Behavioural and Societal Sciences
Wassenaarseweg 56
2333 AL Leiden
P.O. Box 2215
2301 CE Leiden
The Netherlands

www.tno.nl

T +31 88 866 90 00
F +31 88 866 06 10
infodesk@tno.nl

TNO report

TNO/CH 2012.024

Development of a culturally appropriate HIV-preventive intervention for HIV-positive Sub-Saharan Africans in the Netherlands
Process Evaluation Research Project

Date	April 2012
Author(s)	M.G.B.C. Bertens D.G. Korfker J. Maiyo L.N. Nunu Siya J.L.E. de Vries N.C.M. van Kesteren
Number of pages	46 (incl. appendices)
Sponsor	Aids Fonds
Project number	031.13035/01.01

Contents

1 Introduction

In 2007, the research proposal for the project “Development of a culturally appropriate HIV-preventive intervention for HIV-positive Sub-Saharan Africans in the Netherlands” was submitted to and approved by the Aids Fonds (2007074). The project was originally divided into four phases: 1) a needs assessment phase, 2) an intervention development phase, 3) an intervention design phase, and 4) a piloting and refinement (evaluation) phase. As funding was offered for the first two phases, the decision was made to solely focus on the first two phases of intervention development: needs assessment and formulation of program objectives and suggestions for the intervention methods and strategies. This report is an overview of the activities and results of these activities that were undertaken in the project between 2007 – 2011.

The goal of the present project was to propose and recommend culturally appropriate objectives, methods and strategies to be integrated in the development of this intervention; and to actively involve members of the target group in its development.

The PEN3 Model (Airhihenbuwa, 1995) was used as an analytical framework throughout the project to achieve cultural appropriateness with the target group.

2 Methodology of the present research project

Several approaches were integrated and incorporated in the project.
As a framework for information gathering on the environmental and individual influences on sexual risk behaviors in this target group the PRECEDE model was applied (Green & Kreuter, 2005). Qualitative research methods in data gathering and analyses were used to get more insight into the determinants of HIV-risk in SSA living with HIV. These included: (1) workshops with key representatives of the target population, with health education professionals on migrant (sexual) health, and with HIV prevention and HIV care providers, (2) Focus Group Discussions with sub-Saharan men and women living with HIV and (3) individual interviews with sub-Saharan men and women living with HIV. Furthermore during the project professionals and the target group were consulted in group meetings (i.e., linkage group meetings, see proceeding sections), but also by telephone and email contacts. All data were recorded and analyzed qualitatively.

2.1 Intervention Mapping

The Intervention Mapping (IM) framework was used for systematically developing theory- and evidence-based health promotion programs (Bartholomew et al., 2011). More specifically, IM produces a framework that a) requires a clear understanding of the specific problems and needs of the target population; and b) grounds intervention development (intervention objectives, methods and materials) in evidence and theory.

2.2 PEN-3 Model

In addition, the PEN-3 model (Airhihenbuwa, 1995) was integrated as a relevant model within the Intervention Mapping development process to achieve cultural appropriateness with the target group.

Cultural sensitivity is a precondition for the effectiveness of HIV prevention programs and is very important in program planning. For many years, incorporating culture in intervention development has been recommended as means to develop programs that are relevant and sensitive to the cultural context of the target population (Banner et al, 1995; Erwin et al, 1996; Kreuter et al 2003; Navarro et al, 1998; Tanjasiri et al, 2007). However, there is little guidance about the process of cultural sensitive intervention development. The PEN-3 model, developed by Airhihenbuwa (1995, 2007), places culture at the core of health promotion programs and acknowledges (a) that individuals make health decisions that are consistent with their familial and community roles; (b) that individual, family and community health actions are influenced by health beliefs and practices that arise from a specific cultural context; and (c) that health beliefs and practices can be *positive,* i.e. contribute to improved health status and must be encouraged*, existential,* i.e. no threat to health and do not need to be changed, or *negative*, i.e. threat to health and must be discouraged. According to Airhihenbuwa (1995, 2007), health promotion planners should focus on both negative aspects and positive aspects of culture to ensure a higher level of cultural sensitivity.
The PEN-3 model places culture at the core of health promotion and disease prevention programs and offers ‘a space within which cultural codes and meanings can be centralized in the development, implementation and evaluation of health promotion programs’ (Airhihenbuwa, 1995). The PEN-3 model consists of three dimensions of health beliefs and behavior that are dynamically interrelated and interdependent: health education, educational diagnosis of health behavior, and cultural appropriateness of health behavior. The PEN-3 model is illustrated in the figure below. As can be seen, within each of the three dimensions, three categories

(according to the acronym PEN) are being distinguished. Below the three dimensions of the PEN-3 model and their accompanying categories will shortly be discussed.

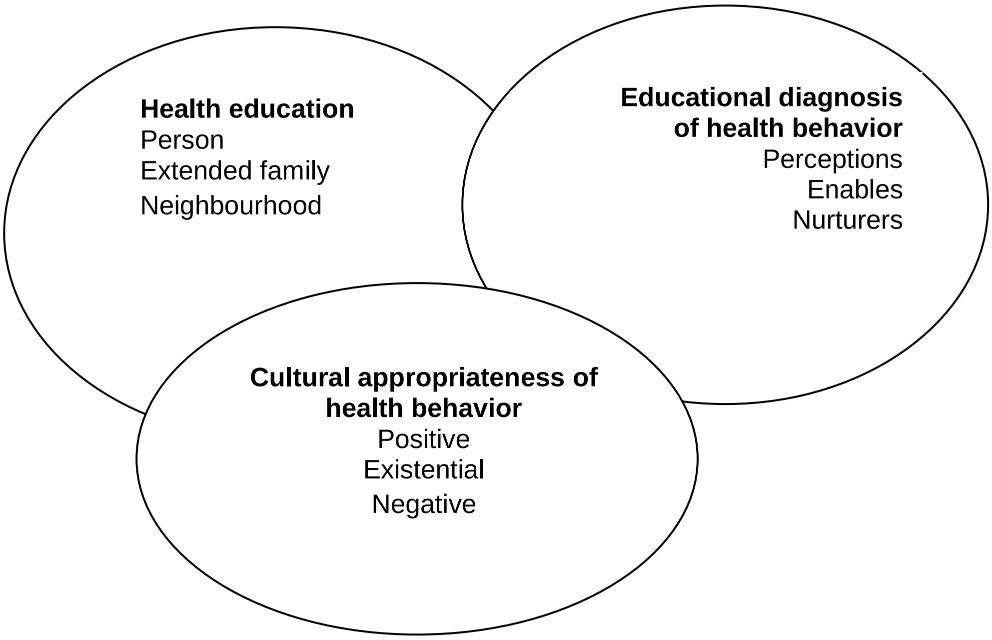

Figure 1: The PEN-3 Model

Dimension 1: Health Education Domain
The first dimension is health education. The domain of *person* is committed to improving the health of all. Therefore, individuals should be empowered to make informed health decisions appropriate to their roles in their families and communities. The domain of *extended family* realizes that health education should be targeted to not only the immediate family but also to the extended family or kinship. The domain of *neighborhood* assumes that the focus of health promotion should be on neighborhoods and communities. Involvement of community members and their leaders is critical to providing cultural appropriate health promotion programs.

Dimension 2: Educational Diagnosis of Health Behavior
The second dimension of the PEN-3 model is the educational diagnosis of health behavior, which includes perceptions, enablers, and nurturers. Educational diagnosis has been used by researchers in an attempt to determine what factors affect individual, family and/or community health actions. *Perceptions* comprise the knowledge, attitudes, values and beliefs that may facilitate or hinder personal motivation to maintain or change health beliefs and/or practices. Two examples of this might be that being overweight is not necessarily associated with a negative body image for many African Americans or that teenage pregnancy among African Americans may, in fact, be desired (Campbell, 2001). *Enablers* are societal, systematic, or structural influences (or forces) that may enhance or be barriers to change. These could include available resources, accessibility, referrals, employers, government officials, skills and types of services. *Nurturers* are the reinforcing factors that an individual may receive from significant others, which could include extended family, peers, employers, health personnel, religious leaders or government officials.

Dimension 3: Cultural Appropriateness of Health Behavior
This dimension consists of the categories of positive, existential, and negative health beliefs and behaviors. *Positive* are the perceptions, enablers and nurturers that may cause an individual, family or community to engage in health practices that contribute to improved health status and must be encouraged. Positive health practices are essential to the empowerment of people, families, neighborhoods and communities. One example is the traditional practice of eating green vegetables. *Existential* comprise the perceptions, enablers and nurturers that have no harmful health consequences, and therefore do not need to be changed. *Negative* are the perceptions, enablers and nurturers that may lead individuals, families or communities to follow health practices that are harmful to their health. An example would be that male dominance inhibits female initiative regarding condom use.
The third dimension, cultural appropriateness of health behavior, is the most critical dimension of the PEN-3 model. Health educators should focus on both the positive (empowerment process) and the negative behaviors (harmful to health) in a health program. This can lead to a higher level of sensitivity when planners are developing a culturally-sensitive health promotion program. According to Airhihenbuwa (1995), often too much attention is focused on negative behaviors with few or no rewards offered for positive behaviors. According to him, the process of ‘culturalizing’ health knowledge, attitudes, and practices should not assume that people are powerless or ignorant, but should affirm diversity in the way people construct their individual and collective realities.
There are several phases in the application of this model. Using surveys and/or interviews, in phase 1 (education diagnosis of health behavior), planners should explore the beliefs and practices that are related to perceptions, enablers and nurturers. The third phase (cultural appropriateness of health behavior) involves categorizing these beliefs and practices as either positive, existential or negative. Finally, planners need to classify all health beliefs into two groups: 1) the identified health beliefs that are rooted in the cultural patterns and lifestyles of the target community and; 2) the identified health beliefs that are newly developed and have only loose or superficial ties with the cultural patterns and lifestyles of the target community. The real challenge for planners is to identify which positive beliefs and practices are supportive of the individual, extended family and neighborhood.
During the workshops and consultation with the professionals en target group the group was asked to label and categorize perceptions, beliefs and behaviors

Planners must understand rationale behind stated beliefs and practices to determine appropriate classification and for selection of proper health education strategies. Finally, planners must determine if the emphasis of the program in health education will be on individuals, the extended family or the community, i.e. they must decide on the point of entry of the intervention.

