these communities are identified in order to come as close as possible to the living environments of the persons who are to be reached."

Nozomi

If you think that there is no community, this may also be due to the fact that you do not know the people well enough to know to which communities they belong. In order to find this out, it is helpful to ask them. You can either pose a very direct question ("Do you belong to a community?") or you can ask them about people with whom they have contact on a regular basis and the places where they meet.

However, it is also possible that a group actually has no or just very little community in the sense of a shared identity, common goals or meeting places (which means shared life-worlds). In such cases, you can think about whether there may be a community somewhere else or whether you would like to build a community:

"If there is no community in my own city, perhaps I can look around in the neighbouring towns or try to establish a community on my own or develop the contact to other similar groups."

Omer

How Can We Build and Strengthen Communities?

Communities are dynamic: they respond to external influences, form themselves in order to achieve something and can be built, organised and mobilised, which means that they are created (*community-building* and *community-organising*).

"You can a build a community by formulating common goals and enable the participation of the members in the activities for their implementation. From my perspective, the strengthening of a community depends on the participation and involvement of the members in the group or the community."

Omer

The following tips for community-building can be found in the bibliography: [5]

Focus on real work

Keep it simple

Act!

Seek what unifies

Do it when people are ready

Design spaces where community can happen

Find and activate informal leaders

Learn how to host good gatherings

Acknowledge people's contributions

Involve the whole person

Celebrate!

In the Anglo-American discussion, two different terms are used: *community-building* (from within) and *community development* (support from the outside). The two can go hand-in-hand.

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[5] Walter 2007

Community-Building in Osnabrück

In the case studies, the first months were used for the identification and invitation of possible community partners and the creation of working groups. This worked best when people from the communities invited other community members. In Osnabrück, the participating Africans approached other Africans (e.g. in Afro shops, associations, churches or at the university) and invited them. This is how the working group grew from three to 15 active members.
In order to better understand the community of Africans in Osnabrück, we made a map of the meeting places for Africans in Osnabrück (***community mapping***). In addition, the community partners conducted informal interviews in order to find out the meaning of community for Africans in the more rural or small-town setting. The question of who and what community is has been discussed in all of the case studies. These discussions generally raised at least as many questions as they proved answers. In the Osnabrück case study, it became clear that there was not much community. As a result, we set ourselves the goal of developing measures for community-building: an African community should be built and strengthened. The group organised activities at the annual Africa Market close to the city hall in order to publicise the idea and enter into conversations with Africans and Germans. There was a nice booth with delicious food, games (e.g. a wheel of fortune with questions about Africa – see ill. 4), flyers, T-shirts with the logo "Love health" and "Join us!" on the reverse side, and a community board that the guests could write and draw on.

In addition, there was dancing on the stage, and everyone present was invited to join in (see ill. 5). This was very fun and the people liked it. For the future, we plan to establish a migrant self-organisation (MSO) with which Africans and others can become informed on health topics and support each other.

"PaKoMi is like a dream come true to me. I have always wanted to do something with the African migrants and PaKoMi has opened a door for me. Now there is this possibility to do this."

Ruth

"Perhaps the most beautiful moment in which I experienced very concretely how community can be created was at the Africa Market in Osnabrück. After all, African Markets in Germany are often rather commercial events that are geared towards German consumers and audiences. It was also a bit like this in Osnabrück. For example, there was a stage programme in which the 'traditional' African dances were performed to drum music and the performers were wearing grass skirts and body painting. In front of the stage, there were mainly Germans watching. But between the professional performances, our African community partners went on the stage and danced to modern African pop music – just for the fun of it. There were only two male students at first, but then the other participants of PaKoMi Osnabrück also joined in: Ruth, Manal, Helen, the Chief and others. The DJ encouraged the people: 'Don't you see what's on the back of the T-shirts? It says "Join us!" So participate!' More and more people got on the stage and danced along: many Africans, small children from mixed marriages, Germans … Then Joe also gave a speech and explained what the group is about. That was pretty great."

Hella

"I am interested in making more contacts with Africans in Osnabrück. Up to now, it has always been difficult to meet Africans or get them together. Many organisations or associations have been established, but they did not really get through. And now with PaKoMi, we have the hope that this is possible. And this is why we want to keep working and see whether we can establish an association after PaKoMi."

Catherine

Illustration 4:
Wheel of fortune at the booth at the Africa Market (PaKoMi Osnabrück)

Illustration 5:
Dancing together and having fun (PaKoMi Osnabrück)

What Is a Migrant Self-Organisation (MSO)?

Self-organisations are voluntary associations of persons pursuing shared goals. The term migrant self-organisation (MSO) is used when people with a migration background come together as a group. MSOs are not just formalised relationships – such as those in the form of registered associations – but also informal relationships like groups, projects and networks.[6] Many MSOs provide information and offer orientation, counselling and support, as well as serving as the point of contact in cases of exclusion and discrimination. They represent the interests of the migrants and enable communication with mainstream society. MSOs may be *homogenous* in terms of their members' places of origin (i.e. the members come from the same region of origin) or *heterogeneous* in terms of the members' origins (i.e. the members come from various regions of origin).[7] This means that intercultural associations and organisations can also be MSOs. But the term is generally understood to mean that the group or association of migrants was established by migrants and that most of the members have a migration background.

What Are the Strengths of MSOs?

MSOs can best identify whether there is a need for health promotion and prevention within their communities. They can establish contact with their members and mobilise resources in the communities. In addition to the individual resources or potentials of the affiliated migrants, MSOs have much to offer that is also important for and can be used in health promotion and HIV prevention. This includes[8]

Social networks, contacts and relationships,

Resources through group affiliation
(e.g. trust and good opportunity for communication),

Self-help potential,

Mobilisation and the potential to act as multipliers
(***peer educators, roles models***) and

Mediating and bridging functions.

These potentials and functions of the MSO should be identified, included and actively supported within the scope of health promotion and prevention. However, professionals involved in prevention and health care must be educated about the situation, function and structure of the MSOs in Germany in order for this to occur. They must find out who the contact persons (key persons) are and seek possible ways of working with them.

Work Guides

Which communities exist in your area?

Where do people meet?

Which elected representatives, other respected persons and associations or migrant self-organisations (MSOs) are present in the communities?

How could these communities be supported and strengthened?

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[6] Thränhardt 2005; Schwenken 2000

[7] BMFSFJ 2010

[8] Zitzelsberger and Latorre 2010

2. Working Together

The PaKoMi project is based on the cooperation of various partners. These include members of the target groups and communities, representatives of migrant self-organisations (MSOs), practitioners of HIV prevention (e.g. social workers at AIDS service organisations, counselling centres and public health authorities) and scientists.

This chapter discusses the collaboration between **those who provide HIV prevention and persons and organisations from the migrant communities. This also involves intercultural aspects of the cooperation.** Questions of power – or in other words, how decisions can be made together – will be the topic of Chapter 3.

Why Is It Important to Work Together?

Cooperation plays a central role in HIV prevention for and with migrants. 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 organisation 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. The situation and needs of migrants are sometimes very complex, making the knowledge and abilities of persons, groups and facilities from various areas (legal, social, health, etc.) essential. In this handbook, we place an emphasis on the collaboration of HIV service providers with migrant self-organisations (MSOs) and key persons in the target groups and communities. Their knowledge, abilities and competences frequently are not recognised, used or promoted in an optimal manner.

> **“To me, cooperation means getting to know each other and being able to ‘benefit’ from each other, as well as developing intercultural competences. We get to know each other better and reduce prejudices and discriminations. As migrants we learn about the methods, approaches and strategies of HIV prevention that have been developed by the German AIDS service organisations; at the same time, we share our knowledge, our methods and experiences with them – e.g. how the HIV/AIDS education is carried out in Burkina Faso and how the discussion on the topic of HIV/AIDS occurs between the various ethnic groups.”**
>
> **Omer**

How Do I Find Partners in the Communities?

“There are leaders, representatives or chairpersons in every community. These are the people who know more about the members and their life because they advise, accompany, inform or serve them. As a result, they are the gatekeepers to the community and have the key to it. This is why establishing contact with a community means meeting the key people.“

Steve

“In order to establish contact with a community, you should first get to know the group. This can be done through a key person or through participating in a public event of the community; then you can think about the possibility of joining the community. The important thing is that a clear topic and clear goals are defined within the community.”

Omer

“Finding partners from the migrant communities is not simple. Especially in the big cities, there are many groups and organisations, some of which do not take public action but still fulfil important functions in the community. Due to the uncertain financing, there is often a fluctuation of personnel, a change of address or even a closure. This is why you should first pay attention to the ‘stability’ of an organisation when looking for a partner. Many smaller groups are part of associations (e.g. in the Parity Welfare Organisation contains many MSOs as members or in the Africa Advisory Council and the Migration Advisory Council in Berlin-Brandenburg in Berlin) so that partners can be identified through these associations. An important criterion for a partner is also her or his standing in the community. This can be researched through the press or by asking members of the respective community before you contact them. Whether the partner you have found is also a good partner ultimately depends on the conditions and definitions of the partnership.”

Nozomi

Educating oneself about the respective community and actively approaching it (e.g. attending events and establishing contact via email/telephone with the facilities and their representatives) thus constitutes the first step. A second step may be thinking about other possible partners in the community together with the existing contacts (e.g. key persons, peers from the communities, volunteer or salaried employees). The method of community-mapping may be used in this process (see Chapter 6, “Doing Research Together”). The literature recommends bringing in project partners who are respected community members anchored in their communities in a credible, visible and good way – which is exactly what Nozomi suggests: working together not just with the official representatives of facilities and organisations (e.g. MSOs and churches) but also with respected community members who do not have a formal status.[1]

Who and what is a key person?

Key persons are contact persons in the communities who make a cooperation possible, which means that they can open doors. They may be official representatives of groups, associations and MSOs, as well as persons without a formal function who are well connected and have a good reputation in their communities.

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[1] Israel et al. 1998

How Can I Spark MSO Interest in the Topic of HIV/AIDS?

> **"HIV/AIDS is a topic that is often not a top priority for MSO. They often deal with many other topics. Some organisations are even afraid of becoming stigmatised if they deal with the topic. Yet every person has a right to be informed. Independent of possible risks of infection, everyone should know what the modes of transmission are, how they can protect themselves and where help is offered. If you can agree on this need to be informed, you will probably spark the interest of the MSO. Experience has shown that one-time information events usually are not rejected. An important question in the process is how the topic can be made 'palatable' to them. Perhaps there are other health topics that play an important role in the community in which the topic of HIV and AIDS can be 'packaged'. Or the topic is openly addressed in connection with pregnancy and HIV. When family and children play an important role in the respective culture, it may well be that the topic is met with much interest. There is certainly not a solution for all people of every origin. Take a precise look – at best together with representatives of the MSO – to see in which context and with which emphasis the topic of HIV and AIDS can best be placed."**

Nozomi

A Canadian colleague with a migration background has told us that she succeeds at sparking interest in the topic in migrant communities by talking about how people with HIV/AIDS are faring and that there are people who are very concretely affected by it – even in the communities. She does not reveal any names but mainly lets the numbers talk. The sympathy for the situation of people from one's own community can then create openness. For more suggestions on how HIV/AIDS can be addressed, see Chapter 4.

> **"In order to create interest in the topic, the work of convincing and sensitising must be done on a continuous basis. It becomes easier when high-profile individuals (key persons) within the communities or the MSOs can be won for the topic and these contacts are continuously cultivated. The additional commitment means a greater investment of time for the respective volunteer and salaried key persons from the MSO. In order to ensure a good and lasting cooperation, this extra time must be compensated. From my perspective, it would be meaningful to offer a certified qualification of key persons (on HIV-relevant topics) that expands their knowledge and competences, as well as being seen as a personal incentive. In addition, it is sensitive to integrate the topic of HIV/AIDS into a broader concept of health promotion since this serves the interests of the MSO and their community and can also create access to the migrant communities in which the topic of HIV/AIDS is seen as a taboo."**

Tanja

Is Good Cooperation between AIDS Service Organisations and MSOs Possible – Or an Illusion?

Good collaboration is possible – there are many examples of this – but it is not always easy.

"It seems to me (from the perspective of the migrants) that working together with the AIDS service organisations is difficult in some cases. I think that different stakeholders have different interests. The cooperation frequently collides with prejudices or intolerance towards unaccustomed ways of approaches to work. The migrants are often called unprofessional. If a cooperation is intended to work, is it important to develop an idea and a concept for a concrete cooperation to develop. The best approach would be to already start here with African and German paid staff on an equal footing. We should encounter each other with respect, with the common goal of fighting the AIDS pandemic and abolishing discrimination towards people with HIV/AIDS – independent of their skin colour or cultural imprint. However, we cannot expect this target group, which tends to be poor, to voluntarily perform all of these tasks. HIV/AIDS prevention work must be adapted to the existing life circumstances, so that the people for whom this work is very important have a realistic chance to participate and become active. This also calls for at least an expense allowance for the active employees. On the basis of a good intercultural cooperation, I also wish for a greater independence of the MSOs within the scope of the AIDS work. It is definitely necessary to have a good concept and a strategic approach. The projects that are developed by us migrants quite frequently do not get any attention. It is difficult to find reliable partners. The authorities also first look at German or European projects before they examine the projects developed by migrants. We are exploited or only consulted when we are needed."

Ibra Zongo

"As a salaried AIDS service organisation employee with a migration background, I can probably spark the interest at MSOs, but where do things go from there? What exact form can cooperation and collaboration take? What happens when the MSO would like to present a long-term concept, but adequate resources are not available? The question of who will finance or support it or who needs whom always arises."

Omer

"During recent years, the AIDS service organisations and public health authorities have had the experience that the willingness to participate in HIV prevention has slowly grown and it has been possible to recruit key persons from the migrant communities – especially when the contacts have been continuously cultivated and financial resources are available. However, this is a problem when the cooperation is tied to one individual person. When these people move inside the organisations, then the cooperation collapses."

Tanja

"It is a fact that MSOs and other projects and facilities performing migration work generally do not have HIV prevention as a purpose of the association. In addition, they are usually supported from other budget pools. There are often project sponsorships of limited duration for programmes in the areas of integration promotion, children, young people, culture, and so on. Programmes in the area of health are only rarely sponsored. In order to maintain the organisation, which often consists of a few part-time employees, new projects must constantly be developed and implemented. The AIDS service organisations that wish to cooperate with an MSO must first understand the limited resources of the MSO. The type of voluntary commitment that is common in Germany is also less widespread among migrants. Many are not even familiar with it in this form or must first cope with their own financial situation. This means that the ASOs need much patience. However, this can work out when the cooperation with ASOs promises certain advantages for the MSO. One advantage can be a financial compensation for the work that is done. But immaterial things such as a new profile or image, personal relationships, and so on, can represent incentives for the MSOs.

Important rules must be observed during the cooperation:

1. Work together on equal footing: participation is a declared goal of integration policies in Germany. As a result, MSOs are increasingly asked to be project partners. But frequently the partners do not have equal rights: the project is already predetermined and the presumed participation is only important in order to fulfil the funding requirements (alibi). Once MSOs have made such negative experience, they pull back.

2. Participation from the start: the earlier the MSOs are included in the planned project, the more promising the cooperation will be, because this is the only way for them to make the project their own.

3. Be as concrete as possible: 'Let's work together – but how?' Due to a lack of experience or because there is no trust in the MSO, the cooperation remains limited to lip service. The result is that the relationship does not continue to develop and becomes forgotten at some point. Anyone who strives for real collaboration should therefore approach the MSO with a concrete objective.

4. Cooperation between organisations is based on cooperation between people: The success of every collaboration depends upon whether the persons involved get along with each other or not. MSOs are frequently initiated by dedicated individuals who often also run the organisation mainly on their own. When you have established a good rapport with such a 'main person' of an organisation, you will already have an advantage on the personal level."

Nozomi

How Can the Various Partners Work Well Together?

Not just the AIDS service organisations and MSOs, but many different stakeholders and facilities must work well together in order to promote the health of people with migration background in Germany and reduce HIV risks. The cooperation between various partners and facilities achieved various levels of success in the case studies. Some of them went very well, but there was sometimes a lack of resources (because cooperation also costs work time), interest and the willingness to cooperate (such as when facilities and agencies are in competition for communal funds and responsibilities). In the PaKoMi workshops, the conditions for good cooperation were discussed and the results then flowed into the development of the recommendations (see Chapter 7). This includes the creation of structural requirements for good cooperation, such as the following:

"Interkulturelle Öffnung" (intercultural opening) of the facilities and regulated services,

provision of resources,

clarification of responsibilities,

creation of incentives for cooperation,

fundamental improvement of migrant participation in the job market and other societal areas,

reduction of legal discrimination,

strengthening of migrant self-organisations and communities.

Careful design of the cooperation relationships by the stakeholders is also important: participants in the PaKoMi projects have had good experiences working together cross-culturally when the partners involved were able to encounter and build trust with other people, work methods and mindsets. This process usually progressed over longer time periods and through joint activities, for example by striving for transparency (e.g. with respect to resources and decisions), clarifying the conditions and rules of the cooperation (e.g. commitment, punctuality, confidentiality) and a constructive approach to conflicts. Chapter 3 describes how participation can be realised in the cooperation and on what level or how MSOs and other migrants from the target groups and communities can participate equally in the decision-making processes.

In addition, it is helpful to set and pursue concrete goals when working together. The SMART criteria can help in the formulation of goals. SMART goals are the following:

Specific

Measurable

Attractive, ambitious, accepted and appropriate

Realistic

Time-bound, that is, having a limited time-frame

For example, a goal could be to implement a joint event to inform a target group or community about counselling services. In order to come to an agreement about a common goal, the SMART criteria can be used as the basis for questions, such as:

S: What exactly do we want to achieve –
and with whom?

M: How many persons do we want to reach?
How can we count them?

A: Does the goal truly correspond with the interests
of all partners?

R: Is it realistic? Do we have enough time, funds,
helping hands and other necessary resources in
order to achieve the goal?

T: When do we want to begin? When exactly
or by when do we want to achieve it?

Afterwards, methods such as the "Projekt-Logik" (Logic Model)[2] can be used to plan
(a) what is needed in order to achieve the goal and
(b) what kind of outcomes and impact you expect.
For example, the cooking evenings with streetwalking prostitutes were planned in the PaKoMi case study in Dortmund by applying the "Projekt-Logik" method (see Chapter 6).

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[2] For SMART criteria and the logic model, see also www.partizipative-qualitaetsentwicklung.de

Why Do We Need Intercultural Competence?

A foundation for good cooperation in HIV prevention for and with migrants are intercultural competences. These are the abilities that make it possible to interact appropriately with persons from various cultures. This is sometimes also called transcultural competences – when people want to make it clear that cultures are flexible and dynamic as they flow into each other and that there are often mixed forms of cultures (see Chapter 4).

Intercultural competences include an understanding of other cultures, as well as a consciousness for the person's own cultural imprint. The same things can have completely different meanings in various cultures. Catherine, a Kenyan who lives in Germany, describes an example:

"In many countries of Africa, a corpulent person is considered to be healthy and prosperous, and people like to assume that the state of a rather slim person was caused by illness, worries and poverty. For an African woman like me who comes to Germany, it is quite astonishing to learn that slimness and corpulence have a completely different meaning here: slim people pay attention to their health and can afford expensive, healthy food, while the corpulent are said to have an unhealthy lifestyle with a cheaper, less healthy diet. This example illuminates the challenges for people who are involved in cultures other than the one they grew up in. As an example, I had to make sure before I visited my homeland that I looked well-fed and wore clothing that made me look more corpulent than I am so that my parents wouldn't worry about my health and the economic well-being of my family."

Catherine

In Catherine's case, intercultural competence means realising the varied meanings of "slim" and "corpulent" on the one hand; on the other hand, it means being able to deal with the respective attributions when she travels from one country to the other.

However, there is a dilemma when we talk about culture and "cultural imprints". An intercultural trainer expresses it as follows:

"On the one hand, there is the danger of discrimination if you connect certain types of actions and attitudes with cultural affiliation or origin. On the other hand, the knowledge about cultural differences and self-reflexivity can constitute an important resource for participation and cooperation."

Elke

This is why it can be helpful to be aware of cultural commonalities and differences, but they should not be overrated. Sometimes the issue at hand may not even be connected to "culture" at all, but to the person and his or her personality, the specific situation or other things. When cultural factors are overrated and people are reduced to their (presumed) culture, this is called **culturalisation**. One example: an Italian woman comes too late to a doctor's appointment. The doctor thinks that she has come too late because she is Italian and "in the Italian culture, there is a different sense of time." Although this may be true, he may be overlooking other reasons, such as the strike of the subway that usually takes her there. So the fact that she came late may not be related at all to her being Italian. This is why we should never put people in a "cultural pigeon-hole" but always remember that there may be completely different reasons and influences and that people are never just members of a culture but much more than that (*Diversity*).

"Intercultural cooperation is always a balancing act for which certain competences are required."

Elke

The development and application of intercultural competence is part of the everyday lives of migrants, who may see themselves faced with cultural differences, pressure to adapt and discrimination experiences. This becomes clear in the following example, which was shared by a workshop participant:

"The story that I am telling happened to me in Brussels. There was a potential for escalating the conflict, but I avoided getting even more deeply into the conflict. I will first tell the story, and then I will explain how I dealt with it:

I got into first class of the ICE at the main train station in Brussels. A lady was sitting there.

The lady: 'Excuse me, Sir, but you are in first class.'

Me: 'Yes, I noticed. Why are you telling me this?'

The lady: 'Because one of your colleagues also made a mistake and was sent to second class by the conductor.'

Me: 'I don't have any colleagues. I'm travelling alone!'

The lady: 'Yes, very well. I mean a dark-skinned man.'

Me: 'Madame, are all light-skinned people your colleagues?'

The lady: 'No, but...'

I interrupted the lady: 'So, for your information: I have a first-class ticket and am travelling with this ICE from Brussels to Cologne.'

Coincidentally, my reserved seat was exactly the one that was vacant next to the lady, which meant that we would be riding from Brussels to Cologne seated next to each other, and the trip takes about two hours. As I sat next to the lady, I asked myself what would happen now after our conflict? In order to defuse the situation, I introduced myself to her in a friendly manner and she also introduced herself to me. We were enthused about the work that each of us did. She apologised to me for her behaviour, and I also apologised to her.

In this story, I learned that we can also use the energy that we invest in escalating a conflict to diffuse it. At the beginning of the story, I found a word in every statement by the lady that I could have responded to in order to escalate the conflict because I felt myself under attack. In order to diffuse the situation and make a positive end possible, I attempted to find out what we had in common and what could make it possible for us to have a neutral conversation. I discovered that we were both seated in the 1st class, riding the same route, both speak German and French and we are sitting next to each other. I found a common ground, an interface, in order to create a new atmosphere for conversation and view my 'opponent' as a 'conversation partner'. So I succeeded in transforming the 'negative' energy into 'positive'. This is how I could make productive use of the conflict situation."

Clement

Clement describes various intercultural competences here: the search for *common ground* (What do we have in common?!), setting aside premature negative responses, the willingness to give the other person a second chance, taking the initiative on one's own, and not taking things too personally.

The following example by Ruth also makes the intercultural competences clear:

"I have already lived in Germany for 14 years, but I still can't really stand up and say 'I am integrated'. Am I integrated if I eat a roast with 'Sauerkraut' every Sunday? Or if I keep my garden completely 'free of weeds' in the summer? Are 'order and cleanliness' a sign of successful integration, or just of the inability of Germans to coexist in tolerance with other cultures? As Africans, we are asked to integrate ourselves here. But how can this happen if we do not receive the support and tolerance of the natives? Many migrants in Germany try to get along with the natives, but get a lot of negative feedback. You could actually say that the only 'positive' that you sometimes hear is, 'Oohh, you speak German well.' What is that supposed to mean? People talk and write so much about integration, but Africans have a more difficult time than any other ethnic group when it comes to being accepted by the Germans. There is still a certain prejudice, especially due to the skin colour. Germany does not try to integrate, but instead tries to make everyone the same. This is why I am happy to be allowed to participate in PaKoMi, because I hope that I can support my 'sisters and brothers' in Germany through it and can offer concrete 'survival help'."

Examples of my first 'steps' in Germany:

When my son ate ice cream for the first time in his life, he was quite frightened at first because the cold ice was 'steaming'. He tried to blow on it because he thought it was very hot.

I still do not understand to this day why there is so much dust in Europe. I always thought that it is so clean here in Europe and that there is no dust. Although people sometimes may not even have glass windows in Africa, there is much less dust in their rooms. This is a mystery to me.

My father-in-law likes to make jokes. At first, it was quite a problem for me not to know how to behave when he makes jokes with a suggestive content. Something like that would be unimaginable in Africa. In Africa, we also would not meet the parents-in-law with clothing that is too provocative (short skirts, shorts, spaghetti straps or open décolleté).

The lack of respect by children for adults or the ignorance and apparent impudent behaviour towards old people still surprises and shames me to this day.

It was astonishing for me to discover how many poorly educated people live in Europe (in view of the school system here), but also how hard the people here must work to earn their living. The idea of a 'Land of Milk and Honey' that is propagated by films and television is wrong. But the reality is simply not imaginable for someone in Africa."

Ruth

In her contribution, Ruth questions the discourse about integration and describes a variety of challenges that a change of culture can bring with it – being able to identify such challenges and learning to deal with them also illustrates intercultural competence.

Another example describes the challenges in an intercultural situation in the health-care system:

"We have a new intern in our building – a handsome man from northern Germany. Before he has hardly entered our office, he shakes the hand of the female colleague from the Africa project in a friendly way and says that he is sorry that people in Africa do not receive the necessary medications against HIV while people in this country have the freedom to neglect the therapy on their own volition. In conclusion, he also adds that as human beings we are all the same. After he leaves, I ask my female colleague which common grounds she sees between herself and a German homosexual man. She doesn't know. We think and probably know that people are different, depending on where they are born, what skin colour they have and what kind of family, surroundings or which country they grew up in and, and, and… How many more steps and efforts does my female colleague need to take compared to the intern in order to work here in the same office? They are not even always equal under the law. They may also differ in their basic needs. Anyone who does not realise this may overlook the fact that all the flyers and brochures that are translated literally from German into other languages are not always appropriate for reaching migrants. It is possible that he may not even know

> **that homosexuality is not allowed in some cultures and therefore cannot be a (direct) topic. One should always be aware of the diversity of people and also of one's own prejudices because someone who is aware of his prejudices would not directly talk to an African woman about HIV and AIDS or come up with the idea of 'decorating' a booth of the AIDS service organisation with African people and food. When in doubt, it is better for ask ourselves how we would feel in the skin of the other person. This is how we can possibly get a bit closer to intercultural competence."**

Employee of an AIDS service organisation facility with a migration background.

This contribution shows how frustrating intercultural contacts can be and that people with a migration background often have a worse starting position for success. In order to better understand the other person, it helps to make fewer assumptions, ask more questions and listen more.

> **"It is important for intercultural collaboration if you have such everyday experiences to create space for the exchange between people. This is where the participants can address their various affiliations and roles, experiences of feeling foreign and of being discriminated against."**

Elke

How can such an exchange be facilitated?

One possibility for approaching the topic is the creation of a world map. This goes like this: Select a room in which all of the people can stand and move freely. The moderator asks everyone present to position their place of birth in relation to the birthplaces of the other people in the room – like a map of the world. Next, the same is done in response to the questions: "Where did you grow up as children?," "Where were you as young people?," "Where were you as young adults?," "Where do you live now?" When we created such a map of the world at the PaKoMi workshop, it became obvious to us how much movement there was and that almost all of those present actually had migration experience in one form or another.

Another tip in dealing with intercultural situations that may pose a challenge is the exercise "How Do You Say That in the Positive?" Intercultural encounters frequently mean that we can give good reasons for our own attitudes and conduct, but tend to have a negative judgement about the others. We can use our approach to time as an example: I prefer to do one thing after the other, tend to have a more linear concept of time, and am well organised and punctual. My counterpart may like to do more than one thing at the same time, has a more circular concept of time, and is less organised and also less punctual. We have the tendency to each think negatively about the other person: He or she is chaotic and unreliable or rigid and inflexible. But when I know that each characteristic has advantages and disadvantages and I ask myself "How do I say that (what irritates me) in positive?“, then I may come to see the positive things – such as a greater sense of serenity and flexibility in the one person or clarity and reliability in the other case. At the same time, I can also ask myself how the other person perceives me: Is it possible that my positive characteristics also have negative aspects?!

At the workshop, we also explored our understanding of intercultural competence and we collected examples of knowledge (head), action (hand) and attitudes (heart). Illustration 6 shows what intercultural competence means to us.

Work Guides

Which key persons and migrant self-organisations (MSOs) exist in the target group or community with which you wish to work?

Which other groups, providers and facilities exist that you could get on board with you?

Which goals do you want to pursue?
Is it possible for you to agree with all partners on a concrete (SMART) goal?

How do you want to deal with misunderstandings, tensions and conflicts in the cooperation?

What would make the cooperation easier?

Which resources exist –
and what do you still need to work together well?

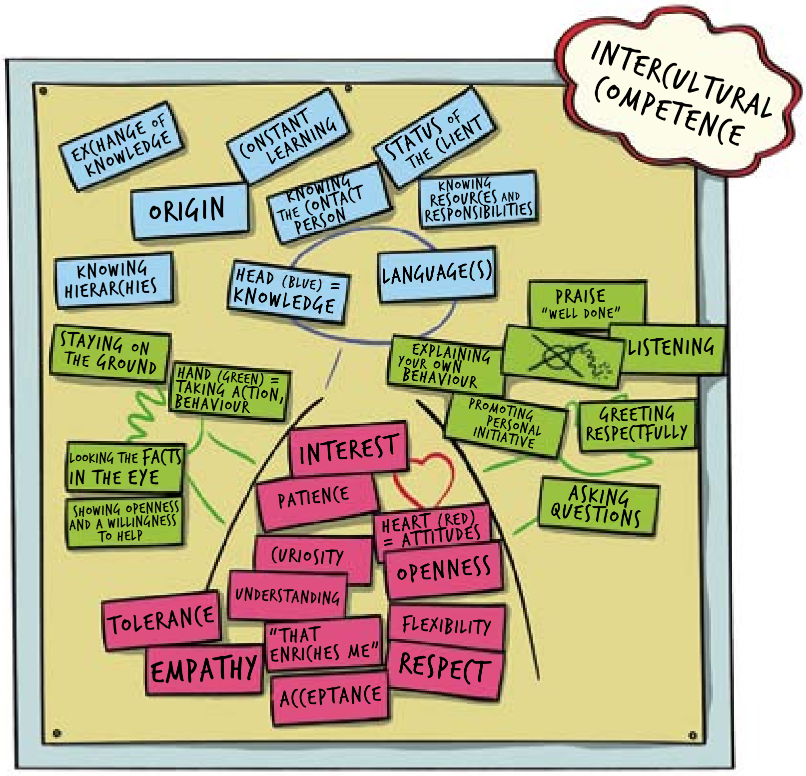


Illustration 6:
Intercultural competence from the perspective of PaKoMi workshop participants

3. Participation

What Does Participation Mean?

Participation means people are involved and have the opportunity to have a say in the decision-making process. So this is not just about taking part ("Teilnahme"), but also about active participation ("Teilhabe"), as in having a say and being involved in making the decisions. In PaKoMi, we specifically tried to involve people with a migration background in the development of HIV prevention services and in the participatory research. In this process, it was important to us to work together on equal footing.

"For me, participation means bringing my own building blocks to the structure. Each of us has special abilities. When different people form a group and their abilities are applied to a common purpose and goal, this can result in outcomes that are efficient and beneficial for everyone. True participation involves an active involvement of the participants and shared decision making power. This means that all suggestions, contributions, opinions, ethics, visions and perspectives are taken into consideration. Community members conduct research on an equal basis with the scientists in this process. So no theory or hypotheses is applied, but our work is based on simplicity and practical experiences."

Steve

"I believe that participation means joining in and getting involved – being able to have a say and including those who are affected from the beginning to the implementation and sometimes to the evaluation. If you want to succeed in getting migrants to participate, then you must deal with the cultural, moral and socioeconomic circumstances of the community's society of origin, as well as their life situation in the residence country. From my perspective, the participation of migrants in HIV prevention contributes to the better combating of HIV and AIDS in Germany. It strengthens and enables the involved employees, promotes community empowerment and leads to more sustainable work. Above all, participation should lead to equal opportunities for people in our society. Because participation demands a certain level of education, more resources (funds, time, premises, etc.) should be invested in health promotion and HIV prevention work."

Omer

"The inclusion of people from our target groups and their networks and communities – which we ourselves in part belong to– on an equal basis in prevention work is what Deutsche AIDS-Hilfe e.V. (DAH) stands for and what our prevention work is built upon. It is one of the most important sources of our professional competence. This approach has characterised the way in which the AIDS service organisations have worked for years with the various target groups. HIV prevention for migrants as a field of work has developed at a relatively late point in time in comparison to the other areas of HIV prevention for various reasons. How far the process has progressed in including people with a migration background in prevention work differs throughout the country. On the one hand, there are very promising developments and successes; on the other hand, there are also challenges. This makes it even more important to record in a systematic and participatory manner how we succeeded in realising the participation of migrants and which factors hindered or promoted it. In the future, improved conditions and/or structures should be created throughout Germany that make it possible for migrants to formulate their needs, contribute their competences and resources and have a say in the work processes. This is especially important for prevention work because migrants are an extremely heterogeneous group. Only when knowledge of the language, the living environment and the culture of the target groups and communities with a migration background flows into the prevention work can prevention measures be designed in a more appropriate manner. At the same time, the involvement of people with migration background on an equal basis makes it possible for us – as the umbrella organisation – and our member organisations to have an authentic representation of interest."

Tanja

Stage Model of Participation

A stage model has been created for the quality development of prevention and health promotion. This model can be used to differentiate between the various stages of involvement and participation (ill. 7). The model is described in detail elsewhere.[1] The decisive difference between participation and the preliminary stages of participation is found in the question of who has how much decision-making power. The model contains two levels of non-participation, three levels of precursors to participation, three levels of participation and one level of self-organisation that goes beyond participation.

Stage 1: Instrumentalisation

The concerns of the community do not play a role. Decisions are made outside the community. The focus is on the interests of the service organisation. Community members are just "decoration."

> **Example:** Someone uses a photo of a person with migration background in order to advertise an event without involving him or her in the decision-making process.

This level does not qualify as participation! It is unethical and community members often experience this level as being exploited.

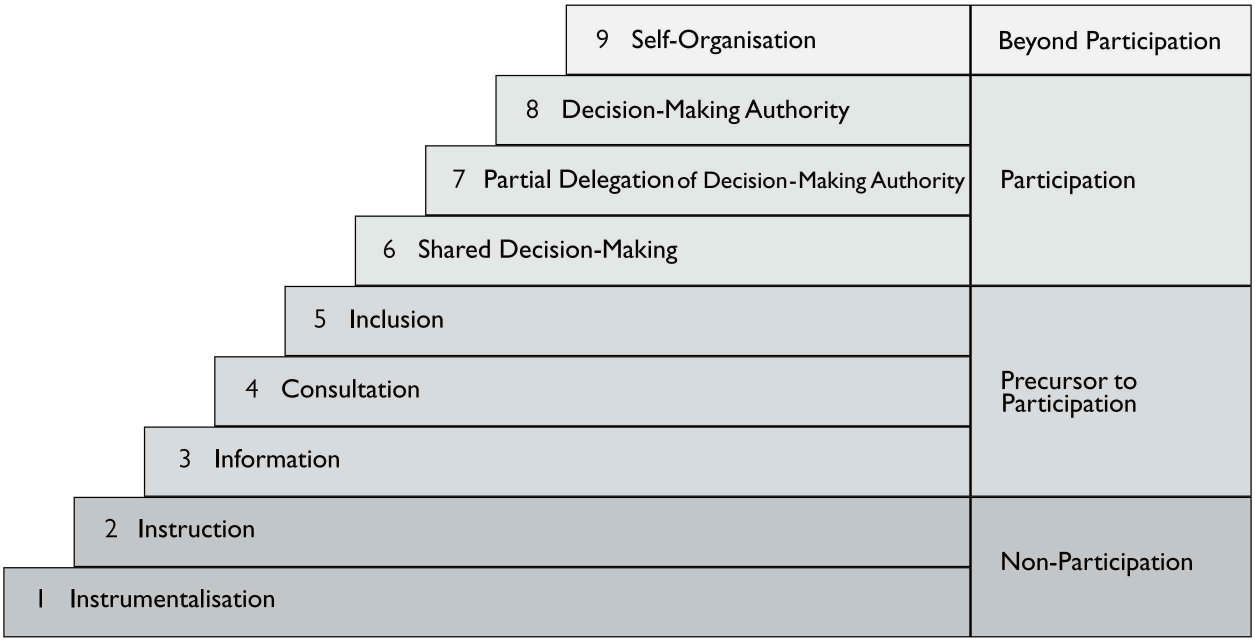
Stage 2: Instruction

Also the second level is not participatory. The situation of the community is perceived, but the problem is solely defined from the perspective of the decision-makers (e.g. professional helpers). The opinion of the community is not taken into consideration. The communication is unilateral (i.e. in one direction).

> **Example:** Someone tells you what you should do: "There's a street festival tomorrow and we want to present prevention there – please set up the booth and look nice!"

There may be situations in which instructions from professional helpers are appropriate (e.g. moments of acute crisis). However, in most cases, community members and clients experience this kind of approach as patronising and unappreciative.

Illustration 7:
Stage model of participation
according to Wright, von Unger and Block 2010



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[1] Wright, von Unger, Block 2010

Stage 3: Information

Information is a precursor to participation. The decision-makers tell the community about the problems that the group has and which help it requires. Various possibilities of action are recommended. The actions of the decision-makers are explained and justified. The perspective of the community is taken into consideration in order to increase the acceptance of the message.

> **Example** of the booth at the street festival:
> You are informed about the matter, which materials should be distributed and why it important is for you to be there.

Information as a precursor to participation plays a major role in HIV prevention, for example in forms of brochures and information material.

Stage 4: Consultation

The decision-makers are interested in the perspective of the community. The members of the community are consulted, but have no control over whether their views are taken into account. This second precursor to participation also plays a major role in HIV prevention since good services consider the perspectives of the target groups and communities. Many service providers are familiar with the needs and perspectives of community members through their contact with their clients. However, level 4 requires that they take the effort to actually ask the clients or the community members what they think they need.

> **Example**: Surveys with the help of focus groups, interviews or questionnaires are possibilities for how people can be consulted (see Chapter 6).

Stage 5: Inclusion

The decision-makers/service organisations ask selected members of the community or target group for advice.

> **Example**: You are called as an expert and asked for advice about what type of campaign should be initiated, but you have no say in the decision.

This precursor to participation is different from level 4 in that selected persons are asked for their specific advice. These individuals (often key persons from the community) can make suggestions and comment on various issues. However, it is still a precursor to participation since they cannot control the final decision on what kinds of services are offered or what campaigns are initiated.

Stage 6: Shared Decision-Making

This level finally constitutes participation. The decision-makers consult the community. Negotiations are carried out between representatives of the community and the decision-makers. Members of the community have a voice and a say in the decision.

> **Example**: You sit at the table and you have a say in deciding which campaign should be implemented. However, you may be the only person with migration background there and/or in the minority and you cannot assert your position.

Stage 7: Partial Delegation of Decision-Making Authority

On this level, community members are involved in the decision-making process and they can determine particular aspects (e.g. of an intervention) themselves. However, their decision-making power is limited to certain aspects.

> **Example**: You can make an independent decision for a certain part of the campaign (e.g. the design of an advertising poster).

Stage 8: Decision-Making Authority

The community members determine all essential aspects of an intervention. This takes place within the framework of an equal partnership with the service organisation or other stakeholders.

> **Example**: Your group independently designs a service for migrants within the AIDS service organisation, such as Café Afrika in AIDS-Hilfe Hamburg.

Stage 9: Self-Organisation

The responsibility for a measure or project lies completely in the hands of the community.

> **Example**: You establish a migrant self-organisation (MSO) just like the African community partners plan to do in the case study in Osnabrück.

Conclusion:

Participation is not an either-or situation,
but a development process.

The participation can be realised 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.

What Hinders the Participation of Migrants in HIV Prevention?

In the case studies and workshops of PaKoMi, we have studied what hinders the participation of migrants in the development of HIV prevention. We have found obstacles on four levels as a result:

Society: The participation of people with a migration background is hindered by legal structures and discrimination, xenophobia and racism and social inequality. As long as migrants do not have equal rights to participate in society – which means equal access to the job market, education and so forth – their possibilities for becoming involved in health promotion and HIV prevention are restricted.

Facilities of the public health system, such as AIDS service organisations, 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: there are not enough salaried employees who have a migration background, not enough multilingual services, and not enough intercultural or transcultural competences.

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 on 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.

The 90 AIDS service organisations that we surveyed in 2009 named various points from their perspective that hinder the HIV prevention for and with migrants. These include cultural differences and taboos, lack of resources, language barriers, restricted access to the communities and problems of stigmatisation.[2]
The conclusion of the study was clear: in order to master the existing challenges, people with a migration background from the communities must be included in an intensified manner.

How Can Participation Be Strengthened?

When we look at the obstacles, it becomes clear that changes are necessary on all four levels (society, facilities of the health-care system, migrants communities and cooperation) in order to promote participation. In the recommendations that we have developed (see Chapter 7), we make concrete recommendations on what can be done in order to make possible or improve the participation of people with a migration background in HIV prevention.
The recommendations are directed at politics, the preventive practice, migrant communities/MSOs and academia. This involves:

opening social structures (such as education and the employment market) on the whole,

abolishing legal discriminations and recognising educational degrees and occupational certifications from the countries of origin,

appreciating cultural diversity,

making resources available,

advancing the intercultural opening of the facilities and hiring more salaried employees with a migration background,

involving volunteers from the communities and supporting their participation financially (through small reimbursements and compensation for expenses),

promoting the migrant self-organisations (MSOs) and the cooperation with them,

strengthening the networking and *community-building* of migrants,

abolishing taboos and the HIV stigma,

developing intercultural and transcultural competences and much more (see chapter 7).

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[2] von Unger, Klumb, Gangarova and Wright 2011

How Can We Convince Migrants to Become Actively Involved?

"For an active collaboration to occur, communication is necessary. This initially includes the language. It is difficult for many of us to express ourselves in a quick, clear and concise way. This leads to misunderstandings and impatience, making the collaboration even more difficult. A good cooperation therefore requires language skills. Another requirement would be the acceptance of various opinions, diversity and the differences. An effective cooperation should take place among the migrants. This means that the will to achieve a mutual goal must stand in the foreground."

Steve

"Migrants can be convinced to actively collaborate by sparking their interest and raising their consciousness for the topic. However, migrants should not be exploited as decorations in the work but employed as independent, responsible stakeholders. Migrants often do volunteer work (not just in Germany but also in their countries of origin), but this work is frequently not recognised by German society. Many of us are involved in various associations (religious and non-religious, cultural, etc.) and work for more understanding between nations, cultural exchange and so forth, but we receive little or no funding. The reason for rejection is frequently given as unprofessional work or that the concepts have not been properly developed. The AIDS service organisations are very professional associations, but they sometimes invite the migrants only to take part, not to plan and organise events with them. Migrants who are considered to be 'hard to reach' should also play a role and the variety of resources that they bring with them should be used. We want to not only participate in the services but also be able to help design and co-determine the services.

The goal should not just be to have more migrant participation in the HIV prevention of the AIDS organisations. The founding of self-help groups within the migrants communities and migrant self-organisations should also be supported financially and morally. This promotes more responsibility and creates independence. Working side-by-side does not mean working against each other. Since we were raised differently, it is no wonder when we sometimes work differently. The important thing is that each of us knows his or her goal. But I also believe that it is important to design projects together with the Germans – interculturally or transculturally – in order to create mutual enrichment.

As an employee of an AIDS service organisation, it is sometimes difficult for me to be understood in the debate on volunteer work – both by the AIDS service organisations and by the migrant communities. I am in favour of a real intercultural or transcultural and participatory opening of the AIDS service organisation towards migrants. Above all, this can occur through the self-organisations established by the migrants. However, this self-organisation of migrants must be supported in terms of its content, organisation and financial aspects. The competences and qualifications that the migrants contribute to the cooperation can be very significant. But laying the groundwork together is very important since we also need the Germans at our side because we live in Germany."

Omer

How Can We Involve Migrants Even When Resources Are Limited?

"Resources for expense compensation or fees are certainly meaningful in order to recruit volunteer migrants and recognise their commitment. But from the perspective of the project, we expect that their motivation will not just be because of the money. We know that we are not in the position of creating a position for each person and we also say this in advance so that no false hopes are awakened. However, we give migrants opportunities for advanced training, mediate contacts for an occupation perspective and accompany them for some part of their life so that their financial existence is secured. This can be an incentive for some migrants to cooperate for a longer period of time. But an organisation that would like to take migrants seriously as a community cannot avoid also hiring salaried employees with a migration background!"

Nozomi

Why Do I Get Involved?

"When I belong to a community, I also bear the responsibility for this community.

Because the other people are important to me.

Because I don't just want to concentrate on myself in life.

Because I see it as an ethical obligation to contribute something to society and the community.

Because I – as a migrant – do not just want to be called a burden on society.

Because I know that we migrants are the resources. We have multilingual abilities, cultural sensitivity and tolerance that has developed from our own migration experience, training and life experience.

Because I am a human being, a woman, a mother and a refugee, I know how to talk about difficult topics with people who have had similar experiences.

Because I would like to spare others of my sad fate!!!"

Melike

"I am involved because the topic is important to me and because it is ultimately my job as a relative of someone who is affected. Many members of my family and compatriots have died of AIDS. Life is simply too valuable to let it be destroyed by an illness against which we can protect ourselves with pure knowledge. I do others things, even if it sometimes difficult, such as reading, going swimming or playing with friends or my family. I can me make it clear to myself that this is a greater whole and I am not the only one who is important with my personal situation. And I can actually see the successes of the work."

Omer

"PaKoMi has decisively influenced my understanding of my role as a prospective social worker. I have learned to be more flexible in my ways of thinking and open up to processes whose results are not clearly predictable. PaKoMi has sharpened my consciousness for the idea that one's own perspective of the world can always just be a small excerpt of it. I have learned to listen to people who make it possible for me to look at another piece of the world and make me more sensitive to the individual life-world as a result. Not just listening to the opinions of many people but also taking them into consideration was a true challenge during the project and encouraged all of the participants to take a critical look at their own thought patterns time and again. To me, this is why participation always also means working on myself. The positive energy and the commitment of the participants that developed during the projects motivates me to act as much in a participatory manner as possible within the existing structures."

Karin

"I would like to provide help for migrants in Germany because my own experience shows me how difficult it is for German society to fully accept foreigners. The German law and German society make immigration either extremely difficult or not even possible. When only money is important, the personality falls by the wayside and social coldness is pre-programmed. The standards used here often vary greatly. It would be important to promote the understanding for the different perspectives of social correlations for fellow human beings and take the respective special cultural origin into consideration. For example: What should you think when a German man marries an African woman and then leaves her with five children because he can't cope with the cultural differences. Instead of Child Protective Services helping this woman and offering her a housekeeping job on an hourly basis, for example, it takes the children away from her. This is how people are driven insane and they turn – as in this example – this woman into an alcoholic."

Ruth

"PaKo-What? Participation and Cooperation in HIV Prevention with Migrants … Your training seminars always have such strange names. Who actually came up with this? What is so new about the idea that people should use condoms that migrants don't know about? After all, there are already so many brochures in every possible language! So what should be different now?"

I heard these kinds of reactions when I told colleagues, friends and acquaintances that I wanted to participate in the PaKoMi advanced training. Correct: The name is not that smooth. Correct: Even migrants know that people can protect themselves against an HIV infection by using a condom during sex. Correct: There are a great many brochures in various languages already. Everything is correct – and yet, it's wrong. PaKoMi shows that participation and cooperation in HIV prevention – not just with migrants – are a lot more than this. Much more than the idea that migrants work in HIV prevention. Much more than the idea that people should be spoken to in their own language whenever this is possible. Much more than the idea that people should be asked what they need. Much more than the idea that not every target group is also a community. Much more than the idea that not every person belongs to the community that others ascribe to him or her. Very much more than I can describe in a brief statement. This is why I recommend, 'MACH MIT!' [Join us/Participate!]"

Gerd

Work Guides

In the PaKoMi case studies, people with and without a migration background worked together. In the end, we discussed who was involved at which stage and whether we considered the respective level as appropriate. In the process, it was interesting that people sometimes had different assessments of the stages such as when one person thought that another could participate in the decision-making but the other person did not feel that he or she actually had decision-making power. This illustrates how important it is not to reflect where we stand as individuals but also discuss this in the group.

At which stage of the participation
are you involved in HIV prevention?

At which stage are (other) migrants involved?

Do you consider this stage to be appropriate?

What could you do to increase participation?

4. HIV Prevention with Migrants

How Can We Address HIV/AIDS?

HIV/AIDS is a sensitive topic. The best way to address it depends on the situation and the person with whom we are talking. Taking an approach that is sensitive to the context and the culture means finding the words that are appropriate to the situation and the person, including an understanding of the meanings that HIV/AIDS has in this context. It is often advisable not to go straight to the issue but first listen to what the other person is interested in. However, being “culturally sensitive” in our work does not mean just accepting everything as it is. There may be attitudes and taboos that we want to change in order to make it easier to deal with HIV/AIDS. In general, the best approach is to provide HIV prevention in the communities together with persons from the communities. Support by people who have a high standing in the communities is also very helpful.

“You can talk about HIV/AIDS with migrants by providing target group–specific and culturally appropriate services. The inclusion of the target group should be promoted so that the work has a lasting effect. From my perspective, methods and strategies of HIV prevention for and with migrants are still incomplete and need to be improved.”

Omer

How Can We Design HIV Prevention in a "Culturally Sensitive" Way?

"To me, culturally sensitive prevention means that we are open to the cultural background of the target group and consider its living situations and life-worlds in our design of prevention services. Knowing that we Africans in Hamburg and the rest of Germany experience stigmatising and discriminating behaviour and are berated as HIV carriers (*Porteurs de virus*), I understand how important it is to ease into discussion about HIV prevention – without charging at them like a bull at the gate. It is difficult to carry out HIV prevention in a culturally sensitive manner – no matter who does it – without breaking the taboos. It is possible to educate people about HIV/AIDS without talking about sex or can we deal with the topic of female circumcision without saying the names of the female genital organs? What I understand as culturally sensitive prevention is taking into consideration the cultural background of the migrants, who should be supported in the health-care system. However, this demands a certain degree of transcultural competence that first requires an intensive examination of one's own moral values. Transcultural competence includes the willingness to revise the familiar knowledge, personal values and one's own morals, as well as the curiosity to better understand and accept or at least tolerate both what is foreign and what is one's own."

Omer

"In the development and implementation of prevention services for various migrant groups, it is very important to consider the complexity and dynamics of the influences specific to migration, but also the extremely large differences among the migrants in Germany and their diverse needs. It is also important to recognise the numerous resources of the migrants, including and promoting them in the conception and implementation of preventive measures. The transcultural approach is best for this purpose. The basis for the terms culture and cultural sensitivity is usually a static concept of culture. This creates the danger of thinking in stereotypes and only perceiving people's deficits. In this process, the competences of migrants and their networks are frequently neglected. The transcultural approach assumes that cultural systems are constantly changing and that there are no closed cultural circles. The focus should be on the common grounds of people with different migration and not their differences. For the promotion of health, this means that projects and models of HIV prevention should be designed in such a way that they correspond with the needs of migrant groups or can be adapted to them. Migrants should not just be addressed with special services but included in all of the HIV prevention services. Migrants and their organisations have the best knowledge of their living environments. They can respond to the question of whether the existing services of HIV prevention correspond with their needs or whether additional services and measures are required in order to more specifically address their migration-specific, language, legal and cultural needs.

Within the scope of an approach that does justice to migration, the process of 'intercultural opening' must also be advanced. Among other things, this includes strengthening the intercultural competences of AIDS service organisation employees and the intensified inclusion and employment of people with a migration background in the salaried and volunteer area. Above all, strengthening intercultural competence means promoting the abilities for critical self-reflection. The employees should view the cultural aspects of the target group's living environment with a reflective, differentiated and dynamic understanding of the culture. Then certain practices, attributions of meaning and intercultural differences can become topics without codifying

and ‘naturalising’ them. When I question my own cultural imprint, it becomes possible for me to avoid such culturalisations. When we comprehend a culture as being dynamic or changeable, we can understand how the migration process and culture mutually influence each other and what this means for sexuality, drug use and the HIV risks of migrants.”

Tanja

Sometimes people speak of “migration-sensitive” instead of “culture-sensitive” prevention, such as when they want to emphasise more strongly the immigration process and focus on the legal situation of migrants. In contrast, use of the term “culturally sensitive” emphasises the *meanings* that sexuality, gender, HIV and so on have in different cultures. Both terms supplement each other well.

The idea that a person is sensitive to the respective culture resonates in the phrase “culturally sensitive”. But does this also mean that it must be accepted as it is? Can we not talk about certain issues due to cultural taboos? Cultures change continually and this also means that they can be changed. We just need to know how. However, the larger changes are not always possible right away. For example, the Berlin case study on HIV prevention for certain men who have sex with men (MSM) included a discussion about not “breaking” taboos but circumventing and subverting them and attempting to make information and education possible in this manner.

When the behaviour of people with a migration background is “explained” in a one-sided and premature way with their cultural origin, this is called culturalisation. On the other hand, a culturally sensitive approach should avoid culturalisations and take into consideration the interplay of cultural and other factors such as legal, social and economic influences.

“The Berlin case study dealt primarily with Turkish- and Russian-speaking men who have sex with men (MSM), who do not openly identify with gay life or do not see themselves as homosexual. The sub-project of GLADT – a self-organisation of mainly gays, lesbians, bisexuals and transsexuals from Turkey – interviewed experts from Turkish- and Russian speaking communities on how HIV/AIDS prevention for MSM could work. The interviews revealed that sexuality is a taboo topic in the communities and that ethnicised concepts of gender roles predominate: masculinity is associated with strength, assertiveness and the willingness to take risks, and frequently related to a certain ethnic background (‘for Turkish men’, ‘the Germans are ...‘). Sex with men is considered a loss of masculinity and is therefore taboo, even though the interview partners were very knowledgeable about MSM. They know about it, but do not speak about what is not allowed to exist. So how should the messages of HIV prevention reach the MSM? By breaking the taboo of openly addressing MSM in the communities? No. Even when the assumption is made that MSM who have come out as gay can be more easily reached with the topic, a culturally sensitive approach to prevention should in no case lead to a ‘forced coming-out’ of MSM. Instead, the community experts recommend addressing the MSM as heterosexuals in ‘normal’ places (the subway, street, cinema, etc.). At the same time, it is important to train key persons – especially gay men and MSM who are sensitive to the topic – as multipliers. This is because addressing individuals within the migrant communities through trusted persons from the private environment, MSOs, religious institutions and the like has a major significance. These perceptions make it clear that we in the AIDS projects must change our way of thinking if we want to address MSM with a migration background who do not self-identify as gay. We should not address them as homosexual and also not as MSM in the public space but as a part of the general population. Communicating the special risks of gay sex becomes a challenge in this situation.”

Nozomi

Why Do I Get Involved in HIV Prevention in My Community?

Various PaKoMi participants with diverse migration backgrounds described the reasons for their commitment to the topic of HIV/AIDS and HIV prevention. Here some examples from people with African origins:

"HIV and AIDS is a topic which is very unpopular. Many people think HIV is far-fetched, forgetting that it is within and amongst us. That's why I do this work to remind them that it exists wherever we are. But then all in all, I want to make a change in my community; for this to be possible, 'I have to be the change that I seek.'"

Ruth

"I do HIV prevention for and with my community because I think it's important. I would like for the members of my community to be better informed about HIV/AIDS and other sexually transmittable diseases and be able to protect themselves against them, but also for them to show solidarity for people with HIV. I personally know how difficult it can be to get a foothold in a foreign country. Above all, the moral and cultural barriers and taboos that people bring with them stand in the way – not just in Europe, but also in Africa itself. I would like the access barriers for migrants in the German health-care system to be abolished and that equal opportunities become possible for everyone."

Omer

"My interest in HIV and AIDS and what it means for African migrants here in Germany is based on my points of contact with this illness in my home country of Kenya. In order to comprehend how HIV and AIDS are understood by a large part of the population in Africa, it is important to recognise that illness in general is understood in a completely different way than here in Germany. A magic spell is often made responsible for the outbreak of an illness. Any possible person is suspected for causing it, including the deceased ancestors. In such cases, the family decides whether to take the sick person to a sorcerer who – for an appropriate payment – conducts complicated rituals for healing and protection against the disease-causing magic. This idea is found in people of all classes and educational backgrounds. I was already very sceptical of this approach as a child and turned against such traditions and superstitions in our family, also because I had seen that much too much of the little money that we had was spent on this without the sick people being healed as a result. I later got medical training as a nurse and was able to better help my family.

The HIV infection and AIDS illness spread in East Africa during the 1980s. During that time I was training to become a nurse. The common name for this new illness was the 'Slim Disease'. This term quite accurately described how the people suffering from this illness looked: they were at first slim, and then clearly emaciated as the illness progressed. At this time, no one in Kenya – not even doctors and nurses – were allowed to talk about it: the government worried about Kenya's reputation as a tourist destination. By contrast, the medical personnel and politicians in the neighbouring country of Uganda were much more open from the start in dealing with the continually growing body of knowledge about the HIV infection. As a result, it was already possible to initiate prevention programmes and support strategies for patients with AIDS ten years earlier than in Kenya. Even though it was already customary in Europe and America at that time, there were no concepts of treatment here. Even in the 1990s, we could just advise the patients on nutrition, hygiene and care, treat some of the complications and instruct and support the relatives in their devoted care of the sick people.

In the poor settlements of the Kenyan capital of Nairobi, I encountered an extraordinary project. There were many slum residents who were ill with AIDS – many of whom were single parents. The project taught their children how to deal with the situation and care for and feed their sick and infirm parents. The children and young people met every week for this small 'course'. This made it possible for them to give each other support and strengthen each other, have a few hours away from their everyday exertions and be carefully prepared for the imminent death of their parents. The ARVs (medications for suppression of the virus activity) have only recently become accessible for normal residents in countries such as Uganda and Kenya since donor organisations have made a controlled distribution possible at no-cost to the residents.

Who falls ill with AIDS? Another aspect of this illness here in Germany that is very interesting to me is that people essentially just talk about HIV and AIDS in relation to the so-called risk groups (e.g. drug addicts, migrants or male homosexuals). This does not apply to Kenya: the illness occurs in all social classes ranging from academics to simple farmers and day labourers, in men and women, in the countryside and in the big cities, among the poor and the rich – and the people also notice this. However, the effects on the poor, less educated population are more severe since they have less access to tests, counselling, treatment and a good nutrition. They may also not have money for the transport to the closest health facility. Another example for these various effects is also the treatment of HIV-positive pregnant women: counselling and voluntary HIV tests within the scope of the pregnancy examinations are available to everyone in the country's health facilities. But very few can afford the caesarean, which protects the newborn with a high degree of certainty against the mother's infection with the HIV virus, because an operation must be paid in cash and most people do not have health insurance.