2.3 Participatory approach

Target group participation refers to a process of understanding and involving the target group in order to create public support and commitment (Wagemakers et al, 2008). Target group participation was therefore an important principal of health promotion in the present project as was reflected by high levels of participation by the target population in all phases of intervention development.

Linkage system
From the onset of the project, an extensive linkage system of several relevant groups (a linkage group, an expert professional sounding board and lay target group sounding board) was formed. This *linkage group*, which also functioned as the advisory board, was comprised of an expert (*professional*) sounding board and a lay (*target group*) sounding board. Both the expert and the target group sounding boards were consulted throughout the process of intervention development.

More specifically, the *linkage group* was comprised of members of both the expert sounding board and target group sounding board, as well as key representatives of the target population. Collaboration between researchers, representatives from key organizations, and members of the target population was regarded as essential during the needs assessment. The main purpose of the linkage group was to develop agreement on the intervention development process, to inform the linkage group about the results of the literature review and research outcomes (e.g., results of the focus group discussions, semi-structured interviews and workshops discussed in paragraphs 4.4, 4.6 and 4.8), and to solicit input regarding needs assessment and planning of activities.
In order to develop an HIV-preventive intervention that ‘fits’ the specific needs, values and beliefs of SSA living with HIV, participation of the target population in all phases of intervention development was required. Therefore, a long-term process of frequent group meetings, expert workshops, individual interviews, telephone and email contacts was set up, in which we moved back and forth between the linkage group, key representatives of the target population and members of the target population to inform them about the process and outcomes of the intervention development at all phases.

Expert (professional) sounding board
The expert sounding board was comprised of a fixed number (8) of professional experts in the field of HIV/AIDS prevention and treatment and/or migrant (sexual) health, and gender issues and representatives of migrant support organizations. More specifically, members of the expert sounding board were Chantal Baziruwisabiye (Positive Africans Mutual AIDS; PAMA), Arjan Bos (expert in the field of HIV-related stigma, Maastricht University), Masego Kanis (theologian and expert in religion and HIV, Kampen Theological University), Herman Schaalma (professor in AIDS prevention and health improvement, Maastricht University), Joshua Maiyo (program officer ethnic diversity, HIV Vereniging Netherland), Iris Shiripinda (medical anthropologist and former program manager HIV prevention ethnic minorities, SOA AIDS Nederland), Laura Nunu Siya (medical doctor and public health researcher, TNO), and Nicole van Kesteren (health scientist, TNO).

The goals of the expert sounding board were 1) to give advice concerning the content - contribution of knowledge on HIV prevention and living with HIV, on the target population and on the implementation of research plans - of the research; 2) informing and involving the target population in the project (thus functioning as intermediaries); 3) creating and keeping support among parties involved.

Lay (target group) sounding board
Since target group participation is critical to developing an HIV-preventive intervention (see PEN3), and community participation is key to ‘program success’, a lay target group sounding board was formed. Members of this sounding board all have experiential expertise on living with HIV/AIDS in the Netherlands; we will from here on call the ‘*target group* sounding board’ instead of using the derogative *‘lay’*. The target group sounding board was composed of SSA men and women living with HIV in the Netherlands. The numbers and members invited and attending the target group sounding board was not fixed and fluctuated according to the specific aims and purposes of each meeting. Each meeting involved members from a variety of SSA living with HIV/AIDS in the Netherlands.
The purpose of the target group sounding board was to reflect on and discuss project proceedings, results, and decision-making processes taking into account the perspectives of the target group. Furthermore, the target group sounding board provided insight into and understanding of the needs and sensitivities of SSA living with HIV in the Netherlands. More specifically, aims were to
1) examine their current situation (what is it like to live with HIV and what are related issues), and

2) to get input on new ideas and ways to implement action for change by coming together and discussing needs and future direction for change during the run of the project.

3 Project Phases and research activities

Project phase	**Research activity** **Aim: to get insight in sociocultural and psychosocial determinants of HIV-risk**	**Sounding board** **Aim: to get feedback on process and outcomes and to involve target population in program planning**	**Date**
Phase 1 = Needs assessment	Literature review		Aug - Nov 2007
		Consultation of professional sounding board	Nov 2007
		Consultation of target group sounding board	Nov 2007
	Professional workshop		Feb 2009
		Consultation of professional sounding board	June 2010
	FGD with HIV+ SSA men and women		June-July 2010
		Consultation of professional sounding board	July 2010
	Individual interviews with HIV+ men and women		Oct 2010 – Jan 2011
Phase 2 = Intervention outline	Formulation preliminary Program objectives		
		5 Consultation meetings/workshops target group	April/May 2011
	2 Professional workshops		June/July 2011
	Formulation of program objectives and intervention method		April 2012

Flowchart 1: Project research activities

In the following sections, each research activity will be discussed in terms of aim, participants, procedure and proceedings, and main outcomes.

4 Results Phase 1: Needs Assessment

The purpose of the first phase was to obtain a better understanding of the behavioral (i.e., sexual risk behavior) and environmental factors (i.e., social economic factors) related to HIV/STI transmission in SSA living with HIV and the psychosocial determinants underlying those behaviors.
As part of intervention development, a needs assessment was conducted to gain insight into the socio-cultural and psychological dynamics of HIV-risk in the target population.
Needs assessment began with a literature review on (a) behavioral and psycho-social determinants related to HIV/STI transmission in SSA living with HIV; and (b) the socio-cultural and economic contexts of HIV/STI transmission within this target group. Based on the outcomes of the literature search an expert workshop was organized to get more insight into the health beliefs and practices in relation to HIV risk among SSA migrants living with HIV in the Netherlands. Panel group discussions with 25 experts who had worked with SSA living with HIV or had expertise on this topic focused on positive, existential and negative health perceptions and practices in relation to sexual (risk) behavior, gender dynamics, stigma, and socio-economic status. Subsequently eight focus groups among 41 male and female SSA living with HIV were conducted to supplement and validate the outcomes of the expert workshop. Finally, individual interviews among 26 SSA men and women living with HIV (N=26) addressed the influence of gender roles, norms and expectations on sexuality and sexual decision-making among the target population.
The samples of the SSA men and women living with HIV in the needs assessment are convenience samples: participants were recruited through contacts of professionals and self-organizations of the target population.
Between research activities, meetings were held with the professional sounding board and the target group sounding board to solicit input regarding needs assessment activities and the data collection process.

4.1 Literature review (August – November 2007)

Procedure and aims: Previous (published and unpublished) research was reviewed on behavioral and psycho-social determinants related to HIV/STI transmission in SSA living with HIV and the socio-cultural and economic contexts of HIV/STI transmission. Also, applicable theories and models were reviewed to get more insight into the proximal factors that may facilitate or hinder HIV risk, such as attitudes, social norms, self-efficacy and more affect-oriented determinants, as sexual motives with regard to sexual risk behavior and fear for stigmatization with regard to HIV-disclosure. Publications on heterosexual HIV-positive, including studies on adolescent migrants living with HIV, in-depth studies on HIV-negative heterosexual African migrants and all meta-analysis and reviews were included.

As a framework for gathering information on the environmental and individual influences on sexual risk behaviors, the PRECEDE model (Green & Kreuter, 2005) was applied. The insights from the literature review were refined to cultural appropriateness by using the PEN-3 model (Airhihenbuwa, 1995).

Outcome:
In short, six main conclusions can be drawn from the literature review:

1. SSA migrant men and women living with HIV have to deal with serious problems in relation to sexuality and intimate partner relationships in addition to numerous psychological and social issues as a consequence of HIV-infection and its treatment. Childbearing concerns are prominent in both women and men.

2. A significant minority of SSA migrant men and women living with HIV practice unprotected (vaginal) intercourse. Furthermore, there is evidence that HIV-risk within this target population is related to several ‘risk profiles’: (a) having concurrent partnerships; (b) having transactional relationships in which women expect gifts or cash or consumer goods from men; (c) sexual mixing with other ethnic groups; and (d) having sex overseas.
3. Gender roles and norms play an important role in sexual risk behavior. Women living with HIV need to cope with potential threats to her ability to ‘connect and enhance relationships’ (feeling a conflict between the need for ‘connection’ and ‘psychological protection’ of self and others), whereas men living with HIV need to deal with their potential threats to their masculinity posed by having HIV (feeling weak and less masculine). Both men and women need to deal with threats to desired fatherhood/motherhood.
4. HIV risk in the HIV-positive African community is strongly associated with socio-economic problems related to immigration, including a lack of formal education, housing, unemployment, inadequate health insurance, and limited access to cultural sensitive HIV prevention and care.
5. HIV-related stigma is an obstacle to a frank and open discussion about HIV and sexuality with sexual partners as well as social support and care for sub-Saharan migrants living with HIV.
6. There is substantial evidence that a number of interpersonal (e.g., perceptions of trust, peer pressure, sexual violence, threat of rejection) as well as personal (e.g., decreased sexual pleasure, sexual discomfort, sexual motives such as need for intimate contact and connection, and low self-efficacy for condom use) factors are strongly related to HIV risk in SSA men and women.

4.2 Consultation with professional sounding board: Kick-off meeting (November 2007)

The first kick-off meeting with the members of the professional sounding board took place at SOA AIDS Netherland (Amsterdam) in November 2007.

Aim: The aim of the meeting was to get to know each other, get insight into everybody’s ideas and views concerning the procedure of the sounding board and the proposed project, and also to collectively determine the project strategy and to discuss the literature review.