On weekends there were more funerals than weddings: in my home country of Kenya, many celebrations take place on the weekend. One of the most important is the wedding, for which a great many relatives always come together. Large numbers of people also congregate for the funerals – the more important the deceased person, the more people come. Towards the end of the 1980s, the people noticed that the number of funerals in a village or community had clearly increased in comparison to the number of the weddings. This is how the people noticed that 'this new illness' actually had very serious effects on their community. They started to talk about it and seek advice. This was the time in which a national public education and prevention programme was also started in Kenya and the politicians admitted that Kenya had problems in dealing with HIV and AIDS. One of the problems is that the parent generation in many families dies of AIDS and the children must be taken care of as orphans by the grandparents, for example, but this is a task for which they traditionally have little preparation. But with the support of the state and many donors from Europe and the USA, the Kenyans have managed to care for the great majority of AIDS orphans within the extended family and have them attend normal schools. Only in situations in which the children are left on their own, as in the poor quarters of Nairobi, it is necessary to have facilities such as the WATOTO WETU (Our Children) school in which the children who would otherwise be forced to fight for their livelihood on the street receive an education, food and supervision during the day.

How huge the challenge is even today for about 1.5 million people with HIV and AIDS in Kenya (overall population of about 35 million) in defending themselves against discrimination and stigmatisation in society has recently been demonstrated by a female minister suggesting that these people should be locked away in order to counteract the further spread of the disease. Such statements obviously do not increase the willingness in the population for taking the tests but just stoke more fears. Fortunately, there are also sensible people – such as the president's wife in this case – who publicly contradict such views.

With such experiences and incidents in my heart, it is a special joy for me to collaborate with others in the PaKoMi group here in Osnabrück. I put myself into the mindset of many Africans, but also know the German health-care system on the other hand. So I try to continually support African migrants here in Germany in the areas of health and HIV prevention."

Catherine

A Bulgarian participant, who collaborated in the Dortmund case study, describes her motivation as follows:

"In my community, the need for HIV prevention became dramatically noticeable directly after the EU enlargement in 2007 due to migration for the purpose of sex work. The majority of the Bulgarian women who worked as street-working prostitutes in Dortmund come from the minorities (Roma and Bulgarian Turks), which are sometimes very neglected. Almost all of the female sex workers from Bulgaria are driven by financial need. In Bulgaria, both of these factors are very frequently the reason for leaving the school prematurely, possibly even before the legally mandated eighth grade (completed at age 14 or 15). But sexual education is also not exactly prioritised in the schools in Bulgaria. Most women come from the lower social classes and do not have a distinct body and health consciousness. The body becomes an instrument for financial security – one's own and that of the family. All of this compelled the KOBER counselling centre to turn to the AIDS service organisation in mid-2007, because it was overwhelmed by the current situation: the women were lacking basic knowledge about contraception, and many knew nothing about condoms. There were new pregnancies every month. There are considerable differences between Germany and Bulgaria in the dealing with the topic of sex, contraception and HIV prevention and in the case of sex work, knowledge about these topics is vital for survival. Education creates safety – for the women themselves, and also for their customers and sexual partners, which means for all of us."

Ivelina

How Do I Promote HIV Prevention in My Community?

"Through info events in the communities during association meetings, cultural events, at football tournaments and the favourite migrant meeting places. I also do on-site HIV prevention work such as conducting personal conversations with key people in the communities, participation in cultural events, workshops and so on. I meet the representatives of the communities personally here and can talk about the meaning of the HIV/AIDS topics for both Germans and the migrants and draw attention to them. In addition, I recruit and train interested Africans so that they can improve their social interactions with people who have HIV/AIDS."

Omer

"It has now been about nine years that I have been doing volunteer work at the AIDS Organisation of Osnabrück. I decided to distribute condoms to my fellow Africans in my community. When I distribute condoms, I show a sense of responsibility; and when the people accept the condoms, they show a kind of acceptance for the idea that 'good health goes with a good life'. Distributing condoms was the easiest way to get access to people in a way that created a good atmosphere. We have even talked about HIV and AIDS – but not always. In order to indirectly start a discussion, I placed condoms on the table when I sat down in an African shop, for example. This usually has worked and has ended in a long discussion about HIV and AIDS. My work continued successfully until people gave me the name 'Mama Condom'. Because of the stigmatisation, it was not an easy decision to work for my community and do HIV prevention. I was afraid of losing my name and my friends and being excluded in a country where I have no roots. Every social contact that I make is very important to me – physically and psychologically."

Ruth

Illustration 8:
HIV prevention at a football tournament

Illustration 9:
Conversations and condoms in the Afro shop

"After the KOBER counselling centre asked the AIDS service organisation for help in advising the Bulgarian sex workers, I began working as a volunteer with a staff member of the AIDS service organisation to organise open circles in which we spoke with the women about the symptoms and course of the most important sexual diseases, about contraception against pregnancy and HIV with pictures as support. There was much interest, and the women who came to these circles were open and interested. You can and should use the interest and the available potential to make it possible for the women to have improved working and living conditions by sensitising them for the dangers of sex work and encouraging them to treat their own bodies in a responsible way."

Ivelina

How Am I Perceived When I Engage in HIV Prevention in My Community?

Ruth has already described that it can be quite difficult when you are associated with the topic of HIV/AIDS in your own community (in her case she was called "Mama Condom"). Omer also experienced mixed reactions to his HIV prevention efforts in the African communities of Hamburg. But he is also very much respected, especially because he has the self-confidence to address this sensitive topic:

"The perception in the communities varies greatly. I am perceived in both the positive and the negative sense; both are a result of the topic, which is seen as a taboo by many migrants. No one wants to talk about it. I have come to terms with this in the meantime, even if I am confronted with defensive reactions. My professional experiences have convinced me how interested some of the African key persons of the religious and non-religious communities are in HIV prevention and the respect that some of them show when you are willing to deal with this difficult topic."

Omer

Can We Speak of Migrants as One Target Group?

In HIV prevention and health promotion, it is customary to define target groups that are to be reached by means of specific services or measures. This allows for a more tailored approach, adapting the measures to the special needs of these groups. However, the question arises as to whether we can talk about migrants as a target group of HIV prevention. There are reasons that speak for this and others that contradict it. Since migrants in Germany are different in so many respects, it is fundamentally a problem to speak of "the migrants" as one group.[1] In any case, it is important to consider whether there are a number of groups or sub-groups and try to describe them as precisely as possible. It can also be helpful to remember that there is a difference between target group and community (see Chapter 1). Omer describes a combination: on the one hand, it helps to speak of migrants as a target group, but we also must be aware of diversity among migrants.

"In my opinion, we can talk about a target group of 'migrants' whose barriers are the same or quite similar. But we should differentiate in our everyday work. There should at least be different services for the various cultural and language regions. Not all migrants get along. Experiences have shown that we Africans are not accepted by some of the Afghans or Turks in Hamburg, who sometimes insult us with words like 'Satan' or 'nigger'. Conflicts can even arise within a target group such as when ethnic, religious or civil-rights conflicts occur in the homeland. It seems appropriate to tease out the group compatibility for cooperation before beginning the work. I think that we can assume that we have loose cooperation among migrant groups instead of real collaboration. In my opinion, the topic and goal-setting of the services play a large role. So it's better to not throw sheep and chickens into the same pot since the people on this planet are very heterogeneous and maintain different cultures. They also have different needs and goals in life."

Omer

"About 16 million people with a migration background live in Germany, which is almost 19.6% of the overall population.[2] This is a very heterogeneous group that is differentiated according to the country of origin, citizenship, residence status, level of education, social situation and migration experience. There are also considerable differences in relation to the HIV risks of intravenous drug consumption, heterosexual or homosexual contacts, and infections that have been brought in from the country of origin. From my perspective, these differences among migrants make it very difficult to speak of 'migrants' as one target group of HIV prevention. Instead, a more differentiated view is required in order to determine which migrant groups have higher HIV risks, and whether these groups need special services and measures in order to more specifically address their migration-specific, language, legal and cultural needs. In order to identify these groups and better determine their needs, we need to have stronger involvement of migrants."

Tanja

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[1] Narimani 1998; von Unger & Klumb 2010

[2] Federal Statistical Office 2009

Does Each Community Need Customised Services?

"Every person has the right to be informed about HIV and AIDS! No matter whether such a measure is directed at the general population or certain target groups (MSM, sex workers, intravenous drug-users, etc.), when the measures of HIV prevention are not effective, we must consider whether specific services are necessary for certain groups and communities of migrants. However, because migration background does not automatically lead to an increased demand for prevention, you should look at the respective municipality, city or region to identify which origin groups are especially conspicuous epidemiologically. Independent of their origin, some migrants who have newly arrived in Germany or are illegal residents and therefore not (yet) integrated into the local assistance system may also have a special need for information and education. In order to enable the realisation of such projects, we recommend working out the priorities. And the wheel also does not always need to be reinvented. There are certainly structures such as language courses, women's meetings and the like where HIV prevention services can be integrated. There are often "Integrationslotsen" [integration pilots] who can carry the important messages on HIV prevention out into the community."

Nozomi

Many people with a migration background are reached by HIV prevention measures that are directed to the general public or one of the main target groups that Nozomi listed. However, the question remains whether this is true for all migrant groups and whether they are reached adequately with these general measures – or whether there are certain groups that require a special approach and customised services. The findings of the PaKoMi project, which serves as an example by determining the needs of various migrant groups and communities in four locations, suggests this to be true. For example, the Bulgarian women who performed sex work in Dortmund had different needs with respect to the HIV prevention than the African communities in the case study of Hamburg. The one group lacked fundamental knowledge about bodily functions, HIV and sexually transmittable illnesses, while the other required specific information about anonymous and free test services in Hamburg and about the effects of an HIV diagnosis on legal residence status. The one group required information in Turkish and Bulgarian, while the others needed English and French. Written materials are relatively useless for the one group because the literacy rate is low; for others, they are quite appropriate because the level of education is quite high. Even this initial comparison illustrates how different the needs of the various migrant groups may be with respect to HIV prevention.

How Do We Assess the Needs of Migrant Groups?

"This is a difficult question in particular since ethnic origin does determine whether or not there is a certain need for prevention services. The social origin, education or the degree of integration are actually more important factors for whether someone is well-informed or not. People who are socially disadvantaged rarely come forward and state their need. If migrants – those who are socially disadvantaged – have specific sexual contacts, we can assume that there is an increased need. But what should we do when these people cannot be found where persons with such sexual contacts can usually be found? In the Berlin case study, this involved men who are considered at risk due to their same-sex sexual behaviour yet who are not in the gay scene. It was possible to anonymously ask these men about their need in the case study. However, the survey was only possible through a 'mediator' who came from the same cultural circle and was quite familiar with the living environments of those who were to be surveyed and had a certain sensitivity towards the group."

Nozomi

"The requirement for recognising a need is to be in contact with the target group, for example migrants in this case. Determining what is needed can occur in a quite uncomplicated manner, such as by speaking to those who are responsible in the communities or through participating and experiencing community life. *Community mapping* can also be very helpful in this process. When a community grows quickly and needs new services, then I must review and evaluate the old services in order to evaluate their success. I can renew or change the old services and adapt them to the current need in the process or I can attempt to initiate new projects with the members and participants. However, the decisive factor for the success of new services is the participation of members of the communities. Especially for the migrants, we should remember that new approaches and developments (e.g. trainings, promotion of intercultural and transcultural competence, low-threshold services, sensitisation events, secure jobs for migrants with HIV/AIDS, counselling services in their native language, home-based care, helping HIV-positive migrants fend off deportation, improvement of the legal situation) play a decisive role in culturally sensitive prevention that reduces the spread of HIV in these groups. New approaches should not be taken without the participation of the people affected. Not only short-term projects should be developed, but also long-term educational programmes in HIV prevention must be supported. Not every migrant group needs prevention work against HIV/AIDS. The need must be determined through a precise assessment that also takes the cultural and moral background into consideration. Sometimes the translation of educational material suffices for more effective work."

Omer

The approach of participatory quality development[3] is helpful in order to conduct a need assessment in a participatory way. You basically assess the need of a group by taking into account various types of information such as epidemiological data (statistics from the Robert Koch Institute), the knowledge and experience of practitioners (professionals in HIV prevention and others) and community members who are experts on the life-worlds. Methods for needs assessments can also be accessed in the Internet.[4]

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[3] Wright 2010

[4] www.quint-essenz.ch
www.partizipative-qualitaetsentwicklung.de

Our Facility Is Modelled on the Concept of "Intercultural Opening" – Is That Enough?

The concept of "Interkulturelle Öffnung" (IKÖ; intercultural opening) of the facilities of the health and social services system pursues the aim of providing the same access to the health-care system and the same quality of care to migrants as to people without a migration background. The IKÖ involves the corresponding goals, standards and measures. These include the following:

the hiring of salaried employees with a migration background,

the provision of multilingual services (in writing and orally),

the networking and cooperation of various providers and services,

diversity trainings and intercultural/transcultural trainings for the employees.

In Chapter 7, we recommend advancing the processes of intercultural opening more consistently, as the reality of implementation often lags behind the idea. In addition, we should determine whether it is necessary to offer special services for certain migrant groups that extend beyond the "Interkulturelle Öffnung" of the facilities.

In prevention and health promotion, the diversity approach means appropriately considering the diversity within the target group(s) or population with respect to gender, age, sexual identity, ethnicity/migration background and so forth. "Interkulturelle Öffnung" (intercultural opening) of the facilities and organisations is one building block in this process.

> **"The Berlin Integration Concept (2007) defines "Interkulturelle Öffnung" as the same access to authorities, services and facilities, as well as the equivalent quality of care for migrants as for the majority population. The AIDS service organisations in Berlin are obliged to realise the Interkulturelle Öffnung through the endowment contract. But what does it look like in practice? We often hear that it is self-evident that services are open to people of all origins. Also some organisations say they established "Interkulturelle Öffnung" as a guiding principle in their mission statement and that an employee was appointed to handle migration. Or the facility works on the basis of a diversity approach and promotes diversity so that migrants are automatically considered like all of the other diversity target groups (women/men, old/young, people with same-gender lifestyles, disabled people, etc.). But experience has shown that good will alone does not suffice to create the same access opportunities for migrants. According to the integration concept in Berlin, the diversity approach also has its boundaries: the problems, needs and situation of migrants are so different from those of the other diversity target groups that measures of "Interkulturelle Öffnung" must be pursued on their own path. Employees must receive advanced intercultural training and language professionals and/or employees with intercultural competence and/or with a migration background must be specifically hired for this purpose. 'Target groups' that primarily consist of migrants have often already automatically completed the process of the intercultural opening. The employees were forced to cope with communication problems, adapt services and develop a new profile if an increase in migrants among the clientele so required.**
>
> **Projects in work areas where migration just plays a subordinate role feel too little 'pressure' and have a hard time with the process of "Interkulturelle Öffnung". Multilingual information is often not enough to convincingly address the migrants. Whether new services must be created especially for certain migrants to better reach them – and whether and when such measures are worthwhile (in terms of the cost-benefit ratio) –are difficult questions that we discussed in Berlin during the case study and that will continue to accompany us."**
>
> Nozomi

"I personally do not consider it adequate when a facility says that it works according to the concept of intercultural opening and that its services are open to all people. In my opinion, this is frequently just propaganda in order to receive the most possible funds. Who is providing the intercultural opening and with whom? To me, "Interkulturelle Öffnung" means developing concepts together with the migrants, implementing them and evaluating them, if necessary. Participation is an indispensable component of the intercultural opening. Just translated info material is not enough to enable intercultural work. We should also be able to offer more personal contacts, on-site work and counselling to increase the accessibility of the target group. However, this requires a diversity of languages, more resources and intercultural and transcultural competences. In addition, 'being open' is only an invitation for people to take part, but not really to get involved – because then they would have to say, 'We look forward to your involvement.'"

Omer

If I Offer HIV Prevention to Africans, Does this Automatically Mean that I Am Stigmatising and Discriminating Against Them?

"HIV prevention for Africans does not automatically mean that they are being stigmatised or discriminated against. It depends upon how, for whom and with whom the HIV education is conducted. Some Africans do not want to hear about HIV/AIDS any more since they have already experienced enough discrimination in Germany, feel inferior or are labelled as such because of the language, the skin colour, the culture and the level of education. This is compounded by the most frequent cause of death in Africa: AIDS. We are frequently called de-facto HIV carriers. And this diminishes the willingness of the Africans living in Germany, who are already very traumatised by the migration process and expectations, but also by the story of their flight and integration, and they suffer as a result."

Omer

Two PaKoMi participants from Munich wanted to develop a target group–specific offer for Africans, but this initiative was questioned by representatives of African communities. The community representatives felt that they were being discriminated against due to the explicit topic of HIV/AIDS in connection with Africans. The two PaKoMi participants had to deal with the following situation: What happens if we are called into question in a participatory way?

"We, Tzeggereda Mihreteab (volunteer employee of the Munich AIDS service organisation) and Antje Sanogo (salaried employee of the Munich AIDS service organisation) have been working since 2009 with participatory approaches on the development of a prevention strategy of the Munich AIDS service organisation for and with the African communities in Munich. We see a major potential in the implementation of participatory work approaches, especially because we were called into question and had to look beyond the usual horizon. Here is an example of what we have learned from the conflict: Africans are frequently perceived in Germany as carriers of infectious diseases, also beyond HIV/AIDS – as can be seen in the newspaper clippings below.

On the other hand, Africans are not only threatened by illnesses such as HIV/AIDS, but also by racist discrimination in the health-care system. This can lead to a false diagnosis, poor quality of care and the like. Due to their skin colour, Africans are generally often said to lack intelligence, talent and education and they are called into question. Especially children are discriminated against by their teachers, for example.

During the course of the project, we discovered that these experiences by people of African descent can lead them to being sceptical about the topic of HIV/AIDS. If they are addressed as a target group for HIV only because of their African origin, they fear that the prejudices of the German population against them are being confirmed and reinforced. We experienced this situation while working on our brochure for parents, which was intended to help them pass on their knowledge about STIs and HIV/AIDS to their children. In the draft of the brochure, we explicitly addressed people of African descent in the introductory text. The members of the African community with whom we cooperated very emphatically drew our attention to the fact that they thought it was discriminating to associate Africans with HIV/AIDS solely on the basis of their origin. They said that this serves the racist prejudices and the people who we want to reach would tend to be alienated. Here are some excerpts from the email correspondence that we received:

'*... Every coin has two sides, and the reverse side could look like this: due to beliefs held in the society at large, such a campaign can also result in dark-skinned individuals – who already do not have an easy time in our society – being associated with HIV/AIDS. Whoever looks at such a campaign in just a superficial way could develop fears. The people who have not yet decided how/whether they want to deal with dark-skinned people will now tend to have an intolerant and limited opinion and avoid dark-skinned people in general (and convey this attitude to their children). So much sensitivity is required in the implementation of the topic. I wish you all the best.*'

'*... The fact that a collective – the African community – is addressed in the singular within this context, in relation to AIDS, is ambiguous and intensifies the reproduction of the stereotypical image of Africa as the paradigm of AIDS, whereby people from Africa and the diaspora are particularly affected. This stigma is forced upon them independent of whether they live in Africa or Europe: AIDS = affected people = Africa = blame for the international spread of AIDS = fear (xenophobia) = intensifier for racism. An offer of help that is built upon this construct does not support people of African origin, even less the affected people among them who disclose their HIV status. It tends to harm them because they already experience discrimination as black people in this society and cannot claim their rights or only do so with difficulty. The majority of German society does not recognise their status as "full-fledged" citizens. This means that there is not even the protective space for black people here to provide a safety net. It is even less available to them as AIDS patients. How would they benefit from coming out if the consequences are increased intolerance and the experience of even more racism...*'

'*... When we met, I also felt like the appeal to the Africans seemed somewhat one-sided – even if you are trying to reach the African public – since all parents should be interested in educating their offspring in these matters. The fact that Tzeggereda comes from Africa is certainly helpful for gaining access to Africans, but it should not scare away parents from other parts of the Earth. I would personally tend to go to an AIDS/HIV event and certainly feel better there if the addressed audience* *is neutral and mixed than when just Africans are targeted as if the danger would only come from them – and, after all, there are enough mixed partnerships in Germany that might want to attend such events together…'*

We responded to these concerns. As the result of this discussion, our parent brochure is addressed to parents for whom it is a problem that their children are so liberally confronted with sexual topics in Germany. We want to encourage them to talk about what they as parents should know in order to educate their children themselves and protect them against sexually transmittable infections, for example. On the basis of these experiences, we gained the perception for our future work that it is very important to be very clear on who we want to address and how to do this for successful prevention concepts and campaigns. The following should always be considered for planned campaigns or concepts by the Munich AIDS organisation: In which concrete life situation would it be important to be educated about HIV/AIDS? It should involve not just the origin, but also the concrete life situations in Germany. It has been very clearly shown that our approach to the participatory work with the communities is actually an important key. We believe that concepts or campaigns for HIV prevention that are more or less forced upon the communities from the outside do not work. (We already have first-hand knowledge of this as an AIDS service organisation that does prevention work in the gay community.)

In this sense, we will continue to discuss the topic of 'Discrimination through HIV: Africans as a target group solely on the basis of their origin?' In this process, we also consider how we can educate German mainstream society about racist myths in relation to HIV/AIDS and Africa. We think that the stigmatisation potential of HIV is a very strong obstacle for HIV prevention with people of an African origin in Germany, above all in connection with the everyday racism that black people are subjected to and the continual refusal to make this a social debate. It is therefore important at first to allow this discussion in relation to HIV, to listen to the arguments and to deal with them."

Antje und Tzeggereda

Illustration 10:
"Sick", "dangerous" and "wild",
"The sick continent grows fastest":
Reporting about Africa (newspaper clippings)

Bild
City
Sonntag
11.7.09
Seite 2

Der kranke Kontinent wächst am schnellsten

CLAUS JACOBI

Mein Tagebuch

Zur Zeit leben nach Angaben der Vereinten Nationen etwa 6,8 Milliarden Menschen auf Erden. Es werden bis 2050 über 9 Milliarden sein.

Hinrichtung

Ewigkeit

Definition

Heinrich Heine (1844)

Berlichingen

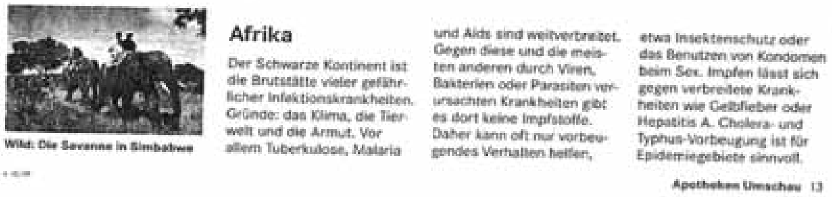
Beziehungen

Gehört – notiert

Immanuel Kant (1724 bis 1804)

Zwerge

Apotheken-
Umschau
10/2009



Wild: Die Savanne in Simbabwe

Afrika

Der Schwarze Kontinent ist die Brutstätte vieler gefährlicher Infektionskrankheiten. Gründe: das Klima, die Tierwelt und die Armut. Vor allem Tuberkulose, Malaria und Aids sind weitverbreitet. Gegen diese und die meisten anderen durch Viren, Bakterien oder Parasiten verursachten Krankheiten gibt es dort keine Impfstoffe. Daher kann oft nur vorbeugendes Verhalten helfen, etwa Insektenschutz oder das Benutzen von Kondomen beim Sex. Impfen lässt sich gegen verbreitete Krankheiten wie Gelbfieber oder Hepatitis A. Cholera- und Typhus-Vorbeugung ist für Epidemiegebiete sinnvoll.

Apotheken Umschau 13

Fear of the Stigma of HIV/AIDS

We have already indicated in the introduction that a stigma is attached to HIV/AIDS. A stigma is a social flaw. A stigmatising illness like HIV/AIDS can harm one's standing and lead to exclusion. For this reason, many people do not want to be associated with HIV/AIDS, and people who live with HIV/AIDS sometimes keep their infection secret. However, the stigma of HIV/AIDS is a cultural phenomenon and not set in stone. It represents a major problem in many societies and communities, but this can be changed and reduced – especially when people succeed in reducing prejudices and fears.

We also discussed the stigma of HIV/AIDS in the case study in Hamburg (see Chapter 6). Mara, a German practitioner, describes what she has learned:

"In my work with Africans, I have learned that an HIV infection is a major taboo. The people do not talk about it and family members tend to die of diseases other than AIDS. I could understand this attitude, but it was also difficult because how could we as an AIDS organisation create a forum in which there is space for Africans with HIV? The analysis of the survey results was then very astonishing for me because 60% of the surveyed Africans stated that they would accept a person with HIV 'without prejudice'. Another 20% were not sure how they would behave, and only 10% said they would keep a distance. So is there no stigmatisation after all? Or just a little? And is this enough to make the topic of HIV taboo? I inquired: Even if individuals support a member of the family with HIV, this definitely does not mean that they would let non-family contacts know about it. An HIV infection is still a disgrace for many people, and also for the family, which means that they would rather remain silent to protect their family against the disgrace. And because everyone (or most people) do this, the issue of HIV is not talked about. But, as our discussion continued, this attitude is changing. People are slowly becoming more open, and this is encouraging. For example, this was one response to the question of 'How would you support a person whom you love?': *Lui donner plus d'amour* – 'I would give her/him even more love.' "

Mara

A social worker who was involved in the Berlin case study describes his impressions as follows:

> **"Most of the boys are aware of the risk that they could become infected with HIV. When we asked them: 'What would happen if you were HIV positive?', they responded without exception that they would not tell anyone in their country of origin ('*I would be afraid that my family would then no longer want any contact with me.*'; '*No one would help me anyway.*'). Although some of the boys believed that HIV/AIDS was not a taboo, they claimed that '*still, no one talks about it.*' Very few of the boys personally know someone who openly lives with HIV. Although the topic is present for them, some of them still believe that it is possible to see whether someone is infected. ('*I don't worry about it – after all, you can see when someone is sick.*'). It is important to us on the one hand to make contact as early as possible with the boys who are new in the scene in order to educated them about the risks of their work in due time. On the other hand, we must continually make a contribution to reducing the stigma of HIV/AIDS. 'How do you respond when one of your acquaintances tells you that he has become infected with HIV?' '*If he was one of my colleagues, then it would be difficult for me*'; '*I would not want to have any contact with such a person – I know that nothing can happen to me in everyday life, but you can't be really certain, can you?.*' Those who have become infected usually feel like they have been very much left alone. If they are lucky, they may have people in whom they can confide but these very rarely are family members or friends. '*In no case would I return to my family – I could only talk about it here [in Berlin].*'; '*In my village, everyone believes that only people who live an immoral life get it.*' Unfortunately, in male prostitution there are still too few affected individuals who have the courage to disclose their HIV infection to their peers. Many boys come from the same area of origin, and they have a deep-seated fear that their family could find out something. ('*I would continue to live like I have up to now so that no one notices anything.*')."**

Stefan

These impressions show that the stigma of HIV/AIDS still exists: the negative meaning attached to the illness, the attribution of blame, the fears and the debasement of people who become ill with it – also in the various migrant groups and communities. The stigma makes it more difficult to talk about HIV/AIDS and to deal with the illness, and it burdens and harms the people who live with HIV/AIDS. It also makes HIV prevention more difficult. However, the case study in Hamburg shows that the stigma should not be overestimated and – above all – the potentials for reducing the stigma should not be underestimated. This especially applies when we succeed in using the resources of the communities and including the opinion-leaders who express solidarity and who serve as role models for others. For example, impressive examples and role models exist for the inclusion of religious leaders around the world.[5] The first steps in this direction have also been taken in Hamburg. In the development of HIV prevention for and with migrants, the reduction of the stigma and the mobilisation of the potentials for support in the communities represent a central objective.

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[5] UNICEF 2003

Work Guides

Which social meeting places and existing structures are there in your community that could be used for HIV prevention?

Which creative strategies are available?

How can the topics of HIV/AIDS and protection against HIV be addressed in your community – and by whom?

Which role does the stigma of HIV/AIDS play and how could it be reduced?

5. Living with HIV/AIDS

How Are Migrants with HIV/AIDS Doing in Germany?

The answer to this question varies, because there are so many different groups and life situations of migrants living with HIV/AIDS. Generally speaking, people with an uncertain residence status are worse off than others, as are those who have already become ill but don't have health insurance. If the legal status is secured, then most migrants receive good health care and support. And if HIV/AIDS is detected early enough, they can expect a very good and long life with HIV.

There is an important difference between HIV and AIDS: HIV is a virus and stands for the infection with the virus, which a person can have for many years without noticing anything. AIDS is the name of the state when a person is ill.[1]

"I have lived in Germany for the past ten years. When I arrived here, I couldn't get health insurance at first because I already had HIV/AIDS. It was not easy to get my medications on a regular basis. I had already started a treatment in my homeland and couldn't just stop it. Back then, when I first came here, I thought that it would be easy to get medications, but this was unfortunately not the case. I often cried back then because I had the feeling that I had done something criminal in my life and had to bear this illness as a result. But then I met people who helped me get my life in order. When I now think back to that time, the feelings from back then still come up. I now have German citizenship (even though I continue to be seen as a migrant) and have my health insurance. This gives me access to all of the new medications that are on the market, and I can continue my therapy. The most important thing to me is my family, my healthy child and a life in spiritual and social health! But I still can't (and don't want to) forget how difficult it is for someone who must fight like I did to establish themselves here in Germany."

Rose

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[1] DAH & BZgA 2010

According to estimates, about 70.000 people live with HIV/AIDS in Germany. There is no precise data on how many migrants are among them, but the proportion is probably between one-fourth and one-third (25-33%). The affected migrants come from a large variety of countries: mainly from sub-Saharan African countries, Southeast Asia, and Western, Central and Eastern European countries (such as Turkey, Poland and Russia). The Robert Koch Institute (RKI) publishes the latest figures on a regular basis as well as special editions on the topic of migrants with HIV in Germany.[2]

"How well or badly migrants live in Germany and are provided with medical care depends upon whether they have a residence permit or not. Those who do not have documents cannot legally be employed and therefore have no claim to social services and also no access to the health-care system. Because of fear of deportation, many HIV-positive migrants go to the doctor only when they are already very ill. As a result, the chances of successful treatment are much lower. Organisations such as the Malteser Migrants Medicine and the MediBüro have doctors who treat people without papers anonymously and free of charge when they suddenly become ill, have injured themselves or are pregnant. But these services cannot cover the necessary ongoing medical treatment and medications for a chronic illness – such as HIV/AIDS. The legal situation for refugees who are in the process of obtaining asylum is also a problem: for example, they can only leave the district of the Foreigner's Registration Office that is responsible for them with its authorisation in order to visit an HIV doctor, for example. The access to the appropriate treatment can become more difficult due to this 'residence requirement'. Refugees are simultaneously obligated to live in a communal accommodation that does not allow for a private sphere. Another factor is that HIV infection is rarely seen as an obstacle to deportation because the legislation assumes that the possibility of medical treatment is also available in the country of origin. In this process, it is highly questionable that only the information from the embassy in the home country is accepted for the appraisal of a refugee's individual situation. Neither the review by large organisations such as Doctors without Borders nor the opinion of NGOs on-site are taken into consideration.

The life of HIV-positive migrants in Germany is often characterised by fear that their HIV-positive status will become known and fear of discrimination from within their own community. This leads them to not reveal their HIV status in order to protect themselves and to accept the risk of isolation and loneliness as a result. The doctor and the AIDS service organisation are frequently the only ones to know about the HIV infection."

Tanja

[2] RKI 2010

The stories of people with HIV/AIDS are all very different. An African woman tells her story like this:

> **"I live with HIV/AIDS. For me, this means having a positive attitude towards life. Everyone who is affect by it may have many different feelings, but the best thing is to simply believe in yourself. Even if it takes a while for you to accept what has happened to you. We are all individuals, so it is also okay for us to respond differently. It is not simple, but at a certain point you must just achieve a level of acceptance since we don't have the power to change what has happened. But we have the power to change our lifestyle. In my country of Zambia, we have a very funny proverb: *Ka laye banoko*. Translated into English, it means, 'Go and say good-bye to your mother.' This refers to how you always still have relatives, father and mother in the village when you live in the city. If you have been sick for a long period of time, it becomes too expensive for your relatives to take care of you and they bring you back to their village because they believe that the funeral is less expensive there. This also happened to me when my sister could no longer take care of me. She also was afraid of catching the disease. I was tested as HIV positive in 2000 and began the medication treatment in 2002. It was difficult at the start: you always think that everyone is staring at you and that everyone knows it. The key is a positive attitude towards life, no matter what your situation – you must always think positively. I go to sleep and wake up in the morning looking forward to a positive, productive day. I live my life as the days come. It is not easy, but I have to remind myself that other people are in worse situations. HIV can be controlled, as long as you know what you must do: start with the drug treatment, in case you are not already in treatment. If you are not, then just try to have a positive attitude and follow the advice on living with HIV. The thought of death may be there, but remember that no one is here to live forever and that people also die when they are not HIV positive. Death is everywhere. I have learned that the real important point is which decisions you make in your life. This is how it always has been and how it always will be. You cannot control life, but you can control your decisions. Remember that every decision has consequences and that you should always be prepared to encounter them."**

Malaika

As already mentioned above, increasingly more people from Central and Eastern European countries are also affected. These also include young men who earn money with sex. One social worker describes this group as follows:

> **"Many newcomers in male-to-male sex work in Berlin are Roma. They get into sex work because they have no prospects in their home countries [such as Romania and Bulgaria] where they belong to a socially disadvantaged ethnic minority. The young men try to escape extreme poverty and exclusion, and they sometimes hardly have any options other than selling or exchanging sex for goods, service or cash. When they arrive in Germany, most of them hardly know anything about HIV/AIDS or other sexually transmitted infections [STIs]. A low education level, sometimes even illiteracy, and inadequate knowledge of German make it difficult to implement successful health promotion and HIV prevention. Many of the boys still believe that you can see who is HIV positive. The boys work as prostitutes in Germany in order to earn money. As EU citizens, they are legally in the country and are also allowed to work. Many boys have a female partner in their country of origin and lead a double life. The separation from their partner leads to loneliness, and the boys also look for sex and intimacy outside of their homeland. In addition, the anonymous lifestyle and lack of social control influences their behaviour. The boys behave differently in Germany than in their home countries. A big problem is that the majority of the boys who prostitute themselves here also have no health insurance protection in their home countries, despite the EU agreements. We need more reliable partner projects for the therapy and medical treatment of the boys who become infected with HIV. The treatment is very protracted and costly, and they have no right to it in Germany. Most of the boys – including those who have been infected with HIV – want to have children with their partner in their home country. They reject the idea of using condoms – which often has fatal consequences. Hardly any of the boys who are infected talk about it. HIV continues to be associated with being homosexual, which despite of – or because of? – their sex work is rejected by most of the boys. They feel abandoned and helpless and don't know who they should talk to about it and how they can**

cope with their shame, anger and fear. Seeking counselling at an AIDS service organisation is often not an option for them because HIV and AIDS are still stigmatised. Our facility [Subway] offers help to these boys."

Stefan

An employee of the AIDS service organisation reports on her experiences and about a man from Eastern Europe who learned that he was HIV positive here in Germany:

"I cannot say in general how migrants with HIV/AIDS live in Germany. However, a brief report can perhaps illustrate an individual's experience and way of dealing with HIV/AIDS. One of my clients learned about his HIV infection some months ago when a doctor did a full health check-up on him because his blood values were not in the 'normal range' after an operation. The news of having become infected with HIV was unexpected and shocking. The initial period of time was difficult. The diagnosis triggered many feelings: fear of death and of possibly having infected his family members; sadness and helplessness. He did not know what he still had to expect from life. As a result, he had many depressed and sleepless nights. He also did not know where to find help.

Through my work at the AIDS service organisation, I frequently get the impression that people with a migration background have little information about whom they can turn to when they have questions about HIV/AIDS and need help. This client still has difficulty in openly dealing with his illness. Up to now, he hasn't told anyone from his environment – friends, acquaintances, neighbours, etc. On the other hand, he can talk freely about his hepatitis. He says the people who find out about his HIV infection would no longer consider him a sensible and smart person. This tempered expression conceals a great fear of exclusion, rejection and discrimination, which always catches up with him. At this point of his life, he is not willing to be confronted with it. However, he was open with his partner from the start and she believed in him. Despite this, there is no discussion within the family (he has two children) about HIV/AIDS. His attitude towards life has changed. His family has become much more important to him. He no longer makes new plans on his own. Even though he previously had wanted a nice car, he now just wants to take care of his children and his family.

In relation to the HIV stigma, our clients have different experiences. A person with a migration background was outed by others and has often experienced discrimination. However, he does not live in his own community but in a shared communal accommodation. On the other hand, a German client said that the fear of being excluded from his personal environment was much greater than the actual experiences. When he informed his family and friends about his illness, they did not respond in such a negative and rejecting way as he had feared."

Kristina

Where Do Migrants with HIV/AIDS Find Help and Support?

There are various facilities, persons and contacts in many cities who help people with HIV/AIDS. When someone is HIV positive or would like to get information about HIV/AIDS, it is best to go to or call an AIDS service organisation or an AIDS counselling centre. People can be tested anonymously at public health authorities and are sent to the right places, if necessary. There are good doctors who specialise in HIV/AIDS and counselling centres that offer help in finding these doctors.

AIDS service organisations (in German, "AIDS-Hilfen") are non-governmental organisations (NGOs). They help in many matters such as how to find organisations that support people without papers. AIDS service organisations offer confidential counselling and support self-help groups by and for people with HIV/AIDS. For people who are HIV positive, they come to understand at the AIDS organisation: You are not alone!

"The regional AIDS service organisations and their federal association – Deutsche AIDS-Hilfe e.V. [DAH] – have worked for many years to at least ease the worries and hardships of migrants through special services, even if they know that they cannot offer solutions for many of them, especially those with legal problems related to residency. Much has changed since the 1990s at the association of the AIDS service organisations in terms of supporting people with HIV/AIDS: increasingly more HIV-positive migrants from various cultures seek the counselling and self-help opportunities provided at the AIDS service organisations, use the services for HIV-positive people and increasingly contribute to the planning and implementation of additional measures and services of the AIDS service organisations. It is not easy for both sides to develop a trusting relationship and communication on an equal footing. But when this succeeds, major successes are possible – for all participants.

AIDS service organisations advise and support people with HIV/AIDS. They try to help in all areas of life and problem situations. This applies not only to HIV/AIDS but also to issues ranging from questions about legal residency to problems in the living and work situation to very personal concerns about daily life. For many HIV-positive migrants, an insecure residence status and the housing in communal accommodations are essential topics in counselling and often play a larger role than HIV/AIDS. Only when the legal residence status is secured can they attend to coping with the illness and a life with HIV/AIDS that has prospects for the future.

Deutsche AIDS-Hilfe e.V. (DAH) and local AIDS service organisations also provide spatial, logistical and financial support for the self-help activities of migrants with HIV/AIDS. In order for this to succeed, there must be a mutual understanding of self-help: many migrants initially desire a safe space for contact with other HIV-positive people away from their own migrant communities. Such offers make it possible for the affected people to develop self-confidence as a group, enabling them to present themselves in public and increasingly look after their interests on their own.

With the annual national Positive Meeting for positive migrants, it has been possible for the DAH to make a contribution to overcoming social isolation by enabling participants to experience mutual support, an exchange and networking. The 50 to 70 participants meet for three days at conference centres in safe spaces, where they learn and participate in workshops on medicine and treatment possibilities (ART), sexuality and partnership, stigma and discrimination, social legislation and legal issues related to asylum. The experiences of recent years have shown that this nationwide offer creates less fear of a person's own HIV infection becoming public knowledge because of its supra-regional nature. The meetings offer the time to develop trust in the organisers, speakers and other participants and ask questions that frequently remain unasked in everyday counselling. For the individual, the meetings mean breaking out of isolation, strengthening their self-confidence and promoting communication with doctors and counsellors. And some people even find the courage after a meeting to make contact with other HIV-positive migrants where they live. In the future, the DAH will also offer interactive workshops for children. Information on the various services of the DAH in the area of migration, as well as the number of our counselling services can be found on our Internet site."

Tanja & Silke

It is not always easy to find the right doctor or physician. An HIV-positive African describes her mixed experiences:

> "As HIV-positive people, we usually go through the same things that people who are not HIV-infected also experience in their life – but it all happens so fast with us. I left my country, was suddenly in a totally new cultural environment with different traditions and had to learn a new language. I found a good family doctor here in Germany who is a trained HIV specialist and has also worked in Africa. I never had any problems with him. But there were also other experiences: I went to a dentist who my husband had also already seen. When I arrived, I received the customary forms to record my personal data. I wrote down that I am HIV positive and take medications. Before I knew what was happening, the nurse held my form in such a careless way that other people in the waiting room could see what I had written. And if that wasn't bad enough, she told an acquaintance about my state of health. I was annoyed and wanted to leave immediately, but my husband said that this was not a good solution and that we should tell the dentist what had happened. The dentist later called in the woman and talked with her in my presence. She apologised. I never went back again. I went to my HIV specialist and told him what had happened. He referred me to another dentist with whom they cooperate. And everything went well there, without any questions. Another time I had problems with my skin and went back to my doctor. He referred me to a dermatologist who also treated me without any problems. I learned to always first ask my doctor when I have a concern. This is much better since he refers me to other doctors with whom he cooperates.
>
> I had another bad experience. I had just been in Germany for three months and had to have surgery. We had already taken care of the paperwork, and my doctor referred me to a gynaecologist. He transferred me to a large clinic. I thought that the employees in the clinic had seen my file, but I believe that this specific person was either curious or wanted to be certain. As I waited for the anaesthesia, he asked me, 'Do you have HIV?' You can certainly imagine that I was new and did not really understand what he meant. It sounded something like, 'Do you have hay fever?' to me, and my response was, 'No, I'm fine.' I thought it was a routine question that they asked patients. While I waited and thought about it, I went through the German alphabet and suddenly realised that he meant HIV and not hay fever. I immediately called him and said, 'Excuse me, did you mean HIV positive?' He looked at me and said, 'Yes.' I responded, 'Excuse me, but I didn't understand you. Yes, I am HIV positive.'
>
> You can imagine what now went through my mind! I was just about to be operated on. Why did he have to ask me now? I thought that this had already been discussed when they talked about my case. As I waited for the anaesthesia, I thought that I would not wake up from it. I was worried and afraid. I think that there should be a way for them to already know about it and not have to ask the patients, especially when it has already been discussed the day before with another doctor.
>
> These are some of the fears. Sometimes you don't want to reveal your HIV status in a new environment.
>
> What really helped me was participating in a seminar by Deutsche AIDS-Hilfe on the social system of Germany. This is where I learned what I do not have to say during the registration and what can wait until I'm in the doctor's office. Then I can describe my situation to the doctor from person to person in order to make the process easier. Information is power!"

Malaika

Solidarity, Self-Help and Empowerment

The Network Afroleben+ (Afro-Life+) is a national Self-Help Group of HIV-positive, primarily African migrants which was founded in 2001. The network members act as regional contact persons for migrants with HIV/AIDS. They offer advice and support on topics related to living with HIV/AIDS in Germany, do prevention work in the communities and initiate regional self-help groups. In addition, they promote exchange and advocacy for the improvement of the living situation of HIV-positive migrants through national networking.

"Deutsche AIDS-Hilfe (DAH) supports the activities of the Network Afroleben+ (Afro-Life+) and has developed a number of prevention materials, media and political campaigns together with the network members. In its migration work, the DAH is currently focussing on improving the participation of migrants with and without HIV/AIDS in the prevention work, as well as supporting their networks and their empowerment. Their competences and resources are promoted through various seminars and advanced training offers. As an example, the DAH has offered mediator trainings for migrants with and without HIV/AIDS for years and supports migrants in the organisation of prevention events in their communities. In addition, migrants participate in decision-making within the scope of what is possible in all new projects of the DAH (through collaboration in the conception and production of print and audiovisual media, through the conception and implementation of theatre performances, etc.). The DAH also participates in discussions related to migration politics and uses its activities (postcard series, plays, etc.) to call for an unrestricted access to medical care, living space and social services for all people with HIV and AIDS in Germany, independent of their origin."

Tanja

What Role Do People with HIV/AIDS Play in HIV Prevention?

Involving people with HIV/AIDS in HIV prevention has many advantages: their experience and their life with HIV/AIDS make it possible for other people to comprehend that the virus is real, that regular people can become infected, that a positive HIV test result does not mean the end and that people with HIV/AIDS are not alone.

"People with HIV/AIDS play an important role in the fight against HIV and in HIV prevention. We can have much influence as role models because we talk about our personal experiences and not about what we read somewhere. Most people can identify with us, see themselves in us and realise that we are also very normal people and not something special. Sharing personal experiences is very important because the people can then see real examples. I will share my own example: I made a documentary film about my life with HIV. It's called *Tikambe*, which translates as 'Let's Talk About It'. The film has won two awards – at the Chicago Film Festival and the New York Film Festival. It is quite realistic in showing my state of health after the AIDS symptoms became visible, as well as the various reactions of my social environment and my family. The start of medical treatment was a real turning point for me. When my health improved, I was able to give my family a better explanation about what their reactions to my state of health meant for me. I showed this film in different locations to various audiences, and the feedback was overwhelmingly positive. The comments included 'It's so genuine! Especially that we also see the person in the film as a human being.' Usually when you watch a film, you still have many unanswered questions. But here, before you know it, the real person walks in and you have the opportunity to ask questions."

Malaika

Individuals with HIV/AIDS who talk openly about their experiences can make a big difference for other people:

> "I have great respect for people who can openly talk about their AIDS illness or their HIV infection. These are my heroes in HIV prevention. Their courage and their stories are difficult to put into words. I had two experiences in this regard: during a visit to my home country of Kenya in 2005, I was invited to participate in a public prayer meeting with and for sick people. About two to three thousand people came together under the open sky. Led by a powerful choir, the people sang and danced and expressed their joy in life. Then about 15 people – young and old, men and women, well-dressed and well-nourished – came onto the stage and reported their very personal story with HIV and AIDS in front of the large crowd. Most of the speakers wanted to make it clear that this illness actually exists, saying that they and their fate were a living example of it. Others wanted to explain why they would soon die and appealed to friends, relatives and the 'community' to look after the well-being of the surviving dependants – their spouses, children or even parents. The event also intended to make a contribution so that young people and the coming generations would take the danger that this illness poses seriously and oriented their life accordingly. After every speech, the gathering knelt on the dusty ground and prayed. And after every prayer, a tense silence spread and the people turned to the next speaker and his or her story with expressions of fear, despair, grief or anger in their faces. I left the gathering with the feeling of grief about the intense spread of HIV and AIDS in my home country, but also with the hopeful perception that a very independent path of prevention and empathy has developed.
>
> The second experience: the introductory round in an HIV/AIDS workshop of the DAH. A woman sitting next to me introduced herself and of her own accord told us that she is HIV positive. As she spoke about herself, I got goose bumps. In the break, I was able to approach her and express my admiration that she had been so courageous to make her illness public.
>
> 'We must relate our stories as HIV positives because such experiences cannot be found in a book,' is what she told me. 'With my activities, I like to make a contribution towards fighting the illness and not the people who are sick.' Another participant in the round told us that she only spoke about her illness among people whom she trusted because she was afraid that her friends and surrounding world would find out something about it. My conclusion: People who are open and strong enough to talk about being HIV positive should increasingly be employed in prevention. We can learn so much from their example."

Catherine

However, an active role in HIV prevention can bring risks for people with HIV/AIDS: there continues to be prejudice and talk about people with HIV/AIDS; openly revealing oneself as HIV positive can make a person vulnerable. This is why many people keep their HIV infection a secret.

"The role of people with HIV/AIDS in HIV prevention is very significant. Unfortunately, very few are involved in HIV prevention. My impression is that people with HIV/AIDS and a migration biography tend to be seen a guests in the AIDS organisations instead of co-creators. We are lacking initiatives by the people themselves. Above all, we need even more competent salaried employees with a migration background who build the participatory work and enable networking."

Ibra Zongo

People with HIV/AIDS are not (solely) responsible for stopping the spread of the virus! They are exactly as responsible as all of the other people. The responsibility of protecting yourself and others is a shared responsibility!

"Despite HIV, I have decided to continue living and to have a life with quality and dignity. I no longer have sense of guilt within me. I bear the responsibility for myself and my fellow human beings. But each and every person who enters into a relationship with me is also responsible for his or her own behaviour. Together we are all responsible for stopping the transmission of the virus. Informing people about HIV/AIDS means much more to me than just informing them about the practical possibilities of preventing transmission."

Rose

Work Guides

Do you know people who live with HIV/AIDS?

How and where do people with HIV/AIDS in your community find support? What could you do?

How is HIV/AIDS spoken about in your community?

What could you do to make it easier for people with HIV/AIDS to become involved in HIV prevention?

6. Doing Research Together

We have researched together in PaKoMi so that we can better understand the living environments and needs of people with a migration background. There were case studies with various migrant communities in four cities: Berlin, Hamburg, Dortmund and Osnabrück. Each case study had at least one project, but sometimes there were also a number of projects. We will describe our approach below. Additional information can be found at **www.pakomi.de**.

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

Our research approach is participatory, which means that representatives from the target groups and communities with a migration background, practitioners (e.g. employees of AIDS organisations, prevention projects, counselling centres, public health authorities) and scientists conducted research together. In North America, this approach is called community-based participatory research (CBPR).[1] Peer researchers play an important role in this process.

"Participatory research makes it possible for us to learn from each other and better understand the target groups and communities. This approach should also be used much more often in Germany."

Hella

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[1] von Unger 2012

What Are Peer Researchers?

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 also better understand the community members than outside researchers.

Peer researchers are not scientists but life-world experts. In order to be able to research, they need training and support. In a Canadian video, peer researchers describe the experiences that they had in Toronto as peer researchers in various studies. [2] In the PaKoMi video, community partners who developed the questionnaires in the case studies, gathered information and evaluated results have a chance to speak (see Chapter 8).

Peer researchers are people from the target groups and communities who are trained to conduct research in their communities.

In the PaKoMi case studies and workshops, we trained various people with a migration background to be peer researchers. We explained what the participatory research involves and how the methods work. We discussed ethical questions such as how important confidentiality is, that the research should not cause any harm and that people must always first be adequately informed and give their consent before they are interviewed. Then we planned and conducted the research projects together.

Honoraria and reimbursements were paid for the completion of the research tasks. Peer researchers are usually dedicated people who want to learn something and make a difference. However, the additional earnings or reimbursements were necessary in order to make their participation possible since research is labour intensive. The peer researchers invested many hours of work in their training, in the planning of the study and in collecting and analysing the information.

Insights into Life-Worlds through Photo Voice (Hamburg)

In the case studies, 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 (e.g. employees of the AIDS service organisations and counselling centres), the knowledge of the community representatives, statistics and scientific findings. The community partners are experts on their living environments: they reported on their communities – how the people live and work, where they meet and which groups exist. They showed pictures, told stories with examples and conducted research.

The case study in Hamburg was coordinated by the AIDS service organisation of Hamburg (Mara Wiebe, Omer Ouedraogo); the scientific research was overseen by Hella von Unger (WZB). The target group was the African community in Hamburg (French-speaking, urban).

During the initial participatory analysis of the current situation, it was determined that, according to the official statistics, approximately 20,000 Africans live in Hamburg. They come from different countries and belong to various communities in Hamburg. In order to get a better understanding of the various life-worlds and communities, we explored the question “How do Africans live in Hamburg?” The African community partners researched and reported about African cultural associations and religious communities, various groups and places where Africans meet (such as Afro shops, discos, workplaces and universities). They sometimes used photos for this purpose.

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[2] Toronto Community-Based Research Network 2010

Illustration 11:
Photo voice project describing a
Muslim African community in Hamburg

Important: When photos are taken of people, the individuals' data protection and personal rights must be observed. Generally, permission should be requested from these persons in advance. It is also possible to digitally process photos to make the faces unrecognisable. Or the photos can be taken in such a way that none of the people in them can be recognised (for example, by photographing the spaces or the people from behind or from very far away, or by showing details only, such as hands, a smile or shoes – depending on what you want to communicate).

In the case of this photo voice project, the imam of the mosque was asked for permission in advance. Rooms and objects of the Muslim community were photographed to explain their meaning in the everyday life of the Muslim community. By asking permission from key persons of the respective settings, this also gives them an opportunity to have a say, ask questions and get involved. This can have many positive effects. For example, the imam of the African Muslim community mentioned above signalled interest in continuing to be involved in the topic of HIV/AIDS and health promotion beyond the duration of the case study.

"What has PaKoMi given me? More respect because people know that there are Africans who fight for their people with regards to this topic and to improve their health!"

Moussa

In the case study of Hamburg, additional photo voice project were made on other topics and the meeting places of Africans in Hamburg such as the Afro shops and discos. On the basis of the photos, stories were told and the living environments were documented. This method can also be applied by having various people take photos for the same topic and explain what they want to show with them.

Africans Survey Africans on HIV/AIDS (Hamburg)

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 organisations – who were mostly trained health ambassadors of the AIDS service organisation – completed the training to become peer researchers. This training was designed and conducted by the scientific partner (Hella von Unger) and coordinated by two salaried employees of the AIDS Service organisation (Mara Wiebe and Omer Ouedraogo). 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? There was a lengthy discussion in which they considered the various topics that had been recognised as relevant in the participatory situation analysis (such as access to the health-care system in general). 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 (not just regarding primary prevention) 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?

Goals of the survey:

Better understanding of the situation, perspectives and needs of Africans

Improving HIV prevention

“Effecting change in our communities“ (“Bewegung in die Communities bringen”)

Supporting HIV-positive people and reduce stigma

Illustration 12:
Recruitment and information on the survey

Illustration 13:
Telephone interviews

Illustration 14:
Data input at the PC

Method

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.[3] 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**.

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.

A focus group is a group interview on a specific topic. It is moderated and generally lasts 60-90 min.

“I found out that when I speak with people about HIV, they are interested and would like to participate.”

Sogah (Video)

The participants were then 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 French, English or German but could not read and write very well). Some were also surveyed via telephone.

The data were processed and jointly analysed. The peer researchers used a software program for this purpose (Grafstat 2). This involved a great deal of work: the data input into the computer was done in teams of two people in order to avoid errors (ill. 14). Open-ended questions were noted, discussed and decided together. The Grafstat program makes it possible to prepare good colour graphics, which are helpful in making the results easier to understand and discuss.

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.

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[3] Sigma Research
www.sigmaresearch.org.uk/go.php?/projects/african/project39

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).

Countries of origin: most people came from Cameroon (21%), Togo (14%), Ghana (11%), Burkina Faso (10%), Benin (10%) und Nigeria (8%); but there were many others.

Religion: 59% were Christian, 28% Muslim and 10% did not belong to a religion.

The respondents are well-educated: 70% have a general certificate of secondary education or a higher level of education (37% have a university degree).

Half (51%) of the questionnaires were completed in French and one-quarter each were in German (25%) and English (24%). The questionnaire was filled out independently by the same proportions of the respondents in writing (48%) or together with a peer researcher (47%), which means in a verbal conversation. Twelve persons (5%) were surveyed on the telephone.

The respondents were **well informed** about the following topics:

HIV is the cause of AIDS (95% already knew this beforehand).

HIV is sexually transmittable (99% knew this).

HIV and AIDS also exist in Germany (90% knew this).

You can have HIV without knowing it (87% knew this).

The respondents were **not so well informed** about the following topics:

There are medications that help people with HIV to stay healthy (80% knew this, 8% were not sure and 11% did not know this).

HIV is not transmitted through kissing and shaking hands (80% knew it, 10% were not sure and 8% did not know).

You cannot tell if someone has HIV from his or her appearance (76% knew it, 9% not sure and 14% did not know).

The majority did not know:

How many persons in Hamburg are diagnosed with HIV per year (205 persons in 2009) (80% did not know this).

That you can take an anonymous and free HIV test in Hamburg (59% did not know this).

There were also **uncertainties** about the following topic:

HIV does not represent a reason for deportation (58% knew this, 23% did not know and 15% were not sure).

The results on the questions about the HIV stigma and taboo are also interesting. The opinions as to whether HIV/AIDS is still a taboo are divided: half (50%) think that HIV/AIDS is no longer a taboo, and almost as many (42%) think that the topic continues to be taboo. When asked how they would behave towards a person with HIV, most (57%) responded that they would accept the person without prejudice. However, 21% said that they did not know and 10% would keep their distance. This question was also asked: "**Imagine that a person whom you love (such as a partner, sister, son or friend) has HIV/AIDS. How would you support this person?**" It was possible to formulate the responses freely, and many forms of support were mentioned:

"Je vais l'aider en lui apportant des informations sur le SIDA."
I would help him by giving him information about AIDS.

"Je vais soutenir la personne. Le SIDA n'est pas une fatalité."
I would support the person. AIDS is not an inevitable fate.

Moral support (*soutien moral*), comfort and encouragement were mentioned frequently, as were statements that they would spend time with the person.

“Entreprendre beaucoup de choses avec lui pour qu’il ne se sent seul.”
Do many things with him so that he doesn’t feel alone.

“Lui donner plus d’amour.”
Give him even more love.

Practical forms of support were also mentioned: financial assistance, as well as orientation and accompaniment in the health-care system.

“I will help him get medicine and I will tell him about CASA blanca.”
(CASA blanca is the centre for AIDS and STIs in Hamburg-Altona; it offers information, counselling, examinations and treatment.)

“I would send him/her to the AIDS organisation centre.”
“L’orienter vers un centre de santé approprié.”
Refer him/her to an appropriate hospital/health-care centre.

A large variety of support was also expressed. However, this was sometimes also coupled with ambivalent reactions and fear:

“A franchement parler j’aurai peur de la personne et je me mefierai de ses gestes et actes mais je l’aiderai a trouver un centre d’aide comme le votre.”
To be honest, I would be afraid of the person and pay attention to his/her movements and actions, but I would help him/her find a help centre like yours.

Some people were uncertain about how they would respond and/or whether they would support the beloved person with HIV/AIDS, if at all.

“Je ne peut rien faire.”
I can’t do anything.

“I don’t know.”

Conclusions

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 (such as the sexual transmissibility of HIV). But there are information gaps (for approximately 20% of the respondents) with regard to other paths of transmission and the possibilities of medical treatment for HIV/AIDS. More information is required on test services – the majority (59%) of the surveyed Africans did know that there is free and anonymous HIV testing in Hamburg. This means that there is a clear need to better inform Africans about:

(a) the free and anonymous testing sites in Hamburg, and

(b) the effects of a positive HIV test result on the legal residence status.

The majority of the Africans surveyed expressed a willingness to support a loved one with HIV/AIDS. They also have ideas about how they would support this person. Although insecurities and negative attitudes are also apparent, the large majority stated support for acceptance and spoke out against prejudices towards people with HIV/AIDS. This support potential that lies dormant in the communities should be used to a much higher degree. The stigma that is sometimes attached to HIV/AIDS still causes fear in many Africans who live with HIV/AIDS. They frequently do not dare to speak openly about their infection. They keep it to themselves and are very alone with this knowledge and their worries. As a result, they often also go much too late to the doctor. The results of this survey clearly show that there is a large potential for support in the African communities that should be further expanded and promoted so that HIV-positive Africans can also receive the support they need from their compatriots in order to live well with the disease.

Outlook

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 event was very well attended, including other service-providers and especially representatives of the African communities. 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.). Christian and Muslim religious leaders were present and expressed their interest in dealing with topics such as HIV/AIDS and other health concerns in their communities. The agency expressed its appreciation, as well as its willingness to provide longer-term financial support for the community work of the AIDS service organisation, health ambassadors and peer researchers.

"The participatory research in Hamburg is an enrichment for my work. PaKoMi helps me to reflect on my work and improves the competence of the involved volunteers and salaried employees in the HIV prevention, especially how they relate to migrants. I am enthused about the approach of doing something with migrants and observing the background of their life in Germany."