Participants: The expert sounding board was comprised of a fixed number (8) of professional experts in the field of HIV/AIDS prevention and treatment and/or migrant (sexual) health and gender issues, and representatives of migrant support organizations

Procedure/proceedings: The aims, methodology and plan of the project were presented. Furthermore the literature review was sent to them beforehand. The group was asked for feedback. Ideas, comments, and criticisms were discussed in the meeting.

Outcome: The ideas generated from this meeting were integrated into the process and content of the project. Also, in the meeting, the proposed professional workshop was discussed.

4.3 Consultation of target group sounding board (November 2007)

Aim:

1. to get to know each other;
2. to get insight in experiences of living with HIV; and
3. to learn from these experiences in order to promote change.

Participants: 2 women and 2 men of Sub Saharan African descent living with HIV/AIDS.

Procedure/proceedings: The aims, methodology and plan of the project were presented. Group discussion and group interview techniques were used to discuss living with HIV in the Netherlands.

Outcome: The ideas generated from this meeting were integrated into the process and content of the project.

4.4 Professional workshop (February 2009)

The first professional workshop took place in February 2009. Twenty-five professionals who had worked with SSA living with HIV or had expertise on this topic were invited.

Aim: (1) Generation of beliefs and practices in relation to HIV risk among SSA living with HIV through group discussion; (2) classification of those beliefs and practices into positive (cultural empowerment), existential (no threat to health) and negative (threat to health) beliefs/behaviors and (3) judgment on recent and historical roots of beliefs and behaviors.

Participants: A workshop with (25) key representatives of the target populations (e.g., key representatives of self-organizations, intermediates from self-help groups), health education professionals on migrant (sexual) health (e.g., representatives of HIV Vereniging Nederland and SoaAids Nederland) and HIV prevention and HIV care providers (including those employed in HIV treatment centers and municipal health services) was organized to get more insight into their perspectives on and experiences with the issues faced by SSA living with HIV. Professionals were included based on the following criteria: 1) Individuals who have experience/have worked at professional levels on HIV/AIDS prevention among SSA migrants (living with HIV), e.g. in an health promotion institute or self-organization; 2) Individuals who have experience and expertise on the subjects of sexual behavior, gender, stigma, socio-economic and culture in the context of HIV/AIDS; 3) Individuals who are working with members of the target population, such as health professionals (e.g. medical doctors, HIV-consultants, volunteers or members of “Voorlichters Eigen Taal en Cultuur”).

Procedure/proceedings:
I: Introductions providing background and knowledge about the subject and the target population
II: Participants were assigned to 4 panel discussion groups. The topics of the groups were based on the literature review:

1. sexual risk behavior;
2. gender dynamics and HIV risk;
3. socio-economic factors and HIV risk; and
4. HIV-related stigma and HIV risk.

Each group brainstormed and generated beliefs, practices and behaviors in relation to HIV risk among SSA living with HIV. These health beliefs and behaviors related to their assigned topic of discussion were labeled positive (cultural empowerment), existential (no threat to health) and negative (threat to health) beliefs / behaviors.

Then the health beliefs/behaviors were classified into health beliefs that are deeply rooted in the tradition and culture, and recent or short-term health beliefs.
III: Group findings were presented and summarized.

Outcome: Overall, the expert workshop showed that many negative health beliefs and practices could be addressed, but that it was more difficult to recognize positive health beliefs and practices. Also, particular behaviors were thought to be both positive and negative. The outcomes of each of the four panel discussion are shortly described below.

Theme 1: Sexual Risk Behavior. With respect to sexual risk behavior, participants agreed that an individual's self-esteem is related to one's capacity to initiate and discuss condom use with one's partner. However, participants did not agree on the issues of concurrency (having multiple partners) and abstinence; opinions on the positive or negative nature of these behaviors varied extensively. Participants found it difficult to not be moralistic about abstinence, refraining from having sex could be considered as positive behavior as it protects you from STI/HIV transmission. On the other hand sexuality was always considered to be good only for reproduction purpose. Most of behaviors that came up were labeled 'negative'. The participants of this panel found it more difficult to come up with positive behaviors. Furthermore categorization in as 'traditional' or 'recent' was very difficult, since traditional and recent health beliefs were thought to be intertwined.

Theme 2: Gender dynamics and HIV risk. Participants in this panel discussion, unfortunately all female, emphasized that behavior of SSA women is to a great extent affected by the drive to improve their economic situation. Again, participants had difficulties classifying particular behaviors as either negative or positive. For example, traditional expectations of SSA men to adopt the role of a 'hypermasculine male' were not only perceived as negative, but also as positive, as it might imply that 'real' men take care of their wife and children; these gender norms and roles could therefore function as a social support mechanism.

Theme 3: Socio-economic factors and HIV risk. Participants in this panel encountered difficulties in brainstorming beliefs and practices associated with SES. They did agree, however, that one's social situation largely affects how one (is able to) deal(s) with HIV. For example, community involvement can improve quality of life and increase empowerment. It is nevertheless quite common that one's social environment restraints the individual, and it may take years for a migrant to break away from the social boundaries and participate in society.

Theme 4: HIV-related stigma and HIV risk. Brainstorming on HIV-related stigma generated a lot of discussion on words related to stigma, e.g. fear, knowledge, ideology versus practice, as well as the different cultural meanings and traditional practices. Participants agreed that particular factors can have both a positive and negative effect on HIV-related stigma and HIV risk, e.g. religion and social control or influence.

See Table 1 for an overview of the positive and negative labeled perceptions, beliefs, practices and behaviors discussed in each panel discussion.

Results from this workshop were integrated into interview schemes used in the Focus Group Discussions and individual interviews.

Table 1: Overview of the positively and negatively labeled perceptions and behaviors in the panel discussions of the expert workshop

	Positive: Cultural Empowerment	**Negative: Threat to Health**
Sexual Risk Behavior	• The idea that sexual abstinence is worthy of emulation in many religions • Sexual abstinence, as it reduces the incidence of HIV/STI • Male circumcision, as it reduces the risk of male-to-female transmission of HIV during sex	• Religious ideas propagation of misinformation HIV/condom use • Beliefs that women are responsible for condom use (also opposite) • Beliefs about condoms as sign of distrust and reduce of pleasure • The (perceived) need for SSA men to pass on sperm • The idea that SSA men need to sleep around is acceptable • Transactional sex practices among women • ‘Dry sex’ practice as a way to prevent STI
Gender dynamics and HIV risk	• Good women will keep their man happy • Real men take care of their family • ‘Dry sex’ practices among women to pleasure their husbands by which they might keep them from leaving • A taboo on talking about sexuality/condom use within the sub-Saharan community might protect people with HIV	• Male dominance hinders condom use • Focus on sexual pleasure of men • Beliefs that good women don’t talk about condom use • ‘Dry sex’ practices among women to please their husbands, as this makes them (feel) dependent on men • A taboo on talking about sexuality/condom use within the sub-Saharan community
Socio-economic factors and HIV risk	• Lack of access to social benefits leads to community norm among professionals to give aid • Lack of access to social benefits makes community members willing to empower themselves and motivates people to organize themselves	• Not speaking own language decreases control over own life and inhibits access to social benefits • Not knowing system inhibits access/promotes withdrawal
HIV-related stigma and HIV risk	• Social control as support system (e.g., positive living groups) Religious belief that God forgives (increases empowerment and acceptance)Religious belief that God takes away the blame increases empowerment and acceptance) • Religion promotes feelings of responsibility for others, community participation and communication about difficult topics • Both men and women should have children	• Being HIV-positive is viewed as norm violation and burden to the family • Being HIV-positive means that you’re promiscuous • Social control as (control) mechanism behind HIV stigma • HIV and sexuality are linked to shame; therefore, these are not openly discussed • Good women are always available to their sexual partner • The (perceived) need for SSA men to have multiple partners • The (perceived) need for SSA men and women to have children

4.5 Consultation with professional sounding board (June 2010)

Aim: The aim of this meeting was to discuss the results from the professional workshop and to prepare the topic list for the focus group discussions.

Consultation with an expert panel of social workers, HIV/AIDS support group coordinators, project officers from the main the sexual and reproductive health (SRH) organizations (SoaAids Nederland and HIV Vereniging Nederland) as well as researchers from Maastricht University and other professionals working in the SRH sector involving SSA migrants in the Netherlands resulted in a concept of the focus group topic list.

4.6 Focus group interviews with the target group (June- July 2010)

Aim: This research aims to answer the question: What are the main cultural and psycho-social factors and determinants of sexual risk behaviors among SSA in the Netherlands living with HIV?

Participants: Eight focus groups consisting of four male and four female focus groups of SSA migrants living with HIV in the Netherlands. Separate groups were held for men and women in order to create a freer atmosphere for openness and disclosure. Two sessions were held for French speaking participants, one for men and another for women. Each focus group comprised of four to six participants with a mean age of 38. In total there were 20 men and 21 women involved in the study originating from countries such as Ghana, Nigeria, Senegal, Rwanda, Burundi, Ivory Coast, Sierra Leone, Liberia, eleven of which had a partner (8 of which with HIV), 16 were without a partner. For 8 missing data on partnership was missing. Twenty-one participants had children, one of which was HIV positive. Most participants had only received low levels of education (16), ten participants medium levels of education and seven completed high levels of education (data on three participants was missing). Participants were reached using a referral method of recruitment through migrant self-support organizations for PLWH mainly in the Randstad of the Netherlands, the cities of Utrecht, Amsterdam, The Hague and Rotterdam. Two focus groups discussions were held in Groningen. In order to get a more representative sample, both English and French speaking migrants of both Muslim and Christian faiths were interviewed.

Procedure/proceedings:
The focus group discussions were facilitated and moderated by trained and/or experienced researchers, community workers or health care practitioners, using the general standard guide or topic list. The focus-group sessions were conducted between the months of June and July 2010. At the beginning of each session, the purpose of the focus group was outlined, reasons for voice-recording the sessions (for subsequent systematic analysis) were explained, and it was emphasized that there were no right or wrong answers. Basic demographic data was obtained through a structured questionnaire for basic personal information that was filled out by each participant.