Omer

"PaKoMi is a very special type of collaboration. It has made many things possible in and for Hamburg."

Mara

"I have learned how to run a focus group and how to develop a questionnaire in order to survey the community, how to plan a project in the battle against HIV/AIDS and how to set goals and plan resources in this process. I have been very glad to do all of this because it brings movement to our communities and supports our prevention work."

Sorgho (*translated from French*)

"I participated in the case study in Hamburg and gained much experience as a result. I have become aware that many people are well informed about HIV/AIDS but there are also quite a few who have had no knowledge about this disease up to now. Because of this, it would be meaningful to keep working on it. I found it very good to be able to help my community through PaKoMi: Due to the events and educational work, I have shared much information about HIV/AIDS. Many people found this interesting and helpful."

Germaine

"What has PaKoMi achieved? For me, knowledge and qualifications with respect to research methods and personal development through the seminars and the participatory research. For my community, it has started a discussion on the topic of 'Sexuality and Protection in the Christian Communities'. For my university, it has brought about sensitisation and answered the questions of my fellow students related to sexually transmissible diseases, HIV and AIDS."

Steve

"It is important to me that the sex education is also received in a better and more effective way by people from Africa or Cameroon and by African Christian Hamburg communities. There are many people in the African Christian communities who suffer from depression and do not have easy access to professional help due to the language or level of education. It would be helpful if the leaders of these communities could receive the corresponding training in psychological counselling or the like."

Chibiy

"Migrants are in the position of bringing about change in their communities – and the people are more trusting when Africans can help Africans."

Armand

"If we can now help our compatriots here in Hamburg with what we learned, then we can also already help those in Africa – at least verbally – by now discussing the topic consciously with our family and being able to give them information."

Armelle

"I hope that we can continue to develop a project in the direction of prevention."

Moussa

"It feels pretty darn good to have participated in a successful project. Thank you! And please give us more of this!"

Vivi-Lore

"For the time after PaKoMi, I wish for a sustainable development project so that the competences and knowledge can be transferred to others."

Gwladys

"How can we start an initiative in Africa on the topic of HIV prevention?"

Sylvie

Expert Interviews with Community Leaders (Berlin)

In the case study in Berlin, new ways to access men with a migration background who have sex with men (MSM) were explored.

The case study was coordinated by the network centre of HIV/AIDS and Migration at the Association for Intercultural Work (VIA), the Regional Association of Berlin/Brandenburg (Nozomi Spennemann) and scientifically accompanied by Michael T. Wright (WZB). In cooperation with manCheck, Subway and GLADT, three sub-projects were conducted. There was a steering group that consisted of employees of these organisations, the Centre for Sexual Health (GA Berlin Charlottenburg-Wilmersdorf) and VIA and WZB.

The goal of the Berlin case study was to gain new knowledge about MSM with a migration background. This involved men who have sex with men who do not consider themselves gay and who do not live their same-sex sexuality openly. It is possible that these men are not reached by the prevention messages directed at gay men, and they are "hard to reach" for the AIDS projects. The case study wanted to find out whether these men have special HIV risks, how well they are informed and how they can be reached. In this case study, the participation of men from the target group was especially difficult to realise. It is difficult to address a man as MSM when he does not reveal his homosexual or bisexual orientation. It is just as difficult for him to participate in this case study. As a result, various approaches were tested.

One approach was realised through Gays and Lesbians from Turkey (GLADT). GLADT is a self-organisation of gay, lesbian, bisexual and transgender*persons with a migration background (especially Turkish). GLADT is well connected with other migrant self-organisations (MSOs).

The sub-project of GLADT in the PaKoMi case study Berlin had the objective of discovering how much knowledge about HIV/AIDS exists in the Turkish- and Russian-speaking communities, as well as which possibilities and obstacles to action exist in the communities. In addition, the intention was to develop ways to take an intensive approach to HIV/AIDS in these communities together with key persons. These paths should be oriented upon the knowledge and resources of such persons and organisations.

Key persons from the Turkish- and Russian-speaking communities were interviewed. These two groups represent the largest migrant groups in Berlin and there have already been contacts between GLADT and representatives of these communities.

Method

People who were familiar with the living environments of the MSM (life-world experts) in these communities were selected as interviewers from among the members and employees of GLADT. The guidelines for the interviews were developed on the basis of their experience and knowledge.

In the first stage of the project (April to May 2010), the possibilities for including Migrant Self-Organisations (MSO) and key persons of the Turkish- and Russian-speaking communities were researched. This primarily occurred through the Migration Council of Berlin-Brandenburg (MRBB), an umbrella organisation of more than 70 MSO – of which GLADT is also a member. In addition, the existing contacts of GLADT were activated or new contacts were developed through recommendations by cooperation partners.

Initial conversations were conducted with key individuals. In this process, it was possible to identify additional key persons from the Turkish- and Russian-speaking communities as interview partners or as "gate keepers" for the community, as well as also recruiting some of them.

Two interview guides and protocol guidelines were developed: one was intended for the key persons and the other for the MSO. Topics for the interviews included questions about the person's understanding of "community", knowledge and information about HIV/AIDS, types of access and barriers to the existing help system and the perception of MSM. The interview guides contained questions such as the following:

Which ideas do people have about the roles men and women within the community?

Which sources do people use in the community to get information about sexuality?

Do "unofficial" sexual contacts such as extramarital contacts, prostitution or sexual contacts between men occur?

Are sexually transmissible diseases a topic?

To what extent do people speak about HIV?

What is your personal level of information?

How would you rate the level of information of different sub-groups or individual organisations within the community?

What types of access to information about HIV/AIDS, as well as systems for help, are used?

In the second stage of the project (June to September 2010), the expert interviews were conducted with representatives of both communities (see ill. 15). Based on the guidelines that had been developed, 20 interviews were conducted with a total of 22 persons from the levels of leadership, MSO employees and voluntary participants; in addition, individual key persons were surveyed. The conversations were not audio-recorded, but documented in writing immediately after the interview.

In the concluding third stage (October to December 2010), the findings of the interviews were systematised and evaluated together with a portion of the respondents in a workshop. This means that the community leaders who were interviewed had the opportunity to participate in the interpretation of the results and the discussion of possible resulting strategies, measures and conclusions.

Findings

A total of 22 key persons were interviewed. The findings show just a minor difference between the Russian- and Turkish-speaking groups. Topics such as gender, sexuality and particularly sexually transmitted diseases were avoided in both groups in public discussions. HIV/AIDS tends to represent a medical topic in both communities. Instead of brochures, information sources tend to be individual conversations with doctors and other persons who are perceived as authorities. The experts estimate that the media from the countries of origin offer increasingly more information on the topic, which also deals primarily with the medical aspects.

With respect to the main question about MSM, it was determined that the respondents from both language groups had an astonishing level of knowledge about MSM. To their knowledge, MSM, bisexual men and "men who don't care who they have sex with" make little use of prevention material for gay men because they do not consider themselves "gay" or "homosexual". Safer sex cannot be taken for granted since HIV/AIDS is only abstractly perceived as a threat. Above all, carelessness in relation to an individual's own health is reported within the Turkish-speaking community ("A person who does something like that must bear the consequences.").

Illustration 15:
Interviews with key persons

Conclusions

Conclusions were drawn from the surveys and the workshop with a portion of the respondents. The basic recommendations were to address MSM as heterosexuals and to target them in "normal" settings (the subway, TV, cinema, etc.). The following individual strategies were recommended:

Embedding, contextualisation and "detour" communication: HIV prevention should be embedded within the scope of a general discussion of health and health promotion, both in terms of the topic and in terms of the occasion (e.g. as a lecture within the scope of a larger event, by a booth among other booths).

Approaching the individual: Trust appears to be the basic necessary condition for sexual communication to take place. Confidants can be from private networks, MSOs, religious institutions or neighbourhood centres and accommodation management. In the case of MSM, sex partners who consider themselves "gay" or staff from locations in the gay scene and cruising locations can fulfil this function.

Professionals assuming responsibility: Persons who are perceived as authorities (e.g. associations of doctors, political groups, lobby organisations, well-known artists, athletes) can be called upon to educate themselves or assume a "sponsorship" for the topic with support by the MSO.

Activate ethnic media: The Turkish-speaking participants suggested that the daily newspapers, which are also read in Germany, and the Turkish television channels, which are also viewed in Germany, could assume an important function.

Use prevention material and concepts from the countries of origin: The Russian-speaking participants suggested evaluating campaigns and material from the countries of origin (especially Ukraine) and examining whether they can be transferred to the situation in Berlin. For the Turkish-speaking MSM, a campaign against domestic violence – which was initiated and accompanied by the *Hürriyet* daily newspaper – was mentioned.

Pay attention to the language and imagery: Material and campaigns should be multilingual and not include any national symbols (such as flags). Addressing people in the Russian or Turkish language was considered to be an inclusive path – not just because some do not speak German well but because it also creates a form of visibility. Pictograms and pictures may facilitate the access. Every item of informational text should use simple language. Examples and arguments should be taken from everyday life ("keep it simple") and not produce fear. Common arguments can be addressed (e.g. "This is my first time", "I just want to try it" or "Don't have money for prostitutes").

Design: The focus should be on allure and surprise moments – free of fear and modesty. MSM who do not consider themselves gay or MSM should be addressed as "normal" heterosexual men – which means also as part of the general population. Exoticisation and generalisation are not helpful, and the social dimension should always be taken into consideration ("opening paths of access for support instead of telling tales from 1001 Nights").

Development process and products: The creation of a campaign should already be accompanied or even coordinated by members from the MSO. HIV prevention should be conceived of as a process in which progress is made step-by-step (trial and error). The usual formats can be tested (e.g. posters, flyers, stickers, advanced trainings/workshops), and new forms can be developed (e.g. a telephone hotline at an MSO, actions in public space or campaigns in/with the media).

Qualification for MSOs: MSOs have many underused resources for HIV prevention (contacts, trust, etc.). They are already used as service providers, counselling centres and exchange forums. ("Once you have solved a small problem together, they will also come to you with bigger problems") and should be qualified as competent (first) points of contact for the topic. In order to do this, it may be necessary to strengthen individual persons and put expertise and argumentation strategies in their hands ("It isn't enough to hang up posters if we don't know what we should do if people actually come to us after the integration course."). It is necessary for the MSOs to become part of the corresponding networks in order to continuously be able to work on the topic ("Aimless activism doesn't helps us!").

Outlook

The participation of GLADT in the case study and the results of the interview study indicate that the cooperation with Migrant Self-Organisations is a real option. It is important to find the right format for the collaboration. MSO cannot replace the AIDS projects. Instead, by cooperating they mutually complement each other with their competences, resources and networks. For example, AIDS service organisations (ASOs) can offer HIV training for key persons from the communities. At the same time, being able to benefit from the existing networks of the MSO is an enrichment for the ASO's direct prevention work on the streets.

In mid-2011, a process of the further development of HIV prevention began in Berlin and is directed by the Senate Administration of Berlin. The extent to which it will succeed in translating the recommendations from this study into action depends on the will of the participating organisations as well as on the basic conditions.

"[At GLadT we] have intensively met with important MSOs regarding the topic and had a lively exchange, which is an important foundation for an activation of additional groups and persons. In addition, we were able to gain new important knowledge through the survey. The participatory approach was taken into consideration with much care from the beginning to the end. Clear goals were set within the scope of our workshops with the MSOs: a mutual articulation of the problem and the subsequent mutual declaration of intention."

Tülin

"It has become apparent that the participation of migrants brings new perspectives of prevention that were not familiar to the responsible bodies of HIV prevention. For us in Berlin, it was primarily the statements of the MSOs in the sub-study by GLADT that showed us new possibilities for HIV prevention under consideration of the life realities of MSM with a migration background."

Michael

"In Berlin, MSM with a migration background have often been the topic of discussion in the working group on HIV Prevention with Migrants since these MSM are hard to reach for prevention services. However, no one knew whether and to what extent they are vulnerable, where exactly they come from, how to reach them, and so on. The case study offered the opportunity to clarify some of these questions with scientific support and simultaneously promoting participation, which had been underdeveloped up to now in the Berlin assistance system."

Nozomi

Internet Chats with MSM (Berlin)

The second sub-project of the Berlin case study was conducted by manCheck. ManCheck is a project of Schwulenberatung Berlin gGmbH (Gay Counselling Berlin), which offers HIV prevention for men who have sex with men (MSM). In order to establish contact with Turkish- and Russian-speaking MSM who do not consider themselves gay, a new type of access was tested - through the Internet. Two peer researchers surveyed more than fifty men in Turkish and Russian through online chats. They were accompanied in this process by a salaried employee of manCheck (Jannis Karamanidis) and a scientist (Michael T. Wright).

ManCheck is a primary preventive health project for men who have sex with men (MSM). The work of manCheck takes place on-site, primarily in the gay scene, but also in other places where MSM meet. The MSM are informed about the risks of HIV infection and other sexually transmitted diseases, as well as about possibilities of protection. MSM with a migration background who spend time in these places are provided with information in the same manner as the MSM with a German origin. However, MSM (with and without a migration background) who do not visit these places can hardly be reached by the on-site work of manCheck. It is not clear whether these MSM are reached by the prevention services and messages for gay men. There are presumably men, especially among the MSM with a migration background, who do not openly live as gay or do not call themselves gay since homosexuality is still strongly taboo in some cultures. We still know too little about the risks and safer-sex behaviour, level of information and needs of these men. In order for us to develop targeted and appropriate HIV prevention services and communicate the appropriate contents, we must first assess the needs of these MSM.

Goals

This is why manCheck wanted to research the possible needs of MSM with a migration background through an Internet-based sub-project within the scope of the Berlin case study. The long-term goal was to better reach MSM with a migration background who have hardly been addressed by the existing services. The sub-project of manCheck is concretely focused on finding out about the level of knowledge regarding HIV/AIDS, the protection behaviour and the need for information, prevention measures and offers of help.

Illustration 16:
Peer researcher interviewing MSM online

Method

As already mentioned, the challenge was to recruit men from the target group for active participation in the study. This has proved to be difficult: first of all, these MSM do not want to or cannot acknowledge their same-sex sexual behaviour; secondly, they do not necessarily feel that they are part of such a target group because the group label has been assigned to them by outsiders (i.e. professional prevention staff), and the respective men do not consider themselves to be “MSM who live their homosexuality in a concealed manner”.

Two men were found who have an openly gay lifestyle but are quite familiar with the living environment of MSM who do not openly live as gay. They acted as peer researchers. Both men have a migration background – one of them comes from Turkey and the other from Ukraine. Their native languages are Turkish or Ukrainian and Russian, are quite familiar with the corresponding cultures and have an appropriately approach to the lifestyle and the special form of sexuality practised by the respondents.

In an initial stage, the interviewers conducted preliminary research on the living environments of Turkish and/or Russian-speaking MSM in order to prepare for the study. The intention was to find the appropriate paths of access for the planned survey. Among other things, it became clear that social Internet platforms for homosexual men – as well as those for the general population – are very frequently used by MSM with a migration background in order to establish contact with other men. Both interviewers found at least one Internet portal that is mainly used by the corresponding origin group (of Turkish origin and Russian-speaking) respectively for their sub-target group and that – even though it is officially directed at the heterosexual general population – is often also used by men who are seeking sexual contacts with other men. Most of these MSM do not openly live as homosexuals or understand do not consider themselves gay. For precisely this reason – because the “hard to reach” target group of MSM with a migration background who do not openly live as homosexuals are encountered in this environment – we decided to conduct the survey on two of these Internet portals. In addition, the inhibition threshold on an Internet portal is very low for MSM who do not want to reveal their identity and for whom discretion is very important.

In a second stage, the survey was prepared in terms of content and technical aspects. The questions were intended to determine the following aspects: level of knowledge, protection behaviour, improvement of prevention and demand for information. The questions were developed together with the interviewers:

1.What do the men who you have met here know about sexually transmitted diseases (venereal diseases) and HIV/AIDS?

2.What do men do to protect themselves?

3.[Before the pilot test was conducted] How can this be improved? What do you (otherwise) need to protect yourself and others? What is important in order for things to stay this way? What can be done even better?

What is important so that they continue to protect themselves? (There were a number of alternatives. The Interviewer could select one of them.)

[After the pilot test had been conducted] Have you experienced sex without condoms? Have you ever not protected yourself/had sex without condoms? For a negative response: Record end of the survey. For a positive response: What happened in that case? What was the situation? Why didn’t it work out? What would have helped you in such a situation?

The first two questions are related to acquaintances or other men in order to avoid deterring the participants with a direct, personal question. However, we also hoped that the participants would talk about themselves. The interviewers translated the questions from German into Turkish and Russian. The interviews for the pilot phase were conducted, documented and evaluated. As a result, we discovered that Question 3 about how to improve HIV/STI prevention and/or the information needed was not understandable enough. It was thus changed (Question 4).

After this step, the two virtual surveys began at the start of the summer 2010. The respondents were informed about the research project at the beginning of the conversation. If further information on HIV/STI was needed, they were referred to the DAH (or GLADT for Turkish-language information). The recruitment of the survey participants took place on the two portals in different ways: on the Turkish-speaking portal, the peer researcher was present online and waited for the men to write him. When this occurred, he informed them that he was not online to look for sex but because of the research project. On the Russian-speaking portal, the peer researcher wrote this to the men: “I have some questions about a serious topic”, followed by information on the research project. In the explanation about the research plans, the client and the assignment were identified. The respondents were informed that their anonymity would be ensured. An email address was provided for follow-up questions to PaKoMi.

The surveys were completed at the end of September 2010. The interviews were evaluated with a content analysis in the fall. During the evaluation stage, much value was placed upon the participation of the two interviewers and their ability to interpret due to their close proximity to the living environment of the target group. Their answers were discussed and the Turkish responses were sorted into categories. In the creation of the categories, attention was paid to the resulting categories actually based on the data – which depict the life realities of the men – and not on our concepts and understanding of the matter. The categories were the following:

Consistently with condoms

Additional protection measures

No sexual experiences with men

Sex without protection

Risk is unclear

Attitude of homosexuality as fate

Suggestions for improvement of prevention

In a second step, the content analysis was condensed. This means that we searched for results that we could gain from the individual categories.

Findings

The Turkish-speaking interviewer was present on the Internet portal where the Turkish-language survey took place for a total of 50 hours and 38 minutes. During this time, the interviewer had a total of 153 virtual contacts with men. Of those, 102 immediately rejected the survey at the start. There were 51 interviews. The majority of the respondents were residents of Berlin and most of the interviews were conducted in the Turkish language. The Russian-speaking interviewer spent 3 hours and 38 minutes on the Internet portal where the Russian-language survey took place. During this time, 17 men were surveyed. Only two Russian-speaking participants came from Berlin; the rest lived in other large or medium-size German cities. All interviews were conducted in the Russian language.

The responses of the surveyed men show that they have thought about the topic of HIV and sexually transmitted diseases. More than half of the respondents said that they use protection measures in order to safeguard themselves against the virus. Many survey participants mentioned that they use condoms regularly and/or practise safer sex in order to protect themselves. Many participants also mentioned using other strategies that they considered protective, such as paying attention to whether the partner has a healthy appearance or looks clean. Very few men reported on experiences of having sex without condoms, and all of them emphasised that it was a one-time experience. This could mean that there could be a so-called selection effect: men who had a number of risky contacts were probably not addressed by the survey and/or rejected it. For some of the participants, it was obvious that they had no experience or very little experience with same-gender sex, but were searching for such experiences. The general impression arose that many of these MSM had a rather restricted sex life, which may be due to an excessive fear of HIV or conflicts about their own sexual desire for men. It also was not rare to recognise fatalistic attitudes towards (homo-)sexuality and HIV risk; these MSM appear to perceive the health risks that occur through their sexual contacts with other men as something unavoidable. Few of the men made concrete statements about how HIV prevention could be improved in their opinion. All of these spoke about the mode of disseminating information such as seminars and info events, media and education in the schools and info stores. Only one man talked about restrictive measures.

The information content from the responses of the Russian-speaking survey participants was smaller. How much these men know about HIV/AIDS can hardly be determined on the basis of their responses. The Russian-speaking MSM also frequently mentioned condoms as their customary protection measure. Some named additional measures such as vaccinations, body hygiene and the post-exposure prophylaxis (PEP, which is the preventive administration of antiretroviral medications briefly after a situation in which an infection may possibly have occurred). Some of them said that unprotected sex also occurs occasionally, and three participants stated that they never protected themselves.

Conclusion

The sub-project of manCheck developed a new, low-threshold means of access to MSM – namely, through "virtual dating services for the general population". On the one hand, the experiment was a success because it reached MSM with a migration background who do not self-identify as homosexual, and assessed their level of knowledge, protection behaviour and preventive needs. On the other hand, the relatively high degree of effort (approximately one contact per working hour for the Turkish MSM) was critically discussed in the working group. The counter-argument was that this group can be reached only by making a special effort. We recommend evaluating whether this way of reaching out is suitable for prevention measures specific to the target group. This would include considering online prevention services, such as the DAH's online counselling and the health support project on the Gayromeo Internet platform.

The participation of two MSM with a migration background throughout the entire research process was very advantageous. Even though the two interviewers identify themselves as gay, they have much knowledge about the living environment of the target group. If we want to address MSM with a migration background in HIV prevention, it would be advisable to hire prevention staff who are familiar with the living environment and cultural aspects such as in this case the fatalistic attitudes towards (homo-)sexuality and HIV risks. In addition, they should demonstrate a high level of lifestyle acceptance and be able to deal with MSM who do not self-identify as gay without judging them. Depending on the need, native speakers should possibly be used for this purpose. A project and/or an intervention should have the lowest possible threshold and ensure discretion and anonymity for the MSM, as well as being oriented upon the living environment of MSM in the design of the interventions.

The answers of these respondents showed that these MSM have already thought about the topic of HIV and sexually transmitted diseases. Almost all of the respondents have thought about their own protection and take protective measures. They did not seem unconcerned. However, it should be noted that MSM who do not protect themselves and for whom HIV is not a relevant topic might have chosen not to participate in the survey (selection effect). The interviewed men appear to know that condoms protect against HIV infection, and the majority uses condoms. However, many mentioned additional "protection strategies" that seemed rather ineffective, revealing a need for further information. Above all, a type of "sero-guessing" – practised by some of the respondents and based on the appearance or cleanliness of the partner – seems to be a problem. Another problem is that the principle of personal responsibility has apparently not fully registered with some of the men because they expect their sex partner to raise the topic and communicate his sero-status so that they can then decide for or against safer sex, depending on what he says.

These results show that there needs to be a stronger focus on the prevention message and contents. The existing safer-sex behaviour should be strengthened. Fatalistic, fate-oriented attitudes should be taken into consideration and the sense of self-efficacy in the target group needs to be promoted. Since some of the respondents put strong restrictions on their sex life, we should think about how excessive fears can be reduced.

***Sero-sorting* describes a strategy of risk management in which the MSM select sex partners who have the same HIV status that they have.**

***Sero-guessing* is a similar strategy, but it is based on assumptions only and is therefore not reliable.**

MSM with a migration background generally do not understand themselves as a community. At the same time, many of these MSM are presumably represented in a great variety of communities (such as communities of origin or sport associations). This is why AIDS organisations and migrant self-organisations (MSOs) should work together in a community approach. In every form of collaboration, the participation of the cooperating MSO and projects must be ensured in all of the processes. It would be even better if the initiative for developing such projects came from the migrant communities themselves and the cooperating prevention projects and sponsors would assume as supporting, accompanying function.

"The principle of lifestyle acceptance has been successfully practised in Germany for years in the prevention work for and with gay and bisexual men, intravenous drug-users, sex workers and other groups. For MSM without a gay identity, specific interventions are required in order to actually address them adequately in their living environment. And these interventions – just like those for other target groups – should be accepting of their lifestyle, primarily aimed at HIV prevention without causing a scandal and making them into a clientele and without wanting to patronise or emancipate the respective men."

Jannis

"For me, the virtual survey showed how recklessly and imprudently the Russian-speaking migrants approach the topic of HIV/AIDS. What have I learned? Not to approach others with a moralistic attitude."

Dmitrij

Telling Stories: Story Dialogues (Berlin)

The third sub-project of the Berlin case study took place with Subway – an organisation that works with young male sex-workers who provide sexual services to men. The sub-project was conducted by Stefan Schröder (a Subway employee) and scientifically accompanied by Michael T. Wright (WZB). In this sub-project, some of the young men were invited to participate in a narrative group conversation – that is, they were asked to tell stories about their work and the men who buy sex from them. Such a "client" was drawn as an outline on the wall as an example. The stories by the participant were noted in key words on slips of paper and pinned onto this outline.

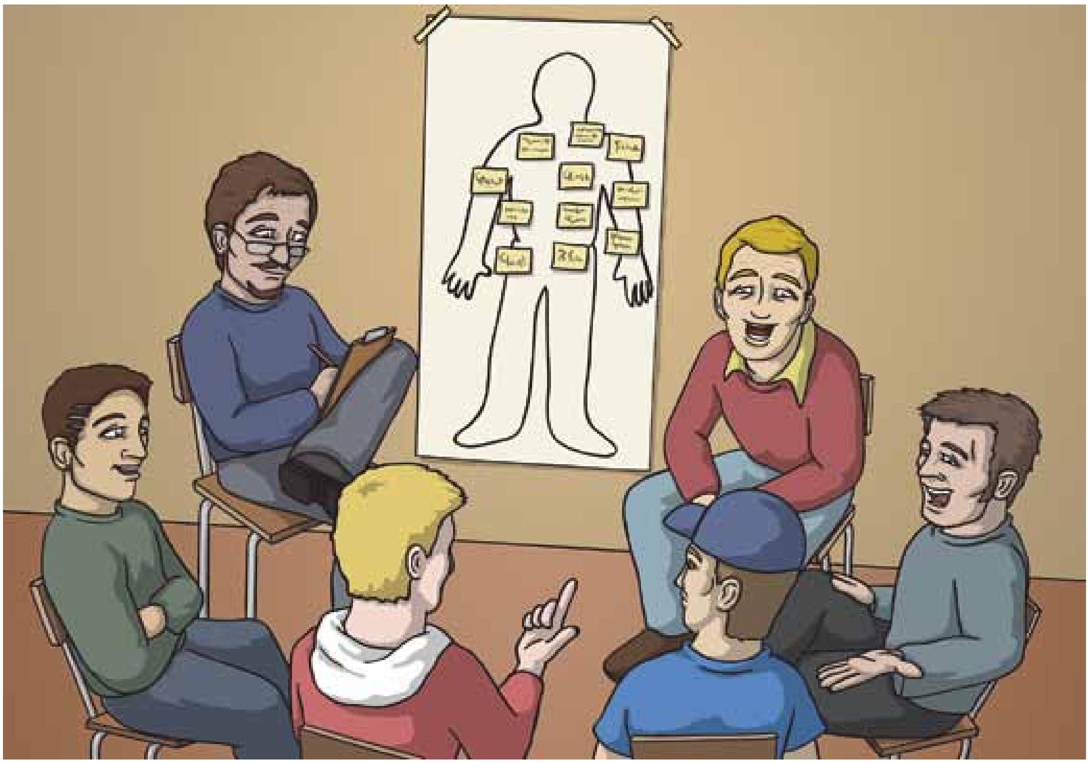
"Boys" is a term commonly used to refer to young male sex workers in the male prostitution scene in public places and in bars. This term was thus adopted by Subway. Another term commonly used for them is "Stricher" (hustler).

"Boys and young men who are on the street and engage in sex work are often affected by sexual exploitation and violence and have only limited access to health care and social services. They are the main target group of Subway. However, this sub-project focused on the clients of the boys – the 'punters'. More precisely, it focused on clients with a migration background who are difficult for us to reach because they are not part of the scene. Our assumption was that these men may have special needs with regards to HIV prevention."

Stefan

The Subway employees visit the scene bars on a regular basis and know the boys well. They are also familiar with many of the boys' clients (punters) and are sometimes approached by them. They now wanted to explore the information needs of the clients who cannot be found in the bars with male prostitutes. These men are loners who seek contact to the boys in porno movie theatres and parks. For Subway, it has not been possible to make direct contact with them up to now – not even though the Internet. A good source of information about this special target group are the boys who are in contact with the clients. Most of the older boys talk openly about their work; however, they say little about how contact is established and about possible differences between groups of clients. The sub-project was an opportunity to learn more about the boys assessment of the situation of these clients in order to better provide them with information – directly or indirectly.

Illustration 17:
Group conversation with boys (story dialogue)



Method

Within the scope of the PaKoMi project, the boys participated in a group conversation that followed the narrative-dialogue method (story dialogue).[4] This means that the boys were asked to tell stories using examples and details from their personal experiences.

Four boys participated in the conversation: one was of German origin and three had a migration background (Romania, Lithuania and Croatia). They were between 21 and 30 years old, engaged in prostitution for at least four years and have already been known to Subway for a number of years. The boys were invited to the conversation because they talk openly about their experiences in prostitution and express themselves about it in a differentiated manner. They had a good enough knowledge of German to be able to participate in a group conversation in German, and they all had contacts with clients who are not involved in the open prostitution scene.

The conversation lasted approximately 100 minutes and took place in a separate room at Subway's contact centre. The participants and the discussion leader sat at a round table and were provided with beverages. In keeping with the data-protection practice and the anonymity rule of Subway, the conversation was not recorded with an audio device. The following questions were asked:

How do you get in contact with the men?

Do clients who are not in the bars treat you differently?

Do these men want to use condoms?

Are they informed about HIV/AIDS?

The migration background of the clients was also addressed in the conversation. The results – as planned in the data-collection protocol – were recorded with the help of little cards on the "picture of the client" (see ill. 17). On the basis of approximately 12 stories about experiences with clients who have a migration background, 17 little cards were produced, which were then grouped as follows:

Places and modes of meeting

Places where the sexual contacts occur

Characteristics of the sexual contacts

Characteristics of the clients

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[4] Labonte 1999

The introduction emphasised that the boys were invited as experts because they know the clients with a migration background better than the social workers of Subway do.