The topic list used in the focus groups was developed in consultation with the professional sounding board (see paragraph 4.5) and based on the results of the literature review, discussed in paragraph 4.1, and the results of the panel discussions during the expert workshop (see paragraph 4.4). The focus groups were therefore designed with the aim of getting insights into the (culturally relevant) health beliefs and practices of risk of transmission of HIV for self and others among HIV positive SSA in the Netherlands.
Using the three domains of the PEN-3 Model (see Figure 1), open ended questions were designed to capture all the nine constructs of the PEN-3 model. On the first domain, questions were formulated to establish cultural identity, incorporating individual, family and community (neighborhood) factors influencing attitudes and practices of safe sex. On the second dimension of ‘relationships and expectations’, detailed questions were developed regarding the role of perceptions, enablers and nurturers. The questions probed the extent of knowledge, beliefs, attitudes and practices that promote or hinder safe sex practices among SSA migrants with HIV

in the Netherlands. Further probing questions sought to establish the role of perceptions of gender and gender roles as well as other family, community and structural factors that influence safe sex practices. Finally, discussions on cultural empowerment were facilitated by questions designed to give more information on positive, existential and/or negative factors that influenced safe sex practices. In this section, questions on the socio-economic status of the participants were found to be relevant in determining empowerment factors associated with the traditional/cultural roles of males and females that may have been compromised partly as a result of their migrant status.

Results from the eight focus group discussions were transcribed verbatim. The two sessions in French were then translated into English. The recorded sessions lasted about two hours each and yielded an average of 25 typed pages per focus group session. Next, the project leader and one analyst discussed the text and using the PEN-3 model came up with a coding system for analyzing the data. The texts were analyzed using Atlas.ti software with coding based on the three domains and nine constructs of the PEN-3 model. In order to capture the full spectrum of responses, a total of 38 codes were developed and assigned to the text. These were later collated in the output to fewer super codes to reflect the PEN-3 constructs.

Outcome and discussion:

In table 2 the positive, existential and negative perceptions, enablers and nurturers identified in the focus group discussions are listed.

Table 2: Focus group discussion results, positive existential and negative perceptions, enablers and nurturers

	POSITIVE: Cultural Empowerment	**EXISTENTIAL: No Threat to Health**	**NEGATIVE: Threat to Health**
PERCEPTIONS / BEHAVIORS	*Perceptions* • Religion/faith helps to be more positive and accepting of HIV • Spirituality/religion as source of comfort and empowerment • Fatalism-Belief in God helps to deal with HIV • Belief and trust in science and medication • Scientific basis of medication • Satisfaction with medical services: Doctors, HIV consultants and internists are trusted sources of information • Knowledge of safe sex as protecting self and partner • Knowledge of condom use for safe sex • Preference for long-term monogamous relationship *Positive behaviors* • Disclosure at onset	*Perceptions* • Women have mothering and caring role • Male gender role as provider and guardian for family *Behavior* • Reduced sexual activity • Reduction of short-term /concurrent sexual relationships • Choosing concordant partner • Sexual (erectile) dysfunction	*Perceptions* • Safe sex and condom use is stressful and risky as it can break. • Condom seen as a psychological barrier and loss of intimacy. • Condoms diminish sexual pleasure and erectile dysfunction • HIV diagnosis and sexual dysfunction • Distrust of condoms efficacy • Familiarity with primary partner and perception of reduced risk- safe not to use protection • Some (mostly)men have negative attitude to medication • Medicine makes people more sick • Disempowerment of women's sexuality • Male dominance of sexuality *Negative behaviors* • Men still tend to make all decisions about sex • Men less likely to

	of a relationship or upon diagnosis • Disclosure to family and close circle of confidants • Women feel empowered and take control of their sexuality • Women have a more positive outlook and accepting of HIV status • Women more likely to seek support and accept help • Women empowered to take responsibility for own sexuality • Women take control of their sexuality • Women take initiative to negotiate safe sex • Women able to negotiate safe sex • Practice of abstinence and celibacy • Sex only for procreation • Consistent Condom use • Abstinence as a prevention tool		seek support Transactional and risky sexual practices • Discordant couples and cross-infection • Unsafe sex for child-conception • Inconsistent condom use • Lack of disclosure to sex partner
ENABLERS	• Society empowers women to be more independent • Acces to medical services		• Churches fail to give support and provide confidentiality • Limited or lack of support and education services from churches, and sometimes high stigma and discrimination • Lack of economic means-discrimination in job market • Low education levels and lack of relevant skills • Denial /lack of work permits • Limited/inaccessible government support • Limited access to social services: housing, legal aid, financial support
NURTURERS	• Extended family gives safety, security and trusting relationships • Family gives support and encouragement • Having own family gives completeness		• Family cultural expectations put pressure on PLWH • Community expectations place pressure on PLWH • High levels of stigma against PLWH in

	and social acceptance • More acceptance and less stigma from (white)Dutch community • Acceptance by friends encourages safer sex behavior through sharing • Support group members help with medication • Partners interested in testing and finding out about their status (generally positive) • Social support from family and community		migrant community • No difference between African community in Africa and Netherlands • Experiences of stigmatization by neighbors and community • Negative experiences of discrimination: not using same utensils , neighbors pointing fingers • Isolation/avoidance by neighbors and community members

The process of coping with a positive HIV diagnosis is complex and highly dependent on individual experiences and circumstances.

The focus group discussions showed that SSA with HIV are also confronted with the challenge of adjusting and finding their way in the new and unfamiliar social environments that pose a challenge to their identity and self-perception. Traditional roles and established perceptions of one’s position in the community may not fit the new environment, and new forms of identities have to be renegotiated. This process is compounded by psycho-social implications of living with a life-long chronic condition of HIV and together can cause enormous trauma for migrants living with HIV. Also other studies have shown that psycho-social processes of identity creation related to a person’s perceived health threat significantly determine their health behaviors (Wiggers et al., 2003).

While family plays a significant role in social, economic and psychological support within traditional African contexts, migrants from sub-Saharan Africa living with HIV in the Netherlands have to do without this traditional bedrock of support. They therefore have to resort to building new relationships of trust and confidence in order to obtain the care and support they need to deal with their positive HIV status. The consequence of this is that many participants experienced several barriers to disclosing their HIV to their family members who were left back in Africa or in third countries. Most of them adopted a utilitarian approach that found less value to be gained vis-à-vis the likelihood of causing more psycho-social harm to their family relations by disclosing. This characteristic therefore underlies the high desire expressed by participants to build new family units and have children in order to rebuild this lost social structure of support and wellbeing. The consequence of this however is that some are likely to engage in unprotected sex for the purposes of conception, thus exposing themselves to higher risks for HIV.

In this research, respondents are asked to give their views regarding safe sex which is in this context is primarily understood as use of condoms for HIV prevention among others. Aspects that emerge in these responses include attitudes and behaviors choices under conditions of concordance and discordance of HIV antibody, abstinence and sex for procreation among others.

The notion of family is therefore culturally central within the SSA community and educational and/or intervention programs for prevention, care and support should also be embedded within this social structure and take into account the centrality of the family unit within the African community.

Subsequently, a sense of identity profoundly impacts on sexual behaviors, as it determines whether people believe in their own actions and how they make their choices (Heus, 2010).

These processes of psycho-social negotiation are often fraught with risks in migrant African communities that tend to exhibit higher levels of stigma associated with HIV and taboos about sexuality than the average Dutch society (Hues, 2010).

Nevertheless, participants in the research were able to overcome these challenge by creating closely knit support groups within their communities. It is in these groups that they obtain information, acquire knowledge and adopt new behavioral strategies of coping with the reality of HIV in their lives. It is however important to note that the degree of affinity that individual members have with the support groups vary significantly and this may affect the extent to which group processes impact individual behaviors change.

Nonetheless, the attitudes and behaviors acquired and shaped within these support groups and the migrant African cultural setting in general have an impact on safe sex behavior. Factors such as real or perceived self-stigma and discrimination, disclosure, ideas about safe sex and gender roles, consistency of condom use, as well as religion, and the desire to have children and sustain a family, all have an impact on attitudes and behaviors regarding safe sex. It is also worth noting that these factors are not fixed, but are constantly negotiated and shaped within the dynamics of interpersonal relationships in the community.

Differences expressed between the general Dutch population, and the SSA communities on the other regarding such attributes as levels of HIV related stigma, acceptance, support and possibilities for disclosure, suggests that there remains significant cultural barriers to safer sex behaviors within SSA migrant communities in the Netherlands. The nature and impact of these barriers require more investigation as it was beyond the scope of this research that dealt more with the identification of positive and empowering cultural attributes. The rationale for this focus was to identify those factors that are already present within the community and are therefore less likely to be resisted if integrated in intervention programs.

It was also evident from the responses that socio-economic circumstances, under which migrants with HIV live in the Netherlands, have significant impact on their vulnerability to HIV infection. These factors tend to have direct consequences on their access to and enjoyment of social services, economic well-being and mental health. Almost all participants expressed dissatisfaction with their socio-economic circumstances, which is directly related to their migrant and residency status and access to employment and other social services. As immigration rules and procedure continue to be tightened, the higher the likelihood that more migrants with HIV will be more vulnerable. A more detailed study of the impact of these factors on sexual health and HIV risk is therefore of vital importance.

The findings in this research shows that for persons living with HIV, the psycho-social trauma, stigma and discrimination associated with their HIV status, has significant implications on the (re)construction of their identity within a given cultural space. Therefore, proper diagnosing of cultural identity factors at the levels of the individual, family and community is considered to be the single most effective step in preventing HIV. According to Guidry et al (1998), “cultural sensitivity and willingness to use ethnic sensitivity on behalf of the minority community were cited as the top items needed in health programs to help eliminate health status disparity in minorities” (Guidry et al., 1998, p. 166).

In order to examine how HIV infection occurs within specific cultural, social, and psychological contexts of interpersonal relationships (DiClemente & Peterson, 1994), the PEN-3 model that centralizes the role of cultural attributes within a given community, and how these factors interact to determine individual behaviors was utilized. By paying particular attention to the positive cultural attributes within the community, it is possible to identify those attitudes and behaviors that promote safe sex to be prioritized for intervention development. The results therefore emphasize the role of the nurturers (family and community members), as opposed to focusing only on the individual (person) in determining behaviors change.

The results of the Focus Group Discussions are presented in a paper to be published:

Maiyo, J., Nunu Siya, L., Shiripinda, I., Bos, A. & Van Kesteren, N.M.C., (in preparation) A study of factors influencing sexual risk among HIV-positive sub-

Saharan Africans in the Netherlands: Applying a culturally sensitive approach using the PEN-3 theoretical model.

4.7 Consultation with the *professional* sounding board (July 2010)

Aim: This meeting was to update the group about the state of the project. Furthermore the preliminary results of the expert workshop and focus groups with SSA living with HIV were presented and discussed and compared. Finally the relevant themes to focus on in the individual interviews were decided on.

The discussion resulted in the following preliminary results organized by the themes of the professional workshop:

Gender*:*
Striking gender related results were found among the focus group discussion participants. SSA live according to traditional gender roles: women are supporting, respectful, homemakers and child caretakers. However the perceptions of male participants and female participants of what 'real men' should be like differ substantially: men believe 'real men' should always stay in control, stand firm and their HIV positive status 'weakens' and makes them 'soft'. Women on the other hand believe 'real men' to be considerate, sensitive and caring. Both men and women believe the HIV positive status is much more detrimental to the male identity than to the female identity. In some cases an HIV positive status seemed to have an empowering effect on women.

Positive elements were considered:

1. Good women will keep their man happy
2. Real men take care of their family
3. 'Dry sex' practices among women to pleasure their husbands by which they might keep them from leaving
4. A taboo on talking about sexuality/condom use within the SSA community might protect people with HIV

Negative elements or threat to health were:

1. Male dominance hinders condom use
2. Focus on sexual pleasure of men
3. Beliefs that good women don't talk about condom use
4. 'Dry sex' practices among women to please their husbands, as this makes them (to feel) dependent on men
5. A taboo on talking about sexuality/condom use within the sub-Saharan community

Also in the sexual risk-taking behavior differences in gender roles and expectations was apparent. Gender expectations might create barriers to condom use. Different meaning of sex, difficulties, need to protect yourself, temptation and expectations/desire to have natural sex

For men:
- Men have difficulties meeting somebody, because “you’re different”
- Men feel pressure to have sex without condom: “I need to have natural sex” or because the women complain that “you don’t love her”
- “Unless there is really love”, in that case it would be easier to have safe sex
- Men have ‘fears and worries’
- And men claim “temptation as reason for not being careful”
- The (perceived) need for SSA men to have multiple partners

For Women:
- Women have difficulties finding a man
- Women speak of ‘pleasure versus worry’
- Women believe they “have to protect yourself”
- They state “Temptation is sometimes strong to have “free sex”
- Some women have the ‘need to have someone to give me money’(in exchange for sex)
- Good women are always available to their sexual partner
- The (perceived) need for SSA men and women to have children

Stigma:
Positive elements
1. Social control as support system (e.g., positive living groups)
2. God forgives (↑ empowerment → ↑ acceptance)
3. God takes away the blame (↑ empowerment → ↑ acceptance)
4. Religion promotes feelings of responsibility for others, community participation and communication about difficult topics

Negative elements or Threat to Health
1. Being HIV-positive is viewed as norm violation and burden to the family
2. Being HIV-positive means that you’re promiscuous
3. Social control as (control) mechanism behind HIV stigma
4. HIV and sexuality are linked to shame; therefore, these are not openly discussed

Concealment
- Concealment within SSA community in Netherlands
- Concealment with religious leaders
- Concealment within close relationships (e.g., family, children, partner, friends)

Disclosure/openness
- Within Dutch community
- With health professionals, that is, SSA living with HIV are very positive about availability of health care
- ≠ Satisfaction with received health care

Regarding the openness of the target group the ease of the organization of the focus group discussions is remarkable. It seems that there is not necessarily a taboo on talking about HIV, sex and sexuality.

Regarding issues relating to Social Economic Status: The participants find the Dutch health care system satisfactory, however they encounter problems finding a job, legal papers appropriate accommodation. Many are left without social support system, yet they are positive about self-help groups and supporting relationships.

Positive elements:
1. Lack of access to social benefits leads to community norm among professionals to give aid
2. Lack of access to social benefits makes community members willing to empower themselves and motivates people to organize themselves

Negative elements or Threat to Health

1. Language barriers → lack of control over own life and inhibit access to social benefits
2. Not knowing the Dutch system inhibits access and promotes withdrawal
3. Many SSA do not (want to) integrate
4. SSA are left without family (no family to help you out) and many feel lonely
5. Sometimes don't know where to go to
6. Financial problems
7. Problems to find work which is related to either skin color or HIV status
8. "White people distrust black people"

Religion:

Religion is important to most SSA, though some have ambivalent feelings towards the church. Most have a positive relationship with God and feel supported.

This ambivalence is also illustrated with the importance of having children, they are an inspiration to live and 'you're never alone'.

4.8 Individual semi-structured interviews with HIV-positive sub-Saharan African men and women (October 2010- January 2011)

Aim: Information gathered from the literature review, consultation of the professional and target group sounding board meetings, linkage group meeting, and the professional workshop were used to develop a semi-structured interview scheme for SSA men and women living with HIV/AIDS. The focus of these interviews was to explore their perspectives on how socio-cultural factors shape their perception of HIV and its influence on their (sexual) lives, HIV/STI risk behaviors, and factors hindering or promoting access to HIV prevention and HIV care. As emphasized by Airhihenbuwa (1995), the focus of these interviews was in particular on those health beliefs and behaviors that are rooted in tradition and culture. More specifically, the interviews were designed to investigate the relationship between processes of gender identity formation and HIV-positive diagnosis among heterosexual SSA living with HIV in the Netherlands. The objective was to establish possible links between culturally determined gender identities and safer sex behavior within the target population.

Participants and procedure: Purposeful sampling was used to recruit participants stratified by ethnicity and gender. The interviews were conducted face-to-face. To enhance participation, 1) participants were recruited via key figures of the target population, 2) individuals of the same or different cultural background (depending on interviewee own preference) conducted the interviews, and 3) both interviewers and interviewees were paid for their contribution. Twenty-six in-depth semi-structure interviews were conducted.

Trained health-care support professionals and social workers with experience in working with PLWH conducted the interviews. The interviews were recorded with the consent of the participants and transcribed verbatim. The interviews conducted in French and Dutch language were translated into English. All participants were members of support groups for SSA living with HIV in the Netherlands, majority of who reside in the four major cities in the Netherlands including Rotterdam, Amsterdam, The Hague, Groningen and Utrecht.

The output was analyzed using the Interpretative Phenomenological Analysis (IPA) method (Smith & Osborn, 2003). IPA is used to explore in detail how participants make sense of their personal and social world by focusing on the meanings that particular experiences, events and states hold for individuals (Smith, Flowers, & Larkin, 2009). This process was achieved by categorizing the participants' responses under three main codes and several sub codes. The main codes were a)

HIV diagnosis and identity, b) HIV and gender identity and c) HIV and safer sex. Using Atlas.ti, the interviews were assigned to these codes and the output generated was further subjected to the IPA analytical process to further determine the categories of relationships and interpret the meanings that participants attached to their experiences living with HIV. This process enabled us to determine how participants make sense of their HIV-positive diagnosis, the impact this has on their (gender) identity and how this affects their perception about safer sex in the context of HIV transmission.

Like the other research activities in this project, this study was guided by the PEN-3 theoretical framework and conceptual model developed by Airhihenbuwa (Airhihenbuwa, 1995) in order to situate the analysis within the cultural context of SSA PLWH in the Netherlands.

Having explored some of the key theoretical and conceptual approaches underpinning the interaction between (gender) identity formation, HIV and safer sex behavior, the results presented in the following sections will seek to empirically establish the psycho-social linkages between the changing processes of gender identity formation resulting from HIV diagnosis and safer sex behavior. The rest of the paper presents the results of the research based on the cluster-coding of responses from the individual interviews. The main elements emerging from the responses are presented in three broad categories: Impact of HIV-positive diagnosis on identity; impact of new identity on perceptions of safer sex; impact of socio-cultural expectations on identity and sexual health.

Outcome: The results show that HIV-positive diagnosis significantly impacts participants' gender identities at the personal, interpersonal and societal levels, influencing perceptions about and experiences regarding safer sex behavior.

This study shows how the construction of gender identities within the HIV positive SSA community in the Netherlands is closely associated with perceptions of the 'ideal' man or woman within the SSA migrant community. These notions are derived largely from norms prevailing in Africa and conveyed into the new migrant African community (re)created in the Netherlands. The process of recreating these identities are mediated by other social factors such as fusion of multiple 'African' identities, experiences of migration and, for the target group, experiences with HIV and associated stigma. This is by no means a linear and homogenous process, but one that is complex and heterogeneous based on such factors as individual experiences, length of stay in the Netherlands, relational networks and levels of integration within the wider Dutch society among others.

Significantly though, individuals living with HIV from SSA Africa in the Netherlands belong to a small and closely knit community. This is especially the case for those with active membership and participation in support groups such as the majority of participants in this study who were drawn from such groups. They therefore share certain common characteristics and experiences that are made explicit in their responses. The outcome of this socially constructed process, in terms of gender identity and roles within the SSA community in the Netherlands, is therefore quite specific. Heightened insecurities and vulnerability associated with low job skills, unemployment and in some cases undocumented migrant status therefore significantly influences processes of identity formation, coping strategies and relations between men and women within this community. New networks and layers of dependency and vulnerability emerge within the group and women are more disadvantaged as they tend to be pushed into even more precarious positions of dependency. While some men tend to take advantage of the emerging gender power imbalances, other men are also forced into new positions of vulnerability as their traditional roles as family providers and bread-winners are compromised.