"Addressing them as experts was flattering for the participants, but it also made them laugh – probably because they had never been called experts and spoken to as such, and they did not perceive themselves this way ('What? We are experts?!'). The central questions were immediately understood by the participants, as well as the request to differentiate between the clients within and outside of the scene. Their stories were somewhat hesitant at first because the participants were uncertain as to how much they should tell and about which specifics. When the anonymity was explained during the introductory round – that each participants had declared that he would not talk about what had been said to others in the scene – some of the concerns in relation to revealing their own experiences were addressed ("Each of us works for ourselves. Each of us is alone."). However, this resolved during the course of the conversation after the first boys reported about their experiences and the moderator actively intervened to provide a framework for the stories. Through the key questions and precise follow-up questions, it was possible to learn more details. The narrative proved to be true-to-life; the participants increasingly reinforced many of their statements through a concrete example without a request from the moderator. The participants' interest in the conversation was apparently not related to our research questions. Our questions whether clients having or not having a migration background makes a difference or them being close to or distant from the scene was foreign to the boys and had no relevance. The desire of the boys to tell their stories could be noticed in the sharing of unusual situations or situations in which the teller has shown a special ability. Competition or other possible disruptive factors in the communication were not noticed during the group discussion."

Stefan

Findings

According to the boys, the findings with regards to safer sex and HIV showed that there were hardly differences between clients with and without a migration background or between clients who were close to the scene or distant from the scene. There was one exception: it may be that the Russian clients more frequently ask for sex without condoms and practise sex that is "harder" (less gentle).

The conversation based on the narrative-dialogical method was different from other group conversations that otherwise take place at Subway. It is unusual for the boys to sit together and focus on just one topic. Conversations about clients and sex work usually contain funny episodes and/or stories that make the boys look good. The boys rarely talk to each other about sex practices or how and where they make contact with men. Each of them knows that the others are involved in prostitution, but none of them speak about it. At the end of the session, the boys said that they really enjoyed the conversation and that it was good to openly report on their experiences and be able to ask questions (which they usually just do in the individual conversations). They said that it was a good feeling for them to hear that the others have had very similar experiences.

So the narrative-dialogical method proved to be valuable. However, it was not possible to confirm the hypothesis upon which the key questions were based (i.e. clients with a migration background who keep a distance from the scene exhibit types of behaviours and/or attitudes that pose a special risk for an HIV infection). One possible exception are the clients of Russian origin.

"It would be desirable to find boys who primarily establish their contacts with clients through the Internet, based on the assumption that the range of their contacts is even larger. In addition, it would be interesting to interview boys who also have clients of Russian origin in order to verify the statements by the first group conversation about this group of men."

Stefan

Needs Assessment for the Founding of an Association (Osnabrück)

The case study in Osnabrück (Lower Saxony) was coordinated by the AIDS service organisation of Osnabrück (Kristina Hesse) and scientifically accompanied by Hella von Unger (WZB). The target group was the Africans in Osnabrück and the surrounding area (English-speaking, rural). Between 12 and 15 African migrants participated as community partners. Some of them had lived in Osnabrück for only a short time as students, and others had already been in Germany for many years and were married to German partners.

Research and informal interviews were initially conducted in order to see how many Africans are in Osnabrück and the surrounding area. How are they doing? Where do they meet? Do they feel that they belong to a community? What do they need within the context of health? What do they think about HIV/AIDS?

The findings of the participatory analysis of the current situation were that approximately 500 Africans are officially registered in Osnabrück, and that there is hardly any sense of an African community among them. They live far apart from each other in rural settings; there are few meeting places and hardly any "community feeling" among them.

"We conducted two sets of interviews. The first was about community. We first wanted to support the people in Osnabrück with the topic of health promotion. So we went to them and asked: 'What is a community to you? Where do the Africans or migrants actually meet?' Due to this research, we found that the people would like to meet other Africans and would like to do more for their common concerns."

Victor (Video)

It became clear that community-building processes are necessary, also as a precondition for developing HIV prevention in a participatory way – for and with Africans. We thus conducted a "Love Health" campaign within the scope of the case study with about 15 African community partners involved in activities at the Africa Market (see Chapter 1 on Community).

In addition, a plan was developed (with the help of a logic model) for founding a migrant self-organisation (Afro-Info). This new MSO 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 (including HIV/AIDS).

Goal

A survey was conducted to assess the needs of Africans in a systematic way and develop the new community-based organisation accordingly.

Method

With the help of a brief questionnaire, Africans in Osnabrück were surveyed in two languages: German and English. The questionnaire contained questions such as the following:

What do you need to improve your health?

Which illness would you like to learn more about?

We are planning a new initiative for Africans in Osnabrück – a place that provides information and support for health and other topics. Do you think that this is a good idea?

Would you personally go to such a place that provides information and support by Africans for Africans?

Do you have any kind of wishes or suggestions for this place?

The questionnaire was tested and 78 persons were subsequently surveyed with it.

Findings

The survey provided the following findings:

78 Africans participated (65% men, 35% women).

93% considered the planned initiative to be a good idea.

90% would personally go to a place that provides information and support by Africans for Africans.

54% would like to learn more about depression, 44% would like to learn more about HIV/AIDS and 43% need help in finding a good doctor.

Wishes and suggestions: It should be centrally located in a place that is easy to reach and child-friendly with advanced training offers and discussion events, information in various languages and the possibility of meeting and getting to know other Africans.

Conclusion and Outlook

The initial research, the experiences with the Love-Health campaign at the Africa Market and the results of the survey suggest that the planned MSO and its services correspond with the needs of Africans in the region of Osnabrück. As a result, plans have been made to found an association (Afro-Info) with which African migrants can organise themselves and provide each other with support and information for accessing the health-care system and learning about HIV/AIDS and other topics. In this process, health will be one important concern among many. The focus is not on HIV, but it also will not be avoided. This association can provide an essential contribution to building an African community in Osnabrück and the surrounding area.

Among other occasions, the results of the case study were presented in June 2011 at a round table on the topic of HIV/AIDS at the Lower Saxony Ministry for Social Affairs, Family Affairs, Health and Integration in Hanover. The community partners are making an effort to find support in the State of Lower Saxony as well as on the communal level, in order to use the results of the case study in a long-term manner and establish an association.

Illustration 18:
Interviews for needs assessment

"PaKoMi has shown me and us the steps that we can take in order to organise ourselves in a self-determined manner and therefore be able to help the migrants much more effectively in every way. PaKoMi has given me new ideas that I would like to translate into action in the future. My wish is to establish an African association in Osnabrück after PaKoMi. Due to the case study, we have realised that our community needs self-organised support. This means 'by Africans for Africans' – for example, to make it easier to deal with the German bureaucracy."

Ruth

"PaKoMi is a project that aims to understand the connection between migration and HIV/AIDS, analyse the health risks of migrants and – in the end – recommend preventive services. (…) PaKoMi has helped me to talk more freely about HIV/AIDS and respond to questions with a new self-confidence. It has also made it possible for me to establish more contacts with other migrants in Osnabrück."

Lucy

"I hope that our message and the news about our group will make its rounds in the African community. I also hope that I will learn new methods for spreading HIV prevention messages."

Dubiede

"PaKoMi has opened my eyes and helped me to get to know endearing African compatriots… What I liked best was the attitude of the members of our group towards each other: the willingness to help others who are disadvantaged, the decisiveness in achieving a remarkable goal without expecting material compensation for it. Our PaKoMi activities reached a climax at the Africa Market in 2010… How will things continue? Don't forget what you have learned. Be decisive!"

Chief Nnamdi Ambrose Ojinnaka

"Through the research, my understanding of the situation of migrants in the health-care system in Osnabrück and Germany has deepened… I think that we need an African community in Osnabrück for all of the Africans from the entire continent. Something like this has not existed up to now."

Helen

"PaKoMi is a home away from home… What do I desire for the future? That African migrants work together independently in order to create awareness about HIV and AIDS in other immigrants, how people can protect themselves and how you can deal with it when you have it."

Angela

"PaKoMi may have a different meaning, but for me PaKoMi stands for a nice, small African group that meets for a good cause. The best part was the Africa Market."

M.

"The participation of migrants in HIV prevention is meaningful because we have easier access to our compatriots. We can build bridges to other migrants here in Germany and to people in our home countries. We are more familiar with the culture and the taboos with regards to health and HIV."

Catherine

Community Mapping with Male Sex Workers from Bulgaria (Dortmund)

The PaKoMi case study in Dortmund was concerned with Bulgarian women and men who are involved in sex work. The case study was coordinated by the AIDS service organisation of Dortmund e.V. (Christian Hölbing, Neonlicht project) and the Centre of Communication and Counselling for Prostitutes at the Social Services Association of Catholic Women (KOBER) (Kirsten Cordes). The scientific partner was Hella von Unger (WZB). The case study was dedicated to the target group of women and men from Bulgaria who are involved in the street-based sex work in Dortmund: women who work on a particular street (Ravensberger Strasse) and men who work as male prostitutes in the local bar scene. Two male Bulgarian male prostitutes, two Bulgarian students and the language professional of KOBER participated as community partners.

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 each of the respective groups (female and male Bulgarian prostitutes). Within the scope of the case study, two sub-projects were carried out:

(a) a community mapping with Bulgarian male prostitutes ("boys"),

(b) development and testing of a concept for cooking evenings with Bulgarian women in the area of street sex work .

Here is a description of the sub-project with the boys.

Initial Situation On-Site

The social-work project Neonlicht works with male prostitutes and callboys who earn money with same-sex prostitution (male prostitution for men) in Dortmund. In 2009, about 70% of the male sex workers had a migration background. The majority of these men were between 18 and 25 years old and came from Eastern 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 male prostitute study of the Eastern Ruhr Area [4] had shown that male prostitutes are generally exposed to a high risk of infections and that about 40% will forgo condoms in their contact with regular clients for more money.

"The experience of taking our prevention work directly to the streets confirmed the study's findings that Bulgarian male prostitutes often hardly have any knowledge about using condoms. This group appears to be a rather closed community, and the usual information flyers on prevention for gay men help only to a limited degree. This is due to the fact that many members of the target group can neither write nor read; also, the individual definition of what gay, hetero or bisexual means has not yet been clearly determined for them."

Christian

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 prostitutes in Dortmund. This step brought the following results:

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[4] SPI 2008

The Bulgarian male prostitutes primarily live in two parts of the city and are relatively insulated from other groups (such as German male prostitutes or other migrant groups).

The housing and living conditions are extremely bad (up to ten boys share one room, one bathroom is used by up to 60 people and hotplates sometimes serve as the sole source of heat).

Very few of the boys could read and write; Turkish and/or Romanesque was spoken at home; Bulgarian was spoken outside of the family; most have very minimal or limited knowledge of German.

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 transmissible diseases.

There is little talk about the risks and dangers within the context of prostitution (such as violence, clients who do not want to pay, clients who do not want to use condoms).

However, there are also resources such as the willingness to help, survival arts, close social contacts between each other and openness towards the project staff member from Neonlicht.

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.

Method

The method of community mapping is a participatory process with 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.

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 become more familiar with the city and the places where they can get help. Two peers from the Bulgarian male prostitute scene were recruited for conducting the community mapping. A flyer was designed that explained what this involved, the steps and roles at the meetings, with the help of drawings (see **www.pakomi.de**).

> **"We illustrated the method in comics. And the boys who are shown in the pictures were very similar to the real boys so that they could see themselves in these pictures. And this was an absolute hit. I handed out this sheet and they sat down together, looked at it and laughed and said 'Ah, you're the one with the glasses and the one with the pad of paper in the hand who is writing everything down…' So it was very clear who would take which role and that these two peers would assume the moderation, that I would stay in the background and actually just unlock the room, perhaps make some coffee, take notes and cooperate with the two peers. They ultimately did the work with the community."**

Christian (Video)

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.

Illustration 19:
Community mapping – first meeting

Illustration 20:
Community mapping – extra meeting

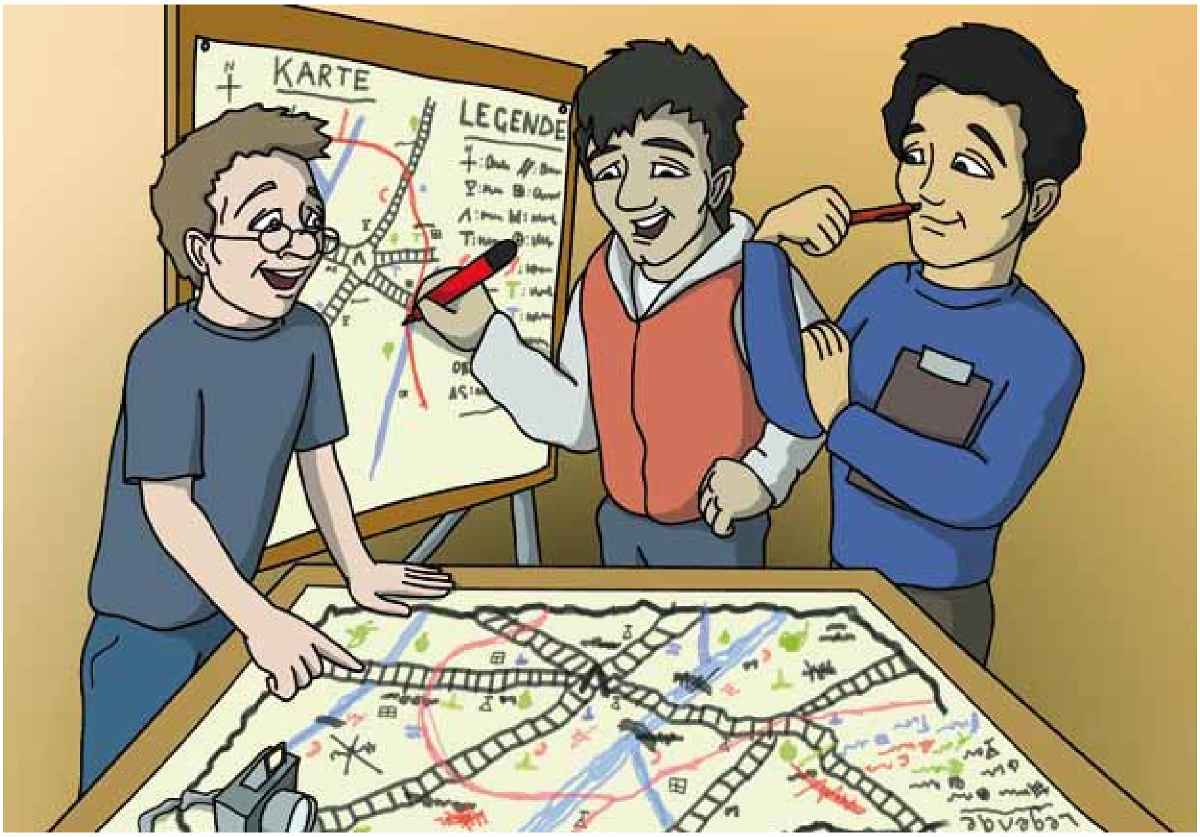

Illustration 21:
Community mapping – 2nd meeting

Illustration 22:
Community mapping – follow-up meeting

The first meeting lasted almost 1.5 hours. The boys drew a map of the city with the places that were important for them in Dortmund ("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 the request of the boys, their faces on the photos were made unrecognisable.

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 had gone well and what had not gone 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 give them information on Dortmund. A total of nine boys participated, which was one more than at 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 which signs should be used or where something was located. This meeting also lasted approximately 1.5 hours. In the end, all of the boys agreed and were also 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, there was a follow-up meeting of the two peers with the project staff member. 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 in only a very restricted 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, it was a confirmation 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. In this respect, their self-confidence was reinforced.

The two peers were positively surprised that PaKoMi had entrusted them with leading the group. It was a big challenge for them to lead a group, but they thought that they “should just try it.” However, they could not imagine taking over the complete direction without accompaniment by the project staff member: “We can’t do that alone … maybe in one or two years?”

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 with and those they were 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, health-care 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.

“This group can now be reached better than before. In addition, the willingness to ask for help has increased. But despite all of this, a great deal must still be done to achieve better reachability. Only the foundations have been laid for this at the moment.”

Christian

Outlook

Unfortunately, this promising development cannot be continued since the basic conditions of the sex work for male prostitutes and the HIV prevention in this environment were fundamentally changed during the evaluation of the case study. A new restricted zone regulation came into effect on 16 May 2011 in Dortmund that makes the use and application of the findings more difficult. This new regulation declares that the overall city area is a restricted zone and thereby prohibits prostitution in public places (also see page 111, sub-project women). The consequences for HIV prevention are very problematic. The politicians believe that the regulation will stop public prostitution. But this is not the case. Public prostitution continues to occur, but the work of the boys in male prostitute bars and parks has now been made illegal. Their work situation has worsened: they earn less, take on bigger risks and have a worse negotiating position for safer sex. Their work area has shifted and expanded, which has made it more difficult for the Neonlicht employee to reach them with his health-care and preventive services.

Cooking with Female Prostitutes Who Work on the Streets (Dortmund)

The second sub-project in the case study in Dortmund focused on Bulgarian women who work in the streetwalking zone. This sub-project was coordinated by the Communications and Counselling Centre for Prostitutes at the Social Services of Catholic Women (KOBER) (Kirsten Cordes) and scientifically accompanied by Hella von Unger (WZB). Three female students with a migration background and Bulgarian and Turkish language skills (Semra, Olja and Ivelina) were substantially involved in the implementation as language professionals, multipliers and peer researchers. During the course of the case study, a concept was developed and tested for cooking evenings in the streetwalking zone as a measure of health promotion and structural HIV prevention. A survey of the prostitutes was conducted after its conclusion.

"PaKoMi is a unique experience for me and a big step in my personal and future professional development."

Semra

Analysis of the Initial Situation On-Site

At the beginning of the case study, the social workers of KOBER explained their work: They described the working conditions in the area of street sex work along Ravensberger Strasse in Dortmund's Nordstadt district, as well as introducing the prevention campaigns together with the employees of the AIDS Organisation at the Counselling Container of KOBER. They conducted research and informally interviewed Bulgarian prostitutes. It became quite clear that these women are very mobile: many have children and family in Bulgaria and travel to Germany for work. During the course of a year, they spend a number of months in Dortmund and a number of months in Bulgaria with their children and family. The group of Bulgarian women has grown since the EU eastward expansion. They live in very restricted circumstances in Dortmund, but these are still good in comparison to the living situation of the region in Bulgaria (Plovdiv), from which most of them come. Like the Bulgarian boys (see above), the women are also largely socially disadvantaged, Turkish- and Romanesque-speaking minorities in Bulgaria. Many of the women could neither read nor write. The women are living and working legally in Germany, but hardly any of them have health insurance protection. They frequently have abortions. The women's diets are very inadequate, and they have almost no recreational activities. Their life in Germany consists of work. They rarely have intensive friendships since the women tend to compete with each other (in the working world). The income is sent to the family in the homeland. There appears to be very little contact with the German women in the streetwalking zone, and there are sometimes arguments and fights. The Bulgarian women remain among themselves, just like the German. The communication with the KOBER Counselling Centre is restricted, but has greatly improved since the employment of a Bulgarian-speaking freelance staff member. In the HIV educational campaign at the container – to which KOBER had invited the AIDS Organisation – it became clear that the women knew very little about female anatomy and sexually transmissible diseases.

"We have determined an urgent need for action. The women were lacking in knowledge about their own body and a consciousness for the necessity of protection and preventive measures."

Ivelina

Goals

Becoming familiar with the target group,

Participatory and cooperative collaboration with the target group,

Creating/promoting a consciousness for health and improving health,

Developing HIV prevention for and with the women.

Method: Cooking Evenings in the Container

In order to become better acquainted with the Bulgarian women, their understanding of health and their needs, as well as simultaneously working with them in a participatory manner, a new measure for the health promotion and structural HIV prevention for prostitutes was developed: cooking evenings at the container in the area of street sex work.

The idea for this arose because the women have bad nutrition and there is a fully functioning kitchen and a large dining table in the container of KOBER in the streetwalking zone. While researching the international bibliography, the social workers discovered that cooking can be used for health promotion especially for women and has been successfully tested in various intercultural contexts – but not yet with sex workers. A project logic was developed in order to plan the cooking events as a health promotion strategy. The resources were determined for the planning stage: there was a container with a kitchen that could be used, language professionals, cooking skills, and so on.

Preparations involved shopping, announcements, and the like. The cooking event in the implementation stage included cooking, eating and cleaning up together. In terms of the intended effects, two aspects were discussed: the immediate outcomes and the longer-term impact. The desired immediate outcomes include the following:

Engaging in conversations, including about their health,

Getting to know each other better,

Building trust,

Eating a healthy and warm meal,

Using the container in a participatory way.

The planned broader impact includes the following:

Promoting the health of the target group in the long term,

Strengthening participation and community-building in the streetwalking zone,

Contributing to structural HIV prevention.

Four cooking evenings were conducted from April to October 2010 (see ill. 23), at which balanced, warm meals were prepared. Different women participated in each of them. The cooking evenings were open to all female sex workers, independent of their migration background, because they were also intended to promote contacts among the women. For their collaboration in the two- to three-hour cooking event with preparation, cooking, setting the table and cleaning up, the women received compensation of €10.

The cooking evenings were documented and evaluated with photos and notes. There were negative experiences in the organisation, preparation, equipment and participation of the women, who sometimes interrupted the cooking when regular clients drove by outside. The positive aspects were the commitment of some of the women who enjoyed participating, the success in the preparation of the meals and the beneficial effect of eating, as well as the conversations and the experience of getting to know each other from a different side and becoming closer. This resulted in friendly contacts among the women who otherwise do not talk with each other or who compete with each other.

"From helplessness to scepticism to a positive surprise: when increasingly more women from the new EU countries, particularly Bulgaria, first appeared at the beginning of 2008 in the Dortmund streetwalking zone, I somehow felt so helpless at first. I am a person who likes to talk and listens well, but these abilities were not useful to me because the women spoke practically no German (and I didn't speak Bulgarian). They clearly signalled that they didn't want to have anything to do with us and just wanted to remain among themselves. There was no smiling as a greeting, no 'hello' and no 'thank you'. Just 'dirty looks' – in my view. I was more than sceptical at the first PaKoMi meeting. 'Participation' and this target group – it seemed to me that there were worlds between them. Through our language professional Olja, I learned that these women and their life-worlds and mine are even further apart I had assumed. On the other hand, I was also curious to learn more about this apparently very foreign world in which they sprinkled sugar over their heads in order not to become pregnant. Torn back and forth between this curiosity and the thought that 'this will never work', I also got involved in the PaKoMi adventure. Now I remember the great moments. When the walls between us fell through laughter and suddenly nothing was left of the foreignness and defensiveness. Now I look back upon the last three years with these women and see that so much has happened. The cooking evenings were a very essential aspect of this development. Anyone who has ever botched pizza together and then bravely ate it with sandwich paper sticking to it will still smile when greeting each other months later. Contact has occurred. Genuine contact.
Cool, isn't it?"

Kirsten

"I've enjoyed seeing how relaxed the women were while cooking and I hope that they take something of the event with them possibly being able to develop a better awareness for themselves, their body and their health. I was pleased that they risked formulating their wishes and I hope that they built more trust in the counselling centre – even if it only involves realising that they are not left alone."

Ivelina

Illustration 23:
Cooking events in the container in the streetwalking zone

Illustration 24:
Interviews at the container in the streetwalking zone

Survey

In the winter of 2010/11, a survey of the women was conducted in order to evaluate the new offer of the cooking events and learn more about their needs. We developed a questionnaire in Bulgarian, German and Turkish for this purpose. This questionnaire was tested at the fourth cooking evening in all three languages (pilot phase). Then the questionnaire was revised: the question and response options were greatly simplified and adjusted to the reality of the women. (One example: "What do you do so you don't get sick?" was asked instead of "What do you do for your health?" Many Bulgarian women did not understand the original question, because they did not understand that their health is related to their behaviour.) A total of 61 women were surveyed at the container (see ill. 24). They received a compensation of €5 for their participation in the interview. The data was input and evaluated using the Grafstat 2 software.

"We interviewed 61 women. We wanted to know whether the women had already participated in the cooking evenings at the counselling container or whether they had already heard about them, what exactly they participated in, how they liked it, and so on. In addition, we wanted to know what the women do for their health, which topics they are interested in and what they need from the KOBER Counselling Centre.... I must say that I imagined this work to be easier, but I underestimated the matter a bit. The problems already started in the pilot phase with the first female interview candidates from Bulgaria. They did not know what I meant with the question 'What do you do for your health?' Even though there were a number of possible responses, the response that I heard most frequently was 'The main thing is that God gives me health!' There were also difficulties with the question of 'Which topics interest you?' Especially when I read them the answer option 'pregnancy' (as a possible topic of interest), I usually got a quick and loud response of "NOOOOO, not pregnant!' I then always had to explain that this was not about whether she was pregnant at the moment or not. But every time I only said the word 'pregnancy', some of the women reacted very loudly in this manner."

Olja

Findings

Among the 61 women who participated in the survey, 58% were Bulgarians, 35% Germans and 7% from Romania or other countries. Of these participants, 13% had participated in the cooking evenings (all of whom enjoyed it), and 70% wanted to participate in the future. In response to the question "What do you do so that you don't become sick?", 98% selected the answer option "I use condoms" and 88% said "I eat fruits and vegetables." For the question "Which topic is important to you?", 88% selected the response "Not becoming infected with HIV/AIDS" and 83% said "Not getting diseases through sex." Other response options were "My rights in Germany" (59%), "Doctor and hospital" (58%), "Taxes" (58%) and "Pregnancy" (53%). To the question "Is there something that you would like from KOBER?", the responses could be open-ended and freely formulated – these included longer opening hours for the container, safer working conditions on the street, more cleanliness and a wider range of services offered in the container (e.g. a bigger selection of snacks, condoms and additional counselling topics).

Concluding Remarks

The Dortmund case study has shown that cooking events are a promising measure for health promotion and structural HIV prevention for prostitutes. Although participation in the cooking events competed with the work interests of the women, the offer was well accepted by some. The positive effects consisted less in the nutritional counselling or in direct changes in behaviour and more in terms of structural prevention: the cooking events have made more community possible, and the women have come to know each other and experienced appreciation. The exchange and communication improved and trust was built, which also applies to the project staff members.

The survey showed that protection against HIV/AIDS is an important topic for the women. The women might have sometimes responded as they believed that it was desired by the social workers. This means that the actual behaviour might not correspond with the stated attitude of protecting themselves. Nevertheless, it is an important finding that the women state that the topic is meaningful to them. The communication problems – which became clear during the pilot phase – are not purely linguistic but show that there is a difference between the life-worlds. The special legal and socio-economic situation of the women (work migration, social marginalisation, illiteracy and lacking health care), as well as the cultural background (e.g. meanings of health), must be taken into appropriate consideration in HIV prevention. The case study showed the women's needs. The target group is particularly marginalised, so that the principles of structural HIV prevention are particularly relevant: it is necessary to include and strengthen the target group and its community, to reduce discrimination and vulnerability to HIV, and to promote protective behaviour not only on the individual level but also on the structural level – that is, within the social context.

"Many of the female sex workers in the area of street sex work still do not know about all of the sexually transmitted diseases, but they know that they exist because we [the multipliers] have spoken about the dangers as part of the PaKoMi campaigns [cooking and interviews]. The moments of happiness experienced by the women during the cooking events at the container should also be appreciated. The short time away from the street, the clients and the entire work stress was very good for some of them. I think that PaKoMi has succeeded in something very meaningful – namely, that many female sex workers surprisingly ask the question, 'Why is she asking us about our health? Why does she want us to talk about well-being and health?' These questions can also be called a milestone because they provide food for thought to many women who never thought about their health up to now."

Semra

Outlook: Limited sustainability due to the new policy regulation

It has not been possible to implement the findings from the case study up to now and the cooking evenings could not be continuously held since the streetwalking zone and the KOBER container were closed in the spring of 2011. As mentioned above, a new restricted zone regulation came into effect on 16/5/2011 in Dortmund, which declared the overall city area as a restricted zone and prostitution in public places illegal as a result. In the run-up, there had already been a public discussion in Dortmund regarding the controversy about the area of street sex work – and about the new group of Bulgarian women who were working there. During the last months, the coverage in the media increasingly stirred up a fear of "foreign infiltration" and xenophobia. It was not always expressed openly, but pictures of the Bulgarian slum near Plovdiv, the Bulgarian prostitutes in the areas of street sex work, and the Roma in Dortmund's Nordstadt district also fed into prejudices against Sinti and Roma. This was accompanied by political activism, which led to new regulation and aggressive action by the regulatory agency/municipal office for public order and police in Nordstadt. This regulation and action took an offensive approach towards prostitutes, young female Bulgarians and women who looked like prostitutes to the officers. The sex work by women was not stopped as a result, but pushed into the illegal realm. Similar to the boys (see page 105), the women's work and life conditions considerably worsened as a result. Their scope of decision-making and options in dealing with pimps and clients became smaller, and the health risks of becoming infected with HIV or another disease increased. This development very clearly shows the importance of a structural prevention approach: when vulnerable groups are socially disadvantaged, it is not enough to try to change their individual behaviour. In order to reduce their socially embedded vulnerability (which actually increased in this case), it is necessary to change the social conditions, eliminate discrimination and strengthen and promote the affected groups (instead of suppressing and ostracising them).

7. Recommendations

on HIV Prevention for and with Migrants

Preliminary Remarks

Independent of their cultural background, all people who live in Germany should have the same access to information, prevention, counselling and care – this is the goal of the German government, as it clearly formulated it in 2007 in the action plan of implementing the strategy for fighting HIV/AIDS. In order to achieve this, various "building blocks" were suggested. These include conducting studies on the attitudes, types of behaviours and living conditions of migrants as the basis for developing education material for them.