Emerging perceptions of desirable or ideal characteristics of men and women within the African community in the Netherlands are therefore renegotiated and reinvented. The resulting gender related identities inform new lifestyle strategies for HIV positive heterosexual men and women within this community, such as partner choice, sexuality, and to some extent, safer sex behavior. What emerges in the research is a general pattern of mutually reinforcing expectations for an ideal partner: a caring and supportive partner who shares in the belief of the importance of family and children as well as providing a sense of stability and socio-economic security. These expectations however place significant social pressures on the group or community members to fulfill these roles and the pressures in turn lead to lifestyle choices that either heighten vulnerability or increase susceptibility to HIV infection or transmission.

Negotiating a new gender identity occurs at several levels cutting across the individual, the interpersonal and societal levels. For many participants in this study, the struggle to make meaning of their new identities in relation to a positive HIV diagnosis includes dealing with social stigma about the patient’s personal morality and social standing. Furthermore, at the interpersonal level, changing perceptions and relationships with partners often contribute, in the case of women, to the perception of loss of acceptable feminine qualities resulting in vulnerability, self-doubt and a loss of self-worth. In a society where a woman’s identity is determined by her ability to find and keep a man, sustain a relationship, and build a family, the failure to live up to these social expectations can have severe consequences on one’s identity.

At the societal level, migrant SSA women living with HIV in the Netherlands, for example, are more likely to be less educated, unemployed and lacking relevant skills for the Dutch job market. Additionally, these women experience marginalization and disempowerment associated with gender-related positions they occupy vis-a-vie their male counterparts. These imbalances are structurally embedded within African cultural traditions that privilege men over women. The strong cultural significance placed on the ability to raise a family and have children exerts strong social pressure, especially for women to have children despite the attendant risks of exposure due to cross-infection.
Exacerbated by vulnerabilities of migration, these dependencies may push women into more humiliating reliance on the men. Women are therefore less likely to have the power and economic independence to negotiate safe sex and insist on condom use. This is especially the case for those who, due to extreme dependency, exchange sex for income as they can rarely mention safe sex at all (Türmen, 2003).

Perceptions of vulnerability and perceived loss of a ‘good’ gender identity cuts across the gender divide, leading to negotiations of new identities and gender-role relations between men and women. Migration and the struggles of curving out an existence in new socio-economic environments also present new dynamics that further influence emerging gender-role relations that may impact safer sex behavior among migrants from SSA living with HIV. Women’s vulnerability for instance, is mitigated by new socio-economic realities associated with changing education levels, income and employment patterns as well as migration makes possible for some women to feel empowered and become proactive in decision-making. However the few examples of growing assertiveness on the part of some women does not negate the fact that the majority of them are still significantly disadvantaged on the basis of gender and still suffer the consequences of gender disparity and socioeconomic vulnerabilities that significantly impact on their self-efficacy for safe sex.

Policy implications
The complexity of these emerging gender-related identity dynamics has significant relevance for public health intervention initiatives. For instance, perceived loss of a masculine identity for a SSA men living with HIV, can impact negatively on their self-efficacy and safer sex behavior. Interventions that seek to shore-up positive self-image and self-esteem are therefore important in prevention strategies for the target community. For example, the desirability of a physically and visibly healthy appearance among African men can be a significant motivating factor to pursue a healthy lifestyle and a potential entry point for intervention programs that promote safer sex as part of a holistic approach to health and healthy living.

Since a positive gender identity for SSA women is associated with notions of femininity derived from a woman's functional role as a mother and wife, societal expectations to fulfill these roles exert significant pressure on women living with HIV. Dealing with these deeply entrenched and internalized sexually constructed self-perceptions can be challenging. Drawing from the PEN-3 model that emphasizes positive cultural attributes in development of intervention strategies, initiatives that seek to empower women to reconstruct and use their sexuality to their advantage may be preferable to those that explicitly promote cultural (behavior) change.

The consequences of migration and HIV related identity formation is not always negative. In some cases, new socio-economic circumstances may also empower women with a new sense of courage, independence and security. This is however only possible if intervention strategies take a holistic approach that include attention to legal residency, skills training, job placement, counseling and other forms of social support. Furthermore, power imbalances that are manifested in such domains as the household and family level require different intervention strategies of community outreach for instance through support groups and religious organizations.

The impact of HIV positive diagnosis on one's identity in relation to gender and gender roles can have significant impact as a psychosocial determinant of safer sex behavior. The study showed that women were less likely to have concurrent partners than men and they were less likely than men to use condoms with concurrent partners. In this study, despite the existence of culturally determined gender identities that seem to exacerbate gender vulnerabilities, participants demonstrated high knowledge of safer sex as well as high levels of self-reporting regarding safer sex behavior such as monogamous sexual relationships and condom use.

Still the research shows mixed and sometimes conflicting results regarding perceived HIV related gender identity deficiencies among the participants. Perceived shortfalls in relation to ideal gender roles in the community were manifested in low levels of self-esteem, feelings of inadequacy and failure to live up to gender identity related social expectations. These mixed results seem to suggest that perceived traditional gender identities may be undergoing a process of constant transformation. For healthcare practitioners, this implies a demand for more nuanced and differentiated as opposed to generalized intervention approaches at the individual level.

Results are described in greater detail in a paper to be published:
Maiyo, J., van Kesteren, N.C.M. & Nunu Siya, L. (in preparation) Africans don't love, it's money: HIV, gender identity and safer sex among HIV positive heterosexual men and women of Sub-Saharan African origin in the Netherlands.

4.9 Integration of results Phase I: Needs assessment

The needs assessment began with a literature review on (a) behavioral and psycho-social determinants related to HIV/STI transmission in SSA living with HIV; and (b) the socio-cultural and economic contexts of HIV/STI transmission within this target group. Based upon the outcomes of the literature search an expert workshop was organized to get more insight into the health beliefs and practices in relation to HIV risk among SSA migrants living with HIV in the Netherlands. Panel group discussions with 25 experts who had worked with SSA living with HIV or had expertise on this topic focused on positive, existential and negative health perceptions and practices in relation sexual (risk) behavior, gender dynamics, stigma, and socio-economic status. Subsequently eight focus groups among 41 male and female SSA living with HIV were conducted to supplement and validate the outcomes of the expert workshop. Finally, individual interviews among SSA men and women living with HIV (N=26) addressed the influence of gender roles, norms and expectations on sexuality and sexual decision-making among the target population.

The samples of the SSA men and women living with HIV in the needs assessment are convenience samples: the men and women were recruited through contacts of professional and self-organizations of the target population.

Between research activities meetings were held with an expert sounding board and a lay sounding board to solicit input regarding needs assessment activities and the data collection process.

In the theme of ***sexuality***, results showed that SSA freely discussed issues of sex and sexuality, which raised a question about the stereotype taboo of discussing sex with the target group. But in regards to relationship, it was difficult to find partners because of fear of disclosure. Individuals feared to transmit infections and/or feared to be discriminated. This could be explained by the fact that the expectations of each other were not the same.

Stigma was still an issue among the target group and it was context related. Although some SSA felt encouraged by support groups, disclosure was limited. Some women were afraid to disclose their status to their partners due to fear of violence. However, disclosure to health care provider was not a problem but had double standard.

Gender did play part in the issue of stigma because of the expectation of the male and female roles. This was more relevant in the case of ***children***. Children were seen as a method of passing a legacy and lineage to the family tree. One of the board members asked if this perception was also relevant if one of the partners was Dutch or not from an African background. This question was not completely answered because it was not integrated into the interview scheme. However, the perception could be said to be relevant because some of the SSA had children with non-African partners. They said children had added meanings to their lives and made them to live a responsible life. Some of SSA hearts were broken because of inability to bring their children to the Netherlands.

In the theme of ***socio economic status (SES)***, not having a job was destructive to their wellbeing. Colored people in particular or migrants in general have problems accessing the labor market, but it was more relevant for individuals living with HIV due to compulsory disclosure of the status.

The role of ***religion*** depended on the individuals. If the individual was just a follower of certain religion or only associated him/her with certain religion, seeking comfort with God depended on how the church or pastors treated people with HIV. If the pastor or the church reacted negatively to individuals living with HIV, then the individuals would be disappointed and turn away from the particular church or religion in general. However if the individual had faith in God, he/she would continue to seek comfort with God even if it meant joining another church.

SSA were, in general, positive about basic access to ***health care*** in the Netherlands. To some treatment helped them to focus on issues other than their

HIV-status, because life expectancy is much longer and better when on treatment. However, the quality of life of some of the very ill SSA residing in Dutch institutions was questioned because of culturally appropriateness.

All in all, the needs assessment research strategy resulted in a better understanding of the beliefs, attitudes, and behaviors of the target population, including the cultural values and behaviors, and the socio-cultural context of HIV risk in diaspora. Living with HIV/AIDS has consequences for (1) one's identity, (2) relationships with others (family, friends, acquaintances), (3) for partner relationships and (4) within migrant situation. The results are summarized in table 3 and figures 2 and 3.

These results provided the evidence base for the specification of the goals and objectives for the intervention (phase 2).
Table 3 shows the summary of the needs assessment. It contains a list of the perceptions, enablers and nurturers which either positively influence/are supportive of safer sexual behavior among SSA men and women living with HIV/AIDS in the Netherlands. These perceptions, enablers and nurturers have been gathered in literature review, semi-structured interviews, focus group discussions, and meetings with the professionals and target group sounding boards.
The results of the needs assessment are visualized in figure 2 and figure 3. Figure 2 shows all the issues, consequences, and corollaries a SSA person living with HIV/AIDS encounters and/or has to cope with. The issues are clustered in five domains: (1) social, (2) economical, (3) religious, (4) emotional, (5) relational and sexual. The outer circle depicts the social environmental actors which are of importance to the SSA living with HIV/AIDS in the Netherlands.
Figure 3 displays the 'needs' of the SSA persons living with HIV/AIDS in the Netherlands for each domain. (1) Social domain: Creating and/or maintaining a support network (e.g., family, friends and neighbors), (2) economical domain: Coping with stress in daily life caused by legal, housing and employment status, (3) religious and (4) emotional domain: Accepting HIV diagnosis and finding positive meaning in being HIV-positive, (5) relational and sexual domain: Creating and/or maintaining a satisfactory and safe relationship with a partner.