By the year 2011, some of these building blocks have been translated into action – at least in part – also within the scope of the PaKoMi project (Participation and Cooperation in HIV Prevention with Migrants).[1] However, the main goal has not yet been achieved: many people with a migration background still do not have the same access to information, prevention, counselling and care as people without a migration background. There are still barriers in terms of language, legal, structural and cultural factors.

Yet the results of the PaKoMi project are encouraging: they show that a key to success lies in the improved cooperation and – above all – the strengthened participation of migrants and migrant self-organisations (MSOs) in the development, implementation and research of HIV prevention. Thus, the idea is to provide HIV prevention not only for migrants but with them. Once members of the target groups and the communities are "on board", no group remains "hard to reach". If life-world experts are included, then the local, language and cultural knowledge can be integrated. This is necessary in order to develop the appropriate HIV prevention for and with the various migrant groups. If communities are supported in organising themselves, mobilising their resources and articulating their needs, many people will learn and profit from it – not only in HIV prevention but far beyond.

The present recommendations were developed in the PaKoMi project: they are based on the findings of the research project and were refined, supplemented and validated over the course of three participatory workshops with our partners from the service providers and migrant communities. Between the workshops, the project advisory board and additional policy experts were included in order to make the recommendations compatible to the respective fields. The recommendations are intended to help strengthen participation and cooperation and improve HIV prevention for and with migrants.

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[1] PaKoMi is a project of Deutsche AIDS-Hilfe e.V. and the Social Science Research Center Berlin (WZB) and was conducted with local partners in four cities (Berlin, Hamburg, Dortmund and Osnabrück) from 2008–2011. The study received support from the Federal Ministry of Health (BMG).

To Whom Are the Recommendations Addressed?

The recommendations are directed towards the stakeholders in politics, prevention practice, the communities and science who contribute to the (further) development of HIV prevention for and with migrants in Germany. Organised according to areas, the addressees are the following:

Politics

National level:
German government (Ministries of Health, Labour and Social Affairs, Justice, the Interior, etc.)

Additional partners on the federal level (e.g. parties, politicians, Bundestag)

State level:
State governments and the corresponding ministries, state politicians

Municipalities:
Communal politicians

Preventive Practice

Federal level:
Federal Centres for Health Education (BZgA)

Deutsche AIDS-Hilfe e.V. (DAH) (umbrella organisation for the AIDS service organisations)

Additional players on the federal level

State level:
State associations, state branch offices (health, HIV/AIDS)

Additional players in the states

Municipalities:
AIDS service organisations, prevention projects

Public health authorities, counselling centres, etc.

Additional players in the municipalities (health and social services)

Communities

Migrant self-organisations (MSO)

Communities to which the migrants belong

Religious communities, associations, persons and groups with a migration background

Science

Universities, academies, research institutes

Robert Koch Institute

Professional societies (such as the German AIDS Society)

Scientists, networks and associations

Additional players

Foundations, organisations (e.g. Deutsche AIDS Stiftung)

Committees with advisory function (e.g. National AIDS Advisory Council)

Overview of the Recommendations

1. Create the preconditions: Promote equality and diversity

Open social structures in order to enable the full participation of migrants

Overcome legal discrimination

Recognise educational degrees and occupational certifications from the countries of origin

Appreciate cultural diversity

2. Make participation possible: Strengthen participation of migrants in HIV prevention

Advance the intercultural opening of the facilities

Make resources available for participation

Make equal access to advanced training and supervision possible

Avoid sham participation

3. Strengthen communities of migrants (*community-building*)

Develop and strengthen communities, promote self-organisation

Promote the networking of migrants: local, national and international

Overcoming taboos, HIV/AIDS stigma and discrimination of people with HIV/AIDS

4. Strengthen cooperation on the communal level

Improve cooperation through political leadership and guidance

Develop local action plans with binding criteria of HIV prevention for migrants

Expand cooperation with migrant self-organisations (MSOs)

Design the cooperation in a reflective and productive manner

5. Further develop concepts and HIV prevention services

Integrate HIV prevention into a broad concept of health promotion

Change behaviour and circumstances (structural prevention)

Take diversity into consideration (diversity approach)

Report epidemiologic and health data on migrants in a more differentiated manner

6. Promote participatory research

Establish participatory research more strongly in Germany

Design all stages of the research processes together

Make it possible for migrants to participate in research

Institutionalise interfaces between science, practice and communities

Practise (self-)reflexivity in migration research

Recommendations

1. Create the preconditions: Promote equality and diversity

Open up social structures in order to enable full participation of migrants

The participation of migrants in HIV prevention is associated with the participation of migrants in other areas of society. Only when the various migrant groups have the same access to the educational system, employment market, political decisions and other areas of social life as people without a migration background can they also collaborate in designing and enriching health care and HIV prevention to the full extent. Opening up social structures and participating in them also means sensitising the specialists for the professional approach to sociocultural variety and diversity in the population. This is also related to the intercultural opening of the regulated services (see below).

Overcome legal discrimination

This means protecting the human rights of refugees and other migrants, as well as overcoming the various forms of legal discrimination that exist in Germany such as restrictions in the permission to live and work here, restrictions of mobility due to the residency obligation in the asylum procedure and restricted access to the health-care system – particularly for people without papers. Because of their fear of deportation, HIV-positive migrants without a secure residence status often only go to the doctor when opportunistic infections have already occurred. This has a negative effect on the treatment possibilities, quality of life and HIV prevention. An uncertain residence status can also intensify HIV vulnerability. When people are dependent on sexual relationships (e.g. sex work or marriage and pregnancy) in order secure their existence, safer sex is not a top priority, and they are limited in their capability to negotiate and assert their wish for safer sex.

HIV testing without the appropriate counselling and consent of the affected people – as it is practised in Bavaria and Saxony within the scope of the asylum procedure – injures the personal rights of asylum-seekers and causes great harm (also for the HIV prevention). This approach should be eliminated.

Recognise the educational degrees and professional qualifications from the countries of origins

Many skills, educational degrees and professional qualifications of migrants are not recognised in Germany. As a result, individual careers are hindered and socially relevant resources and competences are wasted. The knowledge and abilities of migrants are also significant in HIV prevention. These must be identified, recognised and promoted. For example, there should be a legal regulation for recognising the qualifications that have been acquired in other countries (such as doctor, caregiver, psychologist and social workers when hiring salaried employees and in the awarding of service and freelance contracts).

Appreciate cultural diversity

Migrants are often depicted in a one-sided and negative way in Germany due to political discussions and their presentation in the media (e.g. as a danger or burden for the German society). More balanced and differentiated reporting, with more positive images of migrants should be presented. Cultural diversity should basically be depicted as a normality and gain for German society – also for the employment market. Organisations that produce educational materials (such as BZgA and DAH) should more strongly consider cultural diversity and examine their measures and media to see whether they include clichés, stereotypes and omissions in the depiction of migrants. Prevention and health promotion should use positive and inclusive pictures of migrants. For example, more respected persons of public life with a migration background (such as politicians, football stars or musicians) could be recruited as role models for HIV prevention.

2. Make participation possible: Strengthen participation of migrants in HIV prevention

Advance the "Interkulturelle Öffnung"

The "Interkulturelle Öffnung" (intercultural opening) (IKÖ) of health and social services organisations, including AIDS service Organisations and other facilities, is a necessary foundation for the participation of migrants. Many organisations have already begun with the process of IKÖ, but it is important to take it further. This is the only way that migrants receive the same access to the health-care system and same quality of health care as people without a migration background. In order to secure access to health care and the quality of services, the IKÖ comprises the corresponding goal formulations, standards and measures. These include, among other things:

The hiring of salaried employees with a migration background,

Appropriate payment and compensation for the collaboration of migrants on a voluntary basis, as multipliers, health-care interpreters, language mediators, cultural mediators, and related positions.

The provision of multilingual services (in writing and verbally),

Networking and cooperation of organisations, providers and MSOs,

Diversity trainings and intercultural/transcultural trainings for the employees,

Recognition and further development of the competences of migrants.

Making resources available for participation

Successful HIV prevention *for* migrants is also prevention *with* migrants. The PaKoMi project has shown that the participation of migrants – even strongly marginalised groups – is possible. However, resources must be made available for this purpose. In general, more persons with a migration background should be employed in salaried positions. This increases the chances of more migrants becoming involved in the various stages of participation. Job requirements should also include knowledge and competences that are related to the language and life-worlds of migrants. For some jobs in the area of HIV prevention, these are at least as important as formal degrees.

Migrant groups and communities that have a special need in HIV prevention are frequently socioeconomically disadvantaged and their access to the German job market is restricted. Many of these persons live on the poverty line. This must be taken into consideration when migrants from these communities are included as volunteers. This is why expenses must be compensated (e.g. travel, material and subsistence expenditures) and small fees and honoraria should be paid whenever possible for the fulfilment of certain jobs (e.g. events in the communities, seminars). Reimbursements and honoraria are a sign of appreciation, but they also are simply necessary in many cases. Without them, many migrants could not become involved. The payment of expense reimbursements and honoraria must be transparent and comprehensible.

Public sponsors should require that grant recipients specifically hire persons with a migration background and/or ethnic minorities and also make this possible. An example of the impact that resources can have is shown by the case study in Hamburg: through the hiring of a salaried employee with an African migration background at the AIDS service organisation, a quantum leap in the participation of African migrants in HIV prevention became possible. The employee is financed in part by resources from the Agency for Health and Consumer Protection, as well as the AIDS service organisation. Through his employment, his anchoring in an ethnic community, his active outreach to other African communities and his close cooperation with an experienced German female colleague in the AIDS service organisation, the prevention services for and with African migrants have been considerably improved.

Enable equal access to advanced trainings and supervision

In service provision, there is frequently the problem that migrants are involved as volunteers or part-time employees (such as language professionals hired on a fee basis), who do not have equal access to advanced trainings and supervision as paid staff. This means that precisely the individuals who are closest to the stories of hardship of the clients only receive restricted advanced training and support due to their status. This problem must be solved both on the local level in the facilities and on a national level, such as through DAH's continued and advanced training offers. Participants in the PaKoMi project have made it clear that there is a need for a national "service station" where they can be bolstered and find backing for their often difficult work through offers of mutual support, networking, seminars, counselling and mediation.

Avoid sham participation

If migrants are included in HIV prevention as salaried staff, volunteer employees, on a fee basis, as cooperation partners, key persons or consultants, they must be involved in finding the appropriate stage of participation for them (see Stage Model, Chapter 3). Sham participation – that is, supposed participation without having a say in the decision-making – should be avoided under all circumstances! It was clear in the PaKoMi project that sham participation is an essential obstacle for participation in HIV prevention from the migrants' perspective: migrants are frequently permitted to participate in projects by the AIDS service organisations and other facilities, but are not given any voice in the decision-making process. Voice and decision-making power are necessary components of true participation. As a result, here is a recommendation to migrants and MSO: Be sceptical, ask questions, and in the event of sham participation, don't get involved!

3. Strengthen communities of migrants (*community-building*)

Develop and strengthen communities, promote self-organisation

Communities and migrant self-organisations (MSO) are important partners for improving the participation of migrants in German society and HIV prevention. Communities are not isolated units but collectives that continuously develop, also in the dialogue with the society and other communities. Communities can be formed on the basis of an ethnic affiliation, but many migrants also belong to communities in which other characteristics are decisive (e.g. academic studies, sport, religion). The self-organisation of migrants (in associations, for example) is important in order to identify needs, mobilise resources and improve one's own situation. Communities are not always available, but must sometimes also be created. The founding of an MSO can be part of a strategy for strengthening a community.

Communities thrive on the involvement of their members. Such involvement is promoted by having meeting places, common goals and actions, trained volunteers, gender-specific services and compensation (which also may take a non-material form, such as childcare), the building of trust (communication within the community), conflict training and – when necessary – the acceptance of help and support from the outside (such as mediation). In order to be in a position to act, communities need persons who are willing to assume certain tasks and responsibilities, such as spokespersons and supporters in social advocacy and political representation. These persons should be appointed or elected for a limited period of time.

Support the networking of migrants: locally, nationally and internationally

It is important to enable various forms of networking, information exchange and sharing of experiences both within and between the communities. There are various projects in Germany by migrants who are active in HIV prevention and health promotion. However, these are not adequately known and connected with each other. Networking must be promoted on all levels: in the individual communities, between communities, on the communal level, on the state level, nationally and also internationally. A great potential has not yet been fully utilised: existing resources can be used, and the members of the communities can learn from each other and mutually support each other. Within the PaKoMi project, African community partners expressed the need to establish a national network of African groups and organisations in the area of HIV prevention (complementing the existing self-help network of Afroleben+). Such a network should be supported by Deutsche AIDS-Hilfe e.V. (DAH), for example.

In addition, we recommend international networking and cooperation with partners from the African countries of origin. HIV prevention in Germany would benefit from this in many respects: certain approaches to prevention have been further developed in the countries of origin (e.g. the use of cultural/creative forms of expression and the commitment of religious leaders in the fight against HIV/AIDS); prevention concepts, materials, strategies and measures could be exchanged and effective, culturally sensitive approaches do not always have to be reinvented from scratch. The case studies in Hamburg and Osnabrück have shown how strong the interest in the topic of HIV/AIDS is among African migrants, especially when it is not treated in isolation but in connection with the situation in their homeland countries.

Overcoming taboos, HIV/AIDS stigma and discrimination against people with HIV/AIDS

Taboos and HIV stigma exist in many communities. This makes it more difficult to deal with the illness and hinders HIV prevention. Migrants who live with HIV/AIDS rarely have the courage to openly speak about their HIV status in their communities. In order to change this and facilitate the conversation about HIV/AIDS, campaigns and actions should be conducted to help reduce the stigma, taboos and discrimination. For example, it is it very helpful when respected key persons (such as doctors, politicians, imams, priests, ministers, musicians, celebrities) show solidarity and support for people with HIV/AIDS, as well as HIV prevention. The survey conducted in the case study in Hamburg has shown that a majority of the Africans surveyed there would support a person with HIV/AIDS. This potential must be utilised; for example, by integrating religious leaders into the fight against the stigma.

4. Strengthen cooperation on the communal level

Improve the cooperation through political leadership and guidance

In many municipalities, the responsibilities are not clearly defined and there is a lack of political leadership as well as incentives for cooperation. Providers and facilities thus compete for the responsibilities and limited resources. This is an obstacle to cooperation in HIV prevention for and with migrants. Incentives for cooperation must be created, such as financial resources for cooperation projects and networking. The political and professional guidance through the respective authorities, departments or state associations can be very effective when they bring the stakeholders to the table and search for solutions together – even without additional financial resources.

The working group on HIV/AIDS Prevention with Migrants in Berlin as well as the working group for Migration and Health (AMIGES) in Hamburg show that if networks are politically desired and support, they work. Furthermore, the Berlin case study has shown that assignments can be given to the MSO in order to fulfil certain tasks in the communities and enable cooperation with them.

Develop local action plans with binding criteria for HIV prevention for migrants

There is often no consensus in the municipalities regarding how HIV prevention for and with migrants should be designed. A jointly developed action plan with binding and verifiable criteria would be helpful in this case. Such an action plan defines the locally appropriate goals, quality criteria and standards for the “Interkulturelle Öffnung” (intercultural opening) and HIV prevention for and with migrants. For example, it can stipulated that the proportion of persons with a migration background among the paid staff should be as high as the proportion of migrants among the population in the catchment area and/or the target group. The forms of participation that migrants will assume (voluntary, marginal employment on a fee basis, part-time employment or full-time employment) and how each of these will be remunerated could also be clarified. The various stakeholders – and especially the representatives of migrant communities – should be involved (with decision-making power) in the development of such action plans. The initiative should come from the responsible agencies or state associations, which must play a central role in the coordination. Minimum standards should also be jointly established on the national level.

Expand cooperation with migrant self-organisations (MSOs)

Cooperation between those who provide HIV prevention strategies and initiatives (e.g. AIDS service organisations, prevention projects, public health authorities) with migrant self-organisations (MSOs) and key persons and peers from the communities are absolutely necessary. They provide access to the communities and make it possible to activate resources and concentrate expertise in order to develop effective health promotion and HIV prevention. Such cooperation is also advantageous for the migrants and the MSO. However, the cooperation must be feasible in terms of content, organisation and financing (e.g. through actively approaching each other, political supervision, low-threshold services, a willingness to discuss and cooperate on all sides, and the provision of resources).

The cooperation can assume various forms, such as the joint planning and conducting of events and projects, exchanges and networking, mutual counselling, referral of inquiries and persons, and training/qualification of key persons. In this process, the AIDS service organisations and other facilities offering prevention in practice should not restrict their services solely to the area of HIV/AIDS, but rather be more open to other concerns of the communities. MSOs should develop their own projects and initiatives and offer the AIDS service organisations and other stakeholders participation in them. In terms of the cooperation, attention should be paid to finding the respectively appropriate level of participation for everyone involved.

Design the cooperation in a reflective and productive way

A mutual decision (on an equal basis) should be made as to which form of inclusion and which level of involvement by the respective participants is desired and considered to be appropriate in the cooperation of persons with and without a migration background. In addition, it is helpful to practise the following in the cooperation:

Concentrate on the common factors and mutual goals

Cultivate openness for various ways of working and different mindsets

Reflect on and overcome fears such as those of "the unknown/the foreign" and the possible negative consequences of the commitments

Use humour and irony (without ridiculing anyone)

Build trust through mutual activities

Create transparency and communicate about the rules of the cooperation

Use conflicts productively because the participatory process is often accompanied by conflicts that – when they are openly addressed – represent an opportunity to understand problems and improve the cooperation.

Cooperation is promoted when the participants develop an awareness of their own positions (e.g. their privileges as Germans or their various positions within the communities); avoid culturalisation/ethnicisation, pigeon-holing and generalisations; become sensitised to sociocultural aspects of the language used (e.g. using simple German, providing multilingual services and translations, approaching the topic slowly when talking about HIV) and, above all, listening to each other.

5. Further develop concepts and HIV prevention services

Integrate HIV prevention into a broader concept of health promotion

We recommend embedding HIV prevention services for and with migrants into a broader concept of health promotion. HIV/AIDS is generally not the only or the most important health concern of the communities. The chance of sparking interest and starting a conversation is greater when the main concern is promoting the well-being of migrants – in relation to HIV/AIDS and beyond. A topical embedding of HIV prevention in health promotion, women's health, young people's health, pregnancy counselling and information on access to the health-care system can be helpful. In the practical, personal communication prevention work, sensitive topics such as HIV/AIDS should be addressed in an appropriate form. What is appropriate depends on the situation, the context and the participating persons. It is important in this process to find a balance between respectful communication and the overcoming of taboos. A culturally appropriate approach should not contribute to silence and stigmatisation; instead, it should make it possible to talk about HIV and eliminate the stigma in relation to HIV.

Change behaviour and circumstances (structural prevention)

The approach of structural prevention, which has been developed by the DAH, should also be applied in the prevention for and with migrants. This means that the facilities and their umbrella organisations (such as Deutsche AIDS-Hilfe e.V.) must intensify their efforts for a change in the social circumstances that influence the HIV risks and protective behaviour. Prevention services and measures that do not take the social context of individual behaviour into consideration can be ineffective. The case study in Dortmund has shown how structural conditions can produce and intensify vulnerability (in relation to HIV/AIDS). In Dortmund, the overall city area was declared a restricted zone, which means that prostitution was prohibited in public places in the spring of 2011. This measure was the result of a political climate and public discussion characterised by reservations against prostitution and the fear of foreign infiltration, especially with respect to persons from Bulgaria who have become increasingly active in sex work in Dortmund since the EU eastward expansion of recent years. From the perspective of HIV prevention, the measures and their effects are very problematic. Public prostitution was not stopped but suppressed into illegality as a result. Public prostitution continues to occur, but the working situation of male and female prostitutes has dramatically deteriorated: they earn less, experience greater risks and have a worse negotiating position for safer sex (e.g. they now get into the clients' cars more quickly and negotiate the conditions later). Their scope of decision-making and options in dealing with the clients (and pimps) have decreased, and the risks of becoming infected with HIV or other diseases have increased. Their work area has expanded and shifted, and they have become more difficult to reach with health and preventive services. The promising findings of the PaKoMi case study (community mapping and cooking evenings, see Chapter 6) cannot be implemented in a sustainable way. This example demonstrates the importance of the concept of structural prevention: when groups are socially disadvantaged, just attempting to change their individual behaviour is not enough. In order to reduce their structurally produced vulnerability (which was actually increased in this case), the social circumstances must be changed, discrimination eliminated and the affected groups strengthened and included (instead of suppressed and excluded).

Consider diversity (diversity approach)

It is necessary to appropriately consider the diversity of the population according to gender, age, sexual identity, and ethnicity/migration background in all target groups and also among the migrants when it comes to prevention. There is a major variance among migrants in terms of socio-economic characteristics (legal status, education, income, etc.), languages, living environments and HIV risks. In terms of the various migrant groups, this means that clarity must be achieved with regards to which group may have a special need. At the same time, the ethnic and cultural diversity of the population (as an aspect of the diversity approach) must be considered in all areas of prevention work, which also means in prevention for the general population, prevention for men who have sex with men (MSM), sex workers, and others.

Report epidemiologic and health data on migrants in a more differentiated manner

We need improved reporting on the health of migrants and ethnic minorities in Germany in order to be able to better plan preventive measures and services. In the process, the categories should be developed with caution, definitions should be clarified and – as much as possible – standardised to make the findings comparable. Since the various groups with a migration background are very different, it is helpful to not just differentiate between persons with and without a migration background but also form additional subgroups. For example, the latest HIV/AIDS data in the reporting by the Robert Koch Institute should be evaluated (for all groups) on a regular basis according to the regions of origin and infection in order to also make the migrants who do not come from high-prevalence countries visible.

6. Promote participatory research

Establish participatory research in Germany

Participatory research makes it possible to bring together experts from the communities, service provision practice and science in order to better understand problems and develop solutions. PaKoMi has shown that such cooperation can be rewarding for all participants. On the basis of participatory research, we can better understand the living environments, strengthen the target groups and communities and tailor HIV prevention to their needs and resources. This approach is especially suitable for issues in which there is a need for action and for working with marginalised groups that are more difficult to reach with other forms of research.

Internationally, participatory research is more widespread and better funded than in Germany (for example, under the terms of community-based participatory research in the USA and integrated knowledge translation in Canada). The possibilities of participatory research should also be used more intensely in Germany, particularly in the area of health. Participatory approaches to research should also be intensified and applied in science. Grant donors should provide more financing for participatory research.

Jointly design all phases of the research process

Target groups, communities and other stakeholders in the health-care system should be involved in the research process as equals as early as possible; in the best case, this should be from the very beginning. This means that community and practice partners are involved on an equal basis from setting the goal and selecting the method in the planning phase to implementing and evaluating to utilising the research results. However, true participation requires time and must be made possible and developed. Realising participation on the various stages and combining different stages with each other is helpful and feasible: for example, individual community partners can participate at a high level, and a large number of community members can be involved at a lower level, such as through surveys. This was realised in the case studies. This strategy makes it possible to take into consideration the diversity of the perspectives and interests within the communities and it supports the community representatives in their representation function. Participation is a dynamic process with various nuances. The expectations of participation (and not just involvement) of community and practice partners should not be set too low; they should also be realised as quickly as possible. Questions on the decision-making power and participation of the individual partners should be continuously reflected upon and clarified in the cooperation from the beginning on. A division of labour can be used in the activities of practical research and development, but important decisions should be reached jointly during all of the stages.

Enabling participation of migrants in research

More people with a migration background should be employed in science, as well as in leadership functions. In order to increase the proportion of people with a migration background, positive measures for the promotion of migrants in science should be stimulated (such as the introduction of a quota at universities). In addition, it is important to recognise academic achievements and degrees obtained in other countries, to give scholarships to migrants and to eliminate discrimination against migrants in employment.

The potential of peer research should be appreciated and more community members trained as peer researchers (see Chapter 6). Resources such as jobs, honoraria and expense reimbursements must be made available. The idea of participatory research is to develop research on the causes of health problems and strategies for action in and with the communities. The empowerment and capacity-building of the participants are vital in this process and must be made possible through trainings, co-determination and assignment of tasks, etc.

Institutionalise interfaces between science, practice and communities

In order to enable the long-term use of the potentials of participatory research and practice development, it would be helpful to build an infrastructure. This can be supported by stakeholders from the various areas in participatory research programmes and make it possible to plan and conduct joint projects. It is often difficult for partners from the communities, practice and science to find each other, which is why an interface must be created or expanded. It would be helpful to have a point of contact that makes an exchange and dialogue possible, as well as a mutual agreement on topics and the setting of goals. In addition, it should provide services and training offers such as peer researcher trainings for community and practice partners, trainings on intercultural/transcultural cooperation and seminars for scientists. For the participatory research, they require special social and communicative competences such as techniques of moderation, conflict management and mediation; flexibility and the ability to express circumstances and methods in such a way that they can also be understood by non-scientists. Advanced trainings are necessary in order to (further) develop these competences.

Such an interface could also support communities in determining their own concerns for research projects. In the PaKoMi project, the community partners have articulated interest in the following comprehensive topics, which should be researched on a participatory basis:

Migrants in health care,

Racism in the health-care system,

Living environments, life situations and health-related needs of various migrant groups,

HIV stigma and taboos in the communities,

Strategies for dealing with HIV/AIDS and other diseases in the communities and

Evaluation of peer approaches in prevention.

Research on these topics should not just focus on the difficulties, but also examine the resources and successes.

More (self-)reflection in migration research

Scientists should engage in critical self-reflection not just in the participatory research but also in migration research in general: Who is researching whom? Who is listened to? Who is not? Who is reached and represented with which research approaches? Who remains excluded? Which influence does my own positioning and perspective have on the research? The entanglement in social power dynamics (such as racism) should be questioned in a reflective and critical manner. Scientists should actively ask for feedback and criticism – also from the persons and organisations through or with which they research.

8. The PaKoMi Video

In the PaKoMi project, a video (23 min.) was produced in which the various partners explain what PaKoMi is and what it means for them personally. The video contains German, English and French contributions. There is a German and an English version. The video can be viewed and downloaded for free from the PaKoMi website (www.pakomi.de).

The video is oriented towards those who are interested in participation processes – especially those involving migrants – in HIV prevention, research and beyond. Above all, it addresses the professionals of HIV prevention and health promotion, members and representatives of the migrant communities and migrant self-organisations (MSOs), as well as persons who are interested in participatory research such as students and researchers.

The intention of the video is to communicate the project results in a lively way. The focus is on the experience and perception that the participation of migrants in HIV prevention and research is possible and an asset. The main emphasis here is less the concrete project results, which are extensively depicted in other publications and also in this handbook (Chapter 6), but on the “soft” findings – the processes of cooperation and their benefit from the perspectives of the participants. The strengths of PaKoMi are the various people and organisations that have worked together – they receive a voice and a face through the video.

Participation is always a risk: we never know whether it will work and what the results will be. In many cases, this includes conflicts and tensions. Cooperation is not always simple, even in the PaKoMi project. Things “got stormy” in some places: in the case studies, workshops and communication between the meetings – even the production of the video had its share of conflicts. We were ultimately successful because all of the partners approached each other time and again and made an active effort of communicating, understanding and compromising. At the end of almost three years of cooperation, we all agree: It was worth the effort. We want to use the video to encourage others to do the same and take the risk of participatory cooperation.

How the PaKoMi Video Was Created

The idea for the video came about in the middle of the project in March 2010. The case studies and workshops had started some months earlier, and the great potential of the participants and the cooperation was becoming apparent. As part of the Network for Participatory Health Research, a Canadian colleague (Brenda Roche, Wellesley Institute) visited the WZB and held a workshop on the topic of peer research. She showed a video in which peer researchers from Toronto explained what peer research is.[1] They had participated in various projects of health research such as a study with the homeless, with refugees and with drug-users. They were also members of the respective communities who had been trained as peer researchers and were now reporting in retrospect on their experiences. The video is in English, it was sometimes difficult to understand (especially for non-native speakers) and had technical weaknesses. Yet we were enthused by the idea, the authenticity of the statements and the diversity of the people who were presented and their situations in life. So we got the idea: we also wanted to make a video!

We (WZB and DAH) obviously could not make the decision on our own because our community and practice partners also had a word to say about it: they agreed to the idea – with some reservations at first, but the enthusiasm grew over time. The project advisory council welcomed the idea, and the majority of the participants in the case studies and workshops were open to it. However, many people were unsure whether they wanted to personally appear in front of the camera because hardly anyone had prior experience with it. Furthermore, the written statement of consent with which the image rights were transferred to the DAH had raised some insecurities at first.

We assigned the tasks and responsibilities: Tanja Gangarova (DAH) provided the resources and made the ultimate decisions in consultation with Hella von Unger (WZB); Karin Schwickerath (WZB) assumed the coordination of the videos and the majority of the filming. We needed professional support for the editing and awarded a service contract to Petra Sattler.

The community and practice partners were involved in the overall process: in the concept development (for example, they exerted their influence in that the video should also be addressed to the communities), in the shooting of scenes and interviews (for example, they could decide which questions to ask and answer) to the revising and fine editing. Here is a brief overview of the development in terms of time:

05/2010 Presentation of the idea
(Workshop 3 on Project Planning)

09/2010 First filming of the group
at the bridge-building simulation
(Workshop 4 on Intercultural Communication and Cooperation)

12/2010 First interview filming in teams
and small groups
(Workshop 5 on Peer Research)

02/2011 Discussion and feedback on first raw version
(rough cut) and further interview shooting
(Workshop on Participatory Analysis and Recommendations No 1)

04/2011 Discussion and feedback on the first version
of the video
(Workshop on Participatory Analysis and Recommendations No 2)

05/2011 Presentation of the final version
(German and English)
(Workshop on Participatory Analysis and Recommendations No 3)

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[1] Toronto Community-Based Research Network 2010

"For me personally, the overall process of the video production – from the design of the concept to several feedback loops to the fine cut of the video – was very exciting and instructive on various levels. Working in a participatory manner from the beginning to the end on the video was sometimes a true challenge. It often meant finding a compromise between a number of different positions and doing justice to as many wishes and ideas as possible. Sometimes this cost a great deal of time and patience and demanded the constant willingness to once again abandon one's own concept and stay open for new suggestions. But we only reached our original goal for the video – showing that participation can work! – because so many participants contributed their opinions, ideas and experiences in the feedback loops and shared their comments in front of the camera."