These results were used as the basis for and elaborated on in Phase 2 of the project.

Table 3: Summary of positive and negative perceptions, enablers and nurturers of safer sex behavior among SSA living with HIV/AIDS

POSITIVE PERCEPTIONS ***Knowledge, attitudes and/or beliefs that positively influence safer sex behavior***	**NEGATIVE PERCEPTIONS** ***Knowledge, attitudes and/or beliefs that negatively influence safer sex behavior***
women have a more positive outlook and are more accepting of HIV status	men are less likely to seek support
women are more likely to seek and give support	HIV positive diagnosis negatively affects sexual functioning (e.g., erectile dysfunction)
women feel empowered by taking responsibility not transmitting HIV	some men have a negative attitude towards medication
women take initiative to negotiate safe sex	perception that medicine makes people more sick may lead to non-adherence
religion/faith helps to be more positive and accepting of HIV	condoms as not being 100% safe

belief and trust in science and medication	condoms as a psychological barrier and loss of intimacy
strong awareness of the need to protect self and other	condoms diminish sexual pleasure and erectile dysfunction
awareness of condom use for safer sex	familiarity with primary partner and perception of reduced risk
practice of abstinence for safer sex	some men prefer discordant partner to avoid cross infection (protect themselves)
awareness of concordant risk of cross-infection	male dominance of sexuality
women have a mothering and caring role and may therefore be more careful about transmission	practice of unsafe sex for child-conception
women have a mothering and caring role and may therefore be more nurturing for the affected (e.g., partner, children)	practice of transactional sex
men are perceived as provider and guardian for the family and may therefore take better care of their health (avoid cross-infection and improved health-seeking behavior)	lack of disclosure to sex partner(s)
POSITIVE ENABLERS ***Availability, accessibility, acceptability, and affordability of resources that are supportive safer sex behavior***	**NEGATIVE ENABLERS** ***Lack of availability, accessibility, acceptability, and affordability of resources, and which contributes to sexual risk taking behaviors***
Dutch society empowers women to be more independent	lack of social and economic support structures
satisfaction with medical services: Doctors, HIV consultants and internists are trusted sources of information	limited/inaccessible (governmental) services: housing, legal aid, financial support
	lack of economic means-discrimination in job market
	low education levels and lack of relevant skills
	denial/lack of work permits
	limited or lack of support from churches, and sometimes high stigma and discrimination
POSITIVE NURTURERS ***Influence of significant others and community contexts that are supportive of safer sex behaviors***	**NEGATIVE NURTURERS** ***Influence of significant others and community contexts that negatively affect safer sex behaviors***
extended family gives safety, security and trusting relationships	lack of family support structures
extended family gives support and encouragement	family cultural expectations put pressure on HIV-positive SSA

having own family (e.g., partner and children) gives completeness and social acceptance	migrant community expectations put pressure on HIV-positive SSA
partners are generally interested in testing and finding out about their status	high levels of stigma against PLWH in neighborhood and community
more acceptance and less stigma from (white) Dutch community	church leaders and members fail to give support and provide confidentiality
acceptance by friends encourages safer sex behaviors through sharing	
support group members give support (e.g., with medication) and function for information point	

Figure 2: Visual representation of the issues related to living with HIV/AIDS among SSA men and women in the Netherlands

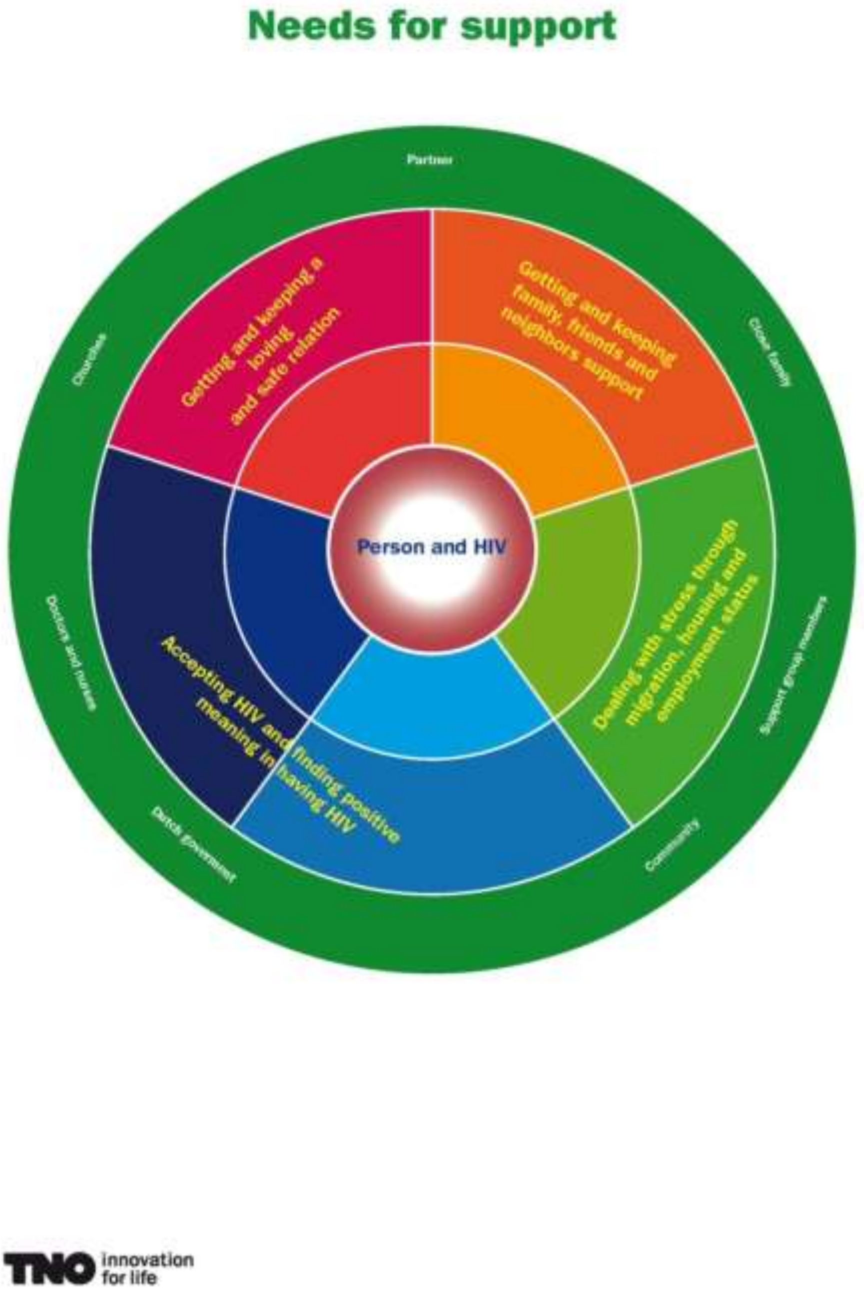

Figure 3: ‘Needs’ of SSA people living with HIV/AIDS in the Netherlands

5 Results Phase 2: Intervention Development

Phase two concerned specifying clear, well-defined intervention goals and objectives and recommending culturally appropriate methods and practical strategies. To do so, both professionals and members from the target group were consulted to give feedback on outcomes of the needs assessment phase during four consultation meetings/workshops. Also, two professional workshops were set up to receive feedback on the initial objectives for a program to reduce HIV/STI infections among SSA living with HIV.

Generally speaking, the process for developing the intervention comprises four steps: (1) optimizing cultural fit by conducting a needs assessment; (2) specifying intervention goals and selecting intervention methods and strategies; (3) designing intervention materials; and (4) pilot testing and refining the intervention.
Intervention development started with four consultation meetings/feedback workshops with the target population to reflect on the interpretation of research results of the needs assessment and to brainstorm future intervention activities. To get more insight into the perspectives of experts of several disciplines on the research outcomes and priorities for intervention development two professional workshops were held.

5.1 Consultation meetings of target group sounding board (April – May 2011)

In April and May 2011, TNO and HVN met with four different HIV-positive migrant self-support organizations and invited representatives of five partner organizations. During these meetings results of the Needs Assessment Phase were discussed.

Aim: The main goal of these meetings was to reflect on the results of the needs assessment, collect, discuss and prioritize objectives for the program development - the second phase of the research process.
On the other hand, the HVN’s Project Diversity Officer was interested in evaluating the HVN’s information materials, and to collect ideas on how to improve HVN’s current provision of information. Both partners integrated their ideas and came up with a single plan for meeting with the target group.

Participants: Together, TNO and HVN met with NOPPAL in Groningen (8 people), PAMA in Amsterdam (10 people) and TAM-TAM in Tilburg (16 people). TNO/HVN also invited representatives of the five partner organizations (Shiva, SOAAIDS Nederland, The World House, PWW and NAMIO) to the HVN offices in Amsterdam for a meeting. Some of these participants had already participated in the sounding boards and workshops in Phase one.