Karin

The Charm of the Non-Professional

The video was not originally planned, but it serves as a utilisation strategy that has developed over the course of the project. The available resources were very limited. We had to improvise a great deal and continually learn in the process. For most of participants, making a video was a new experience. We had to first learn how to set up the equipment, produce usable material and talk in front of the running camera without looking like frightened rabbits. When we looked at the first raw version as a group, the unanimous opinion of the community partners was: "That needs to be more relaxed! The friendly, cheerful mood that characterises PaKoMi must come across better!" On the basis of this maxim, we did more recording and included more photos in which smiling faces could also be seen.

We used a private digital camera, but it produced an unusual format (.mov). This brought more technical difficulties with it. The final result was a product that far from meets professional standards. But it does a good job of reflecting the essential aspects of PaKoMi: the diversity of the people who participated, the various ways of approaching the cooperation, the learning processes at the workshops and in the on-site case studies. And above all, the intensive form of the cooperation that the participants often found very enjoyable. Like so many things in PaKoMi, the production of the videos was also a challenge and a learning experience that has not been completed. If someone is open to it, even the weaknesses that the video undoubtedly has (lacking translations, subtitles that are not uniform, lengthy passages, etc.) can be seen in a different light. The important element is not just the final product but also the process that is behind it and has led to it. And this is distinguished especially by the development, the learning and the unfinished elements. With more time and money, the product would certainly have been even better. But we believe that the product is also mature enough in this form to present it to the public. What is essential will be visible – at least this is what we hope.[2]

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[2] Since then shorter and revised versions of the video have been produced (**www.pakomi.de**).

What Is Said?

The following text reproduces the contents of the video. The English and French contributions were translated into German and English. The language of some quotes was slight revised in order to increase their readability. We have stayed as close to what was actually said as possible in order to maintain the authenticity and the liveliness of the spoken words.

"PaKoMi is a very interesting platform for me, especially for participation and cooperation in HIV prevention for and with migrants. I feel very at home here. And there is also a large linking with other communities, which is very interesting and colourful."

Steve Fotso Ouoguep (PaKoMi Hamburg)

"PaKoMi is like a dream come true to me. I have always wanted to do something with African migrants in Osnabrück and PaKoMi has opened a door for me."

Ruth Kalinga Kimolo-Lentsch (PaKoMi Osnabrück)

PaKoMi: Participation, Cooperation, and Migration
Learning from Each Other for HIV Prevention

Every third, new HIV diagnosis in Germany affects a person who has immigrated. In order to develop HIV prevention together with migrants, we also need participatory research. PaKoMi is a project of Deutsche AIDS-Hilfe e.V.; it receives scientific project support and supervision from the Social Science Research Center Berlin. In addition to organisations that offer HIV prevention, partners from African, Turkish, Bulgarian and Russian communities are involved.
(Speaker from off-screen: **Karin Schwickerath**)

"PaKoMi stands for participation and cooperation in HIV prevention with migrants in Germany. Our PaKoMi project has the goal of promoting and scientifically studying the participatory development of HIV prevention for people with a migration background from vulnerable groups."

Tanja Gangarova (DAH)

Pictures of participants in the PaKoMi Workshop 4 for Building Intercultural Bridges

"The idea of PaKoMi is quite simple. Various people work together and contribute their respective expertise. These are, first and foremost, persons from the target groups and communities with a migration background, the professional practitioners of HIV prevention and we scientists. We work together, explore the life-worlds and needs of the migrants, strengthen the participation of the migrants and develop HIV prevention together."

Hella von Unger (WZB)

"… And this is what really fascinates me because it is what the DAH stands for and what the overall work in the area of HIV/AIDS stands for – namely, designing prevention in all of its dimensions not for the people and forcing it on the people but working together with the people."

Silke Klumb (DAH)

"The special thing about PaKoMi for me is that we as people with a migration background… consider ourselves to be a resource with our multilingual abilities. This can be used for prevention in our own community, which is important to me. It is important that we also recognise our values and use them for a good purpose."

Melike Yildiz (PaKoMi Project Advisory Council)

"The abilities and skills of the target groups and the communities are activated and supported during the process. Their expertise on their living environments, language and also culture flows directly into the work."

Tanja Gangarova (DAH)

"The special thing about PaKoMi is that it is participatory health research in which people are involved on-site – and not just the practitioners but people directly from the communities who are involved with the topic. This is not common in Germany, even though there are many good international examples. This was really an opportunity to demonstrate that something like this is possible in Germany and that studies of this type really bring results for the further development of prevention, which is HIV prevention in this case."

Michael T. Wright (WZB)

"I do believe that many people of my generation – but unfortunately also many people who are much younger – here in Germany have an image of 'Those who are educated and who have something to say are German.' And suddenly there are people from every possible country who have just as much to say and who perhaps can say even more because they are on a completely different level with what they do and with the people with whom they work. Also that there is immediately completely different access: when I am of Turkish origin, then I may have different access to Turkish migrants in Germany than I would have as an ordinary German."

Stefan Schröder (PaKoMi Berlin)

"PaKoMi? I understand the acronym of PaKoMi to mean participatory research. This allows us to further promote the involvement of the participants. And PaKoMi is also a concept for me that gives people the opportunity to also participate and make decisions. And this is very interesting."

Omer Ouedraogo (PaKoMi Hamburg)

There were case studies in four cities. In the beginning, the partners – which were the AIDS organisations, the counselling centres and public health authorities – and persons from the target groups and communities with a migration background were invited.
(Speaker from off-screen: **Karin Schwickerath**)

Why did you participate in PaKoMi?

"I was invited by Fred and I was very uncertain about what to expect. But once I was there, I immediately thought, Okay, this is where I want to belong."

Victor Oteku (PaKoMi Osnabrück)

"I participated because I thought that the concept was also interesting and I still think this. I participated because I want to offer something in Hamburg in our community within the scope of HIV/AIDS together with the employees. And I also personally think that this is a great concept where many decisions can be made together."

Omer Ouedraogo (PaKoMi Hamburg)

"To me, PaKoMi is an innovative project where the migrants in Germany not only get a voice but also a body because the migrant not only is subject to a decision but can participate in the decision."

Kelly Cavalcanti (PaKoMi Project Advisory Council)

The PaKoMi Case Studies

The case studies each had their own objective, depending on what the local demand for action was.
(Speaker from off-screen: **Karin Schwickerath**)

Photos of the cooking events in the Dortmund streetwalking zone and comics of the community mapping

“In the case study, we did interviews at the beginning to find out who the women are and what group we are dealing with. Then we organised the cooking events so that we could have conversations with each other to get to know the women better before we engaged in HIV prevention. We learned a great deal about how they live, what they see as health and that the traditional HIV prevention measures are not always equally suited for female sex workers.”

Semra Mestan (PaKoMi Dortmund)

“We illustrated it with comics. And the boys who are shown in the pictures are very similar to the real boys so that they could see themselves in these pictures. And this was an absolute hit. I handed out this sheet and they sat down together, looked at it and laughed and said ‘Ah, you’re the one with the glasses and the one with the pad of paper in the hand who is writing everything down…’ So it was very clear who would take which role and that these two peers would assume the moderation, that I would stay in the background and actually just unlock the room, perhaps make some coffee, take notes and cooperation with the two peers. They ultimately did the work with the community.”

Christian Hölbing (PaKoMi Dortmund)

Pictures of participants at the Community Mapping (PaKoMi Workshop 2), as well as of the PaKoMi booth at the Africa Market in Osnabrück

“We conducted two important surveys, and the first was about community. We initially wanted to support the people in Osnabrück with the topic of health promotion, so we went to them and asked, ‘What do you understand as community? Where do the Africans or migrants actually meet?’ Through this research, we learned that the people would really like to meet and do more for their own concerns.”

Victor Oteku (PaKoMi Osnabrück)

“We are from GLADT, and as GLADT we did a sub-study for PaKoMi in Berlin. We conducted interviews with the key people of migrant self-organisations, which meant 23 key persons of various associations.”

Ulas Yilmaz (PaKoMi Berlin)

“The questions were how people in the respective communities – meaning the Turkish- or Russian-speaking communities – deal with topics like HIV and AIDS or whether they even talk about it.”

Tugba Tanyilmaz (PaKoMi Berlin)

“PaKoMi is a very good opportunity and to me it means a very good chance to hear the voice of the target group. This is also the basis for our case study in Berlin, in which we would like to assess their needs and [enable] their participation in order to include the target group in additional, future decision-making processes in the sense of recommendations or concepts or the like.”

Jannis Karamanidis (PaKoMi Berlin)

“That we say to the boys in a conversation where a highly official scientist from the USA is also present, ‘Hey, you could tell us something, we want of learn something from you, we want to find out from you how we can reach these men?’ Otherwise, it has always been like this: We are the great social workers, and we obviously know what we are doing and the boys ask us. But this time it was the other way around.”

Stefan Schröder (PaKoMi Berlin)

Pictures of participants at Community Mapping (PaKoMi Workshop 2), as well as the questionnaires and flyers produced in the case study of Hamburg

"We were supposed to do a study on Africans. So we first had a brainstorming session: Where are the Africans in Hamburg? Who are they? Which types of communities are there? How exactly do they live? What access do they have to health care and other services? We came up with three questions: access to health care, opinions and attitudes about HIV, and the stigma. And then we developed a questionnaire on this basis. We went to them to get information, to find out what exactly they know about HIV, and we conducted a survey."

Steve Fotso Ouoguep (PaKoMi Hamburg)

"I want to contribute my experience: I would say it was our first experience that really motivated us because after our training we had the opportunity to meet with members of our community and confront the topic of AIDS. It was a first approach, and I as a Muslim was in the community. I first began with the prevention and then introduced the questionnaire. I was lucky to meet many people who were willing to answer the questions, and that was good. Then we were able to form a focus group and invite ten members of the mosque community. These were relevant people, and I did this together with someone else who had also taken the training. We asked direct questions and got concrete responses. And we have really been able to make progress in this Muslim community and the African community that lives in Hamburg. Above all, this involves breaking the taboos represented by AIDS, AIDS patients and condoms. And we could really gain access to the religious communities of the Muslims and Christians. This has meant much to me in this project."

Moussa Abakar (PaKoMi Hamburg)
(*übersetzt aus dem Französischen*)

"I also found out that when I speak with people about HIV, then they are interested in hearing about it and glad to talk."

Sogah Koussowa (PaKoMi Hamburg)

What are possible inhibitions for participation?

One goal of PaKoMi was to clarify what promotes participation, but also what inhibits it.
(Speaker from off-screen: **Karin Schwickerath**)

Pictures from the discussion by participants at the Evaluation Workshop 1 on possible barriers to participation

Discussion by the small group:

"Doesn't this result in a lack of trust?"

"I think that they are both connected: the HIV stigma and taboos."

"There is an HIV stigma and other taboos, and this is why people have bad experiences."

"And then there is a lack of trust."

"A lack of trust, exactly…"

"This results in a lack of trust, exactly…"

"But these are truly connected. I mean that they do not follow each other and are not separated from each other, but are truly connected things."

"Yes, and then there is the togetherness."

"And this is why people have bad experiences?"

"That's what causes the lack of trust."

"And when someone has a lack of trust, then this results in a…"

"Conflict!"

"Yes, conflict."

"And a lack of resources don't play a role?"

"Yes, they do!"

"But money is also important…"

"Money and even if you don't have any space, resources can be anything – knowledge, experience, these are all resources…"

“We not only analysed the conditions that support or hinder participation, we also developed recommendations together. This means that every area that has invested in the cooperation should also have a benefit from the cooperation. For the communities this meant community-building and strengthening of the communities. For the practice of HIV prevention, this meant improving the services and for example, the handbook that we are developing. The policy realm receives very concrete recommendations on how to create the structural requirements needed for improving participation; in science, we obviously also want to get methodical and theoretical findings, as well as publications, out of the cooperation.”

Hella von Unger (WZB)

The PaKoMi Workshops

The workshops served the purpose of capacity-building, networking and participatory analysis.
(Speaker from off-screen: **Karin Schwickerath**)

Pictures of participants in the group work, role-play, discussions and presentations in the plenum at various workshops

One component of PaKoMi is the workshops that we organise. These were intended as more of an accompaniment at the beginning; but the longer PaKoMi exists, the more important they have become. How significant these workshops are has become clearer to me over time. This is where the practitioners and community members meet face to face, they share their thoughts, get to know each other and receive input in terms of methods, contents and concepts. Then they also help us with the analysis in the workshops because the practice and community partners are just as involved as we scientists in the various phases of the project’s research process from beginning to end.
(Speaker from off-screen: **Hella von Unger**)

What have you learned through PaKoMi?

“My way of working with others: I notice that ... PaKoMi has shown me how important it is that not only the educated people are significant but also the people with experience – and how they work together very closely.”

Kelly Cavalcanti (PaKoMi Project Advisory Council)

“My view of how a community defines itself has changed. Because there is much more in relation to … which circumstances or which group of people make a community.”

Fredrick Oluoch (PaKoMi Osnabrück)

“Much has changed through PaKoMi. PaKoMi has also given me the chance to have many contacts throughout Germany. I have also acquired many skills through PaKoMi due to the trainings, both at the workshops in Berlin and in Hamburg. This peer researcher training was also done in Hamburg; many people acquired skills there that will be useful for their entire life, and I personally have met another group of people there and am very proud of this.”

Omer Ouedraogo (PaKoMi Hamburg)

“What I feel to be very special about PaKoMi is that I now have the ability to talk about HIV wherever I may be and without any fear. I previously had many friends who were infected with the virus, but it was not a topic that we could talk about. But now with this type of research, I felt very much like… I felt that I was more free to talk about this disease and about what effects it has, even on my own continent.”

Lucy Gbem (PaKoMi Osnabrück)

“What I feel to be very special about PaKoMi is that I now have the ability to talk about HIV wherever I may be and without any fear. I previously had many friends who were infected with the virus, but it was not a topic that we could talk about. But now with this type of research, I felt very much like… I felt that I was more free to talk about this disease and about what effects it has, even on my own continent.”

Gerhard Peters (PaKoMi Berlin)

“If someone would now ask me, ‘What community do you belong to?’, I would answer, ‘The PaKoMi community.’”

Helen Nintemann (PaKoMi Osnabrück)

"I believe that PaKoMi was a very good thing for me. I was trained as a health ambassador, and we then went on the street with this training [as a peer researcher] and surveyed people. In this survey, I determined that HIV/AIDS is no longer a taboo topic when people talk about it in public."

Sogah Koussowa (PaKoMi Hamburg)

Recommendations were established for the further development of HIV prevention for and with migrants in Germany. (Speaker from off-screen: **Karin Schwickerath**)

Pictures of participants from one of the PaKoMi workshops, as well as of a work meeting for the case study of Hamburg

What are your wishes for the future?

"For the future I would say that it would be very important to me that the recommendations by PaKoMi [are put into action] and that the implementation becomes a reality. Without it becoming a reality, this would really be a big loss because we have invested so much in PaKoMi, so much energy, and it's important that the politicians also listen to us."

Omer Ouedraogo (PaKoMi Hamburg)

"I believe that we are on the right track. Why do I say that? If we continue with what we have done during the last months, we will succeed in getting a place for us all, as a community. We can invite more people and say, 'Come join us!'"

Helen Nintemann (PaKoMi Osnabrück)

"The primary question for me is how we can include people with a migration background over the long term in the prevention work in a time when the funds for prevention are generally being cut. This makes it even more important to me that the voice of PaKoMi is heard because we have proven with PaKoMi that participation among equals is possible if we create the necessary preconditions for it – and this also includes the financial resources."

Tanja Gangarova (DAH)

"This project has also made the following clear: if you create a framework, if you open up a space, open a door and give people the opportunity to formulate what they think, what they feel, what they need and make communication possible, but also make encounters possible – encounters among equals – then many things can develop, as well as a feeling of responsibility and mutual responsibility for a topic. And I think that this is what PaKoMi stands for."

Silke Klumb (DAH)

"And so what is PaKoMi? Getting involved, brainstorming, taking part in decisions, laughing with each other – yes, having fun and experiencing joy – is what I have found to be great and sensational. PaKoMi – more of it, please!"

Vivi-Lore Nzouatcham (PaKoMi Hamburg)

Group photos of the PaKoMi workshops and closing credits

Tips: How Can the Video Be Used?

As already mentioned, the objective of the video is to communicate in a lively way that the participation of migrants in HIV prevention and research is possible and worthwhile. It is directed towards people who are interested in the participation processes and working together with migrants – in HIV prevention and research and also beyond it. The video can be used as an example and illustration in order to further educate oneself and others such as specialists for HIV prevention and health promotion, members and representatives of migrant communities and migrant self-organisations (MSO), social service and health-care professions, students and scientists.

We have shown the video to various groups of people. The reactions were very different: they were primarily positive, but they also ranged from appreciation and enthusiasm to irritation and disinterest. There was also constructive criticism and suggestions. At this point, we would like to share a few tips that can be helpful in the use of the video.

1. Before you show the video, clarify the expectations

What are your expectations? What do you hope to achieve by showing the video? What are the expectations of the people in the audience? It is not realistic to assume that the video can produce a basic change of heart or report on detailed project results. It can show the possibilities of participation through a concrete example. It can encourage people, whet their appetites and – above all – spark their curiosity! However, it can also cause scepticism and irritation (see below).

2. Clarify the framework and the time frames

The video lasts 23 minutes. It makes sense to give a brief introduction before showing the video to explain some basic facts about the three-year PaKoMi project (goals, partners, funding, participatory approach, etc.). It is also helpful to mention that the detailed project results can be seen in the handbook and at the PaKoMi website. The video illustrates the diversity of perspectives and it shows in the words of the participants that participation is possible. Afterwards, at least 20 minutes are generally required for the discussion. So an overall time frame of 60 to 90 minutes is appropriate for watching and discussing the video. It is also possible to interrupt the presentation of the video and allow interposed questions. A possible point to do this could be following the section on the case studies and before "What are possible inhibitions for participation?" (at 12.58 min).

3. Technical requirements

The video can either be viewed on the Internet (through **www.pakomi.de**) or played from a DVD. In order to see the video, the appropriate software (such as VLC or Media Player) is required. When showing it to groups, a projector and speakers are required for the sound. The video is available in the German original with English and French contributions, as well as in an English version (the German texts were translated and dubbed). A French contribution is in the original in both language versions, so we recommend also having the German translation on hand when required (see above).

4. Questions and answers

We were frequently asked the following questions:

Who are the people shown in the video?

All of the people who appear in the video participated in the PaKoMi project. These include partners from migrant communities who conducted the on-site projects and attended the advanced training workshops; the salaried and volunteer employees of AIDS service organisations, prevention projects and counselling centres; an employee of a public health authority; employees of Deutsche AIDS-Hilfe and scientists from WZB. For additional information on the participants, see the Introduction.

What are peer researchers?

Peer researchers are people from the target groups and communities who are trained to conduct research in their communities (see Chapter 6). For example, African migrants were trained as peer researchers to survey Africans and Bulgarian migrants were trained to survey Bulgarians in the PaKoMi project. In Hamburg, the peer researchers were trained health ambassadors of the AIDS service organisation (i.e. multipliers or peer educators). In other cities, language professionals, freelance employees, committed volunteers and salaried employees of MSOs assumed the tasks of peer researchers. It is helpful – but not necessary – for peer researchers to have prior knowledge of health topics. It is important that they are a part of the respective community and have good access to the people (i.e. language and cultural/life-world competences).

Are people with HIV/AIDS involved?

Yes, a number of people who live with HIV/AIDS have made essential contributions to the PaKoMi project. But not every person who is shown in the video is HIV positive. PaKoMi is a project of primary prevention. Most participants are not directly affected by HIV but are involved out of solidarity and often know someone who lives with HIV/AIDS.

Why are the migrants in the video so cheerful?

To answer a question with a question: Why not? Seriously: the cheerful and laughing faces of the peer researchers and people who are illustrated in the comic drawings irritate some of the people who watch the video. They object that the lived reality of many migrants in Germany in anything but jolly – which is true in some cases, but not in others. It is important to remember that not every woman who works in prostitution is a victim of human trafficking, and not every African experiences racism in the same way. Humour is an important resource in dealing with problems, and our community partners urged us to show in the video the friendly, warm and humorous tone that characterised how people treated each other in the PaKoMi project (see section above "How the Video Was Made"). We don't want to whitewash reality. On the other hand, why shouldn't we show reality when it is beautiful for a change? The pictures of the migrants involved in the PaKoMi project certainly do not correspond with the common clichés of "hard to reach" migrants. This may also contribute to the irritation.

Where was it filmed?

Most of the filming was done at the PaKoMi Workshop (i.e. at the conference rooms in Berlin). Individual shots were also taken during visits to the case studies (Osnabrück) and at individual interviews, such as at the offices of Deutsche AIDS-Hilfe e.V. and the Social Science Research Center of Berlin (WZB). (The picture that appears in the interviews with Hella, Stefan, Melike and Michael was painted by Asta von Unger, Hella's sister.)

All of the participants could decide for themselves what they wanted to talk about. Most of them requested that Karin ask them a question so they could then respond to it. Karin Schwickerath recorded 90% of the film material.

What happened in the case studies?

Projects with scientific support (i.e. case studies) took place in four cities: Berlin, Dortmund, Hamburg and Osnabrück. Each case study had a somewhat different objective, depending on the nature of the local need for action. All of the case studies involved joint research in order to better understand the life-worlds and needs of the migrants. The goal was to develop HIV prevention for and with migrants by studying and strengthening the participation of migrants and the cooperation between various providers. Primarily Africans from the Francophone countries of West Africa were involved as community partners in Hamburg; in Osnabrück, there were English-speaking Africans from the East African countries. In Dortmund, sex workers of both genders from Bulgaria were involved, as well as students from this language area. Various people with access to the Russian- and Turkish-speaking communities and men who have sex with men (MSM) were involved in Berlin. A detailed description of the case studies can be found in Chapter 6.

What results has PaKoMi achieved?

Above all, the PaKoMi project has shown that the participation of migrants in HIV prevention and research is possible and provides many benefits: to the participants, who further develop their skills; to the communities, which are strengthened when structures – like the planned founding of an MSO in Osnabrück – are developed; to HIV prevention (e.g. through improved understanding of the communities and enhanced access); and to the salaried and voluntary employees (e.g. through improved cooperation). For more information on the findings of the case studies, see Chapter 6. For more project results, see the publications on the website (**www.pakomi.de**).

What is unique about PaKoMi?

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 customised, 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 utilisation of the results).

Where do we go from here?

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. We made efforts on-site to ensure that the findings of the case studies can be and are being implemented, for example through the development and stabilisation of structures (MSOs, associations, cooperation, etc.). This has been very successful in Hamburg, for example. In other case studies – such as Dortmund – sustained long-term use has become very difficult due to events that are beyond our control (see page 105). On 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.

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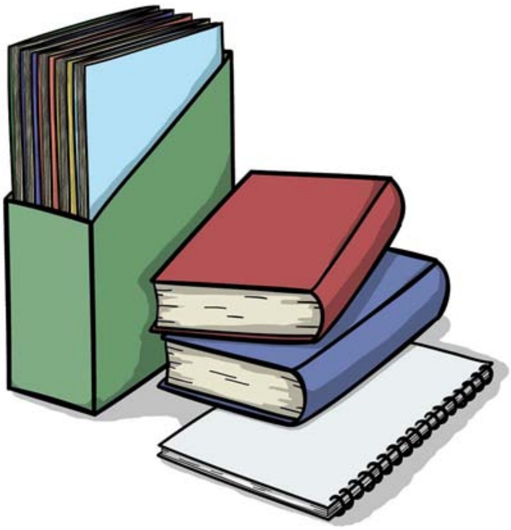

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Selected Prevention Materials

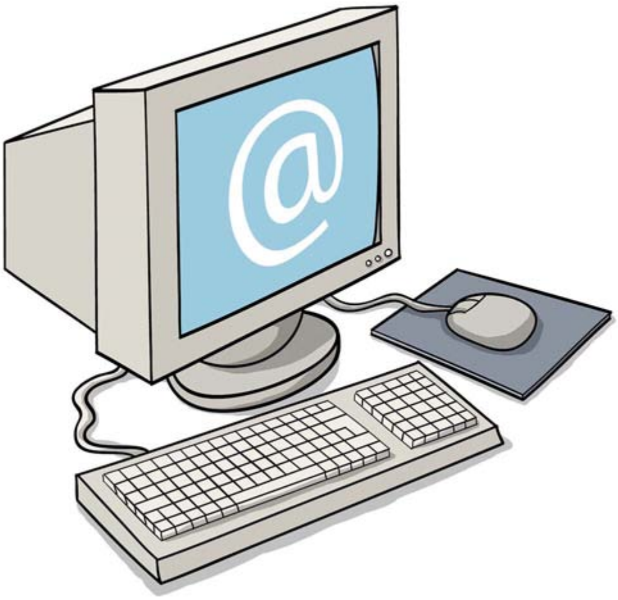
The Federal Centre for Health Education (BZgA) and the Deutsche AIDS-Hilfe e.V. (DAH) offer a large variety of materials (mostly free of charge) that can be used for HIV prevention. These include multilingual materials, videos, DVDs and illustrated brochures.
Here is a small selection. For the extensive offer, see the www.bzga.de and
www.aidshilfe.de websites.

BZgA (2011). Love Life Stop AIDS – DVD zur Aids-Aufklärung in 13 Sprachen. *Order at:* www.gib-aids-keine-chance.de

BZgA (2010). Präventionsmappe sexuell übertragbare Krankheiten: Text und Bildtafeln zur Information und Beratung für Menschen verschiedener Kulturen. Köln: Bundeszentrale für gesundheitliche Aufklärung. *Order at:* www.gib-aids-keine-chance.de

DAH (2011). Deine Gesundheit, deine Rechte: Informationen, Tipps und Adressen. Your health, your rights: information, tips and addresses. Berlin: Deutsche AIDS-Hilfe. *Order at:* www.aidshilfe.de

DAH (2009). Positiv schwanger. Information für Ärzte/Ärtzinnen und Berater/innen. Berlin: Deutsche AIDS-Hilfe. *Order at:* www.aidshilfe.de



Useful Links (Internet)

Afro-Leben+
(German Network of Positive Migrants)
www.afrolebenplus.de

Bundesamt für Migration und Flüchtlinge (BAMF)
www.bamf.de

Bundesministerium für Gesundheit (BMG)
www.bmg.bund.de

Bundesministerium für Familie,
Senioren, Frauen und Jugend (BMFSFJ)
www.bmfsfj.de

Bundeszentrale für gesundheitliche Aufklärung (BZgA)
www.bzga.de

Community-Campus Partnerships for Health (CCPH)
www.ccph.info

Deutsche AIDS-Hilfe e.V. (DAH)
www.aidshilfe.de

Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ)
www.giz.de

European AIDS Treatment Group (EATG)
www.eatg.org

Health Care in NOWHERELAND.
Improving Services for undocumented migrants in the EU.
www.nowhereland.info

Joint United Nations Programme on HIV/AIDS (UNAIDS)
www.unaids.org

Kooperation für nachhaltige Präventionsforschung
www.knp-forschung.de

Kooperationsverbund Gesundheitsförderung
bei sozial Benachteiligten
www.gesundheitliche-chancengleichheit.de

Partizipative Qualitätsentwicklung in der
Gesundheitsförderung bei sozial Benachteiligten
www.partizipative-qualitaetsentwicklung.de

PaKoMi website
www.pakomi.de

Quint-Essenz Qualitätsentwicklung in Gesundheitsförderung und Prävention
www.quint-essenz.ch

Robert Koch Institut
www.rki.de

Toronto Community-Based Research Network
torontocbr.ning.com

World Health Organisation (WHO)
www.who.int

Wissenschaftszentrum Berlin für Sozialforschung gGmbH (WZB)
www.wzb.eu

Zentrum für Flüchtlingshilfe und Migrationsdienste
www.migrationsdienste.org

Participating Organisations (Case Studies)

aidshilfe dortmund e. V.
Möllerstraße 15
44137 Dortmund
www.aidshilfe-dortmund.de

AIDS-Hilfe Hamburg e. V.
Lange Reihe 30-32
20099 Hamburg
www.aidshilfe-hamburg.de

Aids-Hilfe Osnabrück e. V.
Möserstraße 44
49074 Osnabrück
www.aidshilfe-osnabrueck.de

GLADT e. V. (Gays and Lesbians aus der Türkei)
Kluckstraße 11
10785 Berlin
www.gladt.de

Hilfe-für-Jungs e. V. (Subway)
Nollendorfstraße 31
10777 Berlin
www.hilfe-fuer-jungs.de

Kommunikations- und Beratungsstelle für Prostituierte des Sozialdienstes katholischer Frauen e. V. (KOBER)
Nordstr. 50
44145 Dortmund
www.kober-do.de/ und
www.ksd-dortmund.de

Netzwerkstelle HIV/Aids und Migration
Verband für interkulturelle Arbeit (VIA)
Regionalverband Berlin/Brandenburg e. V.
Petersburger Str. 92
10247 Berlin
E-Mail: netzwerkstelle@via-in-berlin.de

Schwulenberatung gGmbH (manCheck)
Mommsenstraße 45
10629 Berlin
www.schwulenberatungberlin.de/mancheck.php

Zentrum für sexuelle Gesundheit und Familienplanung
Gesundheitsamt Berlin Charlottenburg-Wilmersdorf
Hohenzollerdamm 174-177
10713 Berlin
www.berlin.de/ba-charlottenburg-wilmersdorf/org/gesundheit/fachbereich_4.html

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