Procedure/proceedings:
The following issues were discussed during the consultation meetings of the target group sounding board:
Phase I, needs assessment, resulted in four main domains of needs among SSA people living with HIV/AIDS in the Netherlands. These four ‘needs’ were the starting points for the program objectives:

a. Accepting HIV diagnosis and finding positive meaning in being HIV-positive
b. Creating and/or maintaining a support network (e.g., family, friends and neighbors)
c. Creating and/or maintaining a satisfactory and safe relationship with a partner
d. Coping with stress in daily life caused by legal, housing and employment status (see figure 3)

Other possible objectives the program could focus on as a result of the needs assessment were:

- Understand one's own sexual identity, including a sense of being male or being female
  a. Be aware of one's own gender identity
  b. Understand family, friends and community pressures to be masculine or feminine
  c. Identify perceptions/actions that feel encouraged about sexual relationships
- Being able to be emotionally close to another human being and to accept closeness in return
  a. share intimacy (be emotional close)
  b. care about others
  c. connect or attach emotionally to others
  d. Be open and share feelings and personal information with others
- Have healthy and enjoyable sexual relationships

Four meetings/workshops were held each with a theme related to one of the domains: (1) (personal strategies) to live positively with HIV; (2) create and/or maintain a support network (e.g., family, friends and neighbors); (3) a satisfactory and safe relationship with a partner (e.g., family, friends and neighbors); (4) cope with stress in daily life caused by legal, housing and employment status.

Each workshop consisted of several exercises.

Exercise 1: *To get feedback on the research results and on what consider the participants as most important outcomes and strategies?*

- The first question was "Which outcome do you find most important and why"
  - Participants were provided with a visual presentation of the research results (figure 2 and figure 3)
  - Participants were asked to write down most important research result on a post-it (i.e. the most important issue the intervention should focus on)
  - The post-its were collected, sorted and counted

- The second question was related to the specific theme of the workshop: e.g. "What do you do to find positive meaning in being HIV-positive?"
  - Participants were provided with one of the possible aim for intervention development, that is finding positive meaning in being HIV-positive
  - Participants were asked to write down on a post-it what they considered as most important
  - Inventory on a flip-over, open discussion on why

Exercise 2: *To get insight in how familiar participants are with educational materials of HVN*

- First, participants were provided with pictures of relevant pages of the website of HVN. By means of red and green cards participants were asked whether they agreed or disagreed with the statement: "I know these pages".
  - How did they know these pages? → asked to write the answer on a post-it
  - Whether they read the pages → by means of red and green cards
  - Their your opinion in general on the website(pages) → asked to write the key words on post-its
  - Possibly: Whether the website could help in finding positive meaning in being HIV-positive → by means of red and green cards
- Second, participants were provided with a brochure of the HVN

By means of red and green cards participants were asked whether they agreed or disagreed with the statement: “I know this brochure”.

- How did they know the brochure → asked to write the answer on a post-it
- Whether they read the brochure → by means of red and green cards
- Their your opinion in general on the brochure → asked to write the key words on post-its
- Possibly: Whether the brochure could help in finding positive meaning in being HIV-positive → by means of red and green cards

Exercise 3: *To identify preferences for intervention channels*
In this exercise participants were provided with four possible channels for supportive interventions:

1. internet
2. brochures
3. doctor, HIV nurse or others
4. self-help groups

Participants were asked to write down on (separate) post-it’s the most important advantage and disadvantage of each ‘channel’ for supportive interventions in giving positive meaning to being HIV-positive. Then participants were asked to rank the channels from 1 (best option) to 4 (worst option).

Outcome:
The target group expressed “*Dealing with stress with migration, housing and employment status*” as the most important issue to be dealt with.
Most important structural factors to intervene upon according to the target group sounding board were:

1. Migration status
2. Work (not being allowed to work, not having appropriate work)

Other important factors which were prioritized in the meetings/workshops were:
Housing
Financial aspects (costs for living, costs for health insurance)
Availability/accessibility care

- Wish for support on economic aspects
- Priority of migration status and work

In terms of PEN3: the target group participants of the meetings/workshops prioritized the issues to intervene on (in order of importance):

1. Negative enablers: Lack of availability, accessibility, acceptability, and affordability of resources, and which contributes to sexual risk taking behavior – i.e. changing or improving the availability, accessibility, acceptability and affordability if resources
2. Positive perceptions: Knowledge, attitudes and/or beliefs that positively influence safer sex behavior – i.e. reinforcing and supporting these perceptions
3. Positive enablers: Availability, accessibility, acceptability, and affordability of resources that are supportive of safer sex behavior – i.e. reinforcing, supporting and improving these resources

As for the preferred channel: the SSA population is not known for their reading culture. The internet and brochures, despite the fact that they were nicely illustrated were not the preferred channel to receive information. The website was perceived as very ‘Dutch oriented’.
The medical professionals were found to be reliable sources of information and self-help groups were found to be very supportive. In fact most SSA living with

HIV/AIDS were positive about the Dutch medical professionals and the health care they received.

5.2 Professional workshop (June and July 2011)

In June and July 2011, TNO, HVN and SOAAIDS Nederland (SANL) organized two professional workshops.

Aim: The aims of these professional workshops were (a) to present and reflect on the research results of the project and (b) to brainstorm future intervention activities. Professionals from different disciplines and with different specialties and target group members gave feedback on the initial outline for the prevention program. The workshop focused on determining the strength of the cultural embedding of health promoting behaviors and related practices and beliefs, as well as the cultural appropriateness. In addition, ideas on culturally appropriate prevention messages, theory-based intervention methods, practical applications and places for delivery have been discussed. The results of these workshops has nurtured both the specification of intervention goals and the translation of project results into a plan for HIV preventive intervention activities.

Participants: Professionals from various different disciplines and backgrounds working with issues relating to HIV/AIDS from approximately 32 organizations across the country were invited to participate in these workshops.

Procedure/proceedings:
First, the outcomes of the data collection process on HIV-risk (reducing) behaviors and related psycho-social processes were presented (project phase 1). Subsequently, experts were asked to prioritize problems and needs of the target population and to brainstorm on strategies for developing and implementing HIV-preventive interventions. The participants were asked to:

1. Collectively determine priorities in problems and needs based on research results: by placing stickers on the most important perceptions, enablers and nurturers and discussing the reasons the participants prioritized the issues and needs of the target group
2. Compare their ranking with the priorities determined by the target group: the answers were compared to the prioritized issues and needs determined by the target group during the target group consultation meetings/workshops
3. Collectively determine intervention goals
4. Collectively determine intervention options

Outcome:
In terms of PEN3: the professionals in the workshop prioritized the issues to intervene on (in order of importance):

1. Negative nurturers: Influence of significant others and community contexts that negatively affect safer sex behavior
2. Positive enablers: Availability, accessibility, acceptability, and affordability of resources that are supportive of safer sex behavior – i.e. reinforcing, supporting and improving these resources
3. Positive perceptions: Knowledge, attitudes and/or beliefs that positively influence safer sex behavior – i.e. reinforcing and supporting these perceptions.

   Negative Enablers: Lack of availability, accessibility, acceptability, and affordability of resources, and which contributes to sexual risk taking behavior – i.e. changing or improving the availability, accessibility, acceptability and affordability of these resources.

So, the main difference between the priority of the target group and the professionals was that the latter prioritized intervening on an interpersonal or community level, the social environment of the Sub Saharan Africans living with HIV/AIDS, especially focusing on 'HIV-related stigma' in the community, whereas the target group population clearly prioritized intervening on the 'higher' system levels, or the societal environment, focusing on access to housing, legal aid, and financial support. The prioritized objectives are depicted in table 4.

Table 4: Priorities of the target group and professionals

	Target Group	**Professionals**
Positive Perceptions	• Acknowledge importance of (need to) accept HIV • Practices of living positively	• Women feel empowered by taking responsibility not transmitting HIV • Men and women: strong awareness need to protect self and other
Positive Enablers	• Having access to treatment • Having trust in providers of treatment	• Satisfaction with medical services: Doctors, HIV consultants and internists trusted sources of information
Negative Enablers	• Lack of work permit • Lack of access to proper work • Limited access to housing, legal aid, and financial support	• Lack of economic means- discrimination in job market • Low education levels and lack of relevant skills
Positive Nurturers		• High levels of stigma neighborhood and community • Church leaders/ members fail to give support

6 Final Program Objectives and recommended program methods

The main intervention goal as stipulated at the start of the project was: Reduction of sexual transmission of STI/HIV among SSA men and women living with HIV/AIDS.

As discussed at onset of the project the target population of the intervention is:
- Men and women od sub-Saharan African descent living with HIV
- 18 years of age and older
- Migration status: with or waiting for papers (Dutch passport, Permanent residence permit, Temporary residence permit, Waiting for papers (so-called A-status)
- Length of knowing HIV-status: > 1 year

The point of entry is mainly the ‘neighborhood’ or community and ‘Person’.
At large, four categories of themes of influence on safer sex among SSA living with HIV were distinguished in the needs assessment:
1. Religious: Spirituality and the church is an important source of (emotional) support for the target group. “Accepting and living positively with HIV” is of importance.
2. Social: (lack of) social support, coping with social expectations, and HIV-related stigma and disclosure are issues the target group has to cope with
3. Relational and sexual: HIV-related impediments to fulfill gender role expectations and changing to one’s identity, HIV-related hindrance to starting relationships, sexual communication and (un) safe sex are but a few of the mentioned issues.
4. Economical: lack of social (formal) participation in Dutch society, i.e. education, housing, work force which is strongly correlated to migration status. For the SSA men living with HIV this lack of formal participation is closely linked to one’s identity and loss of masculinity. Not being able to live up to the male gender roles and expectations has a two-way interaction with migration status and accepting the HIV-status.

The members of the target group prioritize the following issues to intervene on:
1. Lack of formal participation
2. Issues concerning spiritual or religious comfort and social support in accepting and living positively with HIV
3. Sexual relational aspects: having children and a family is highly valued in SSA cultures.

The issues associated with HIV-related stigma are not mentioned by the target group as an important intervention objective. The target group participants emphasize the importance of structural objectives on societal or supranational level, improving formal participation.
The professionals on the other hand prioritize much more informal social participation at an interpersonal or community level:
1. Social aspects, specifically HIV-related stigma
2. Issues concerning spiritual or religious comfort and social support in accepting and living positively with HIV

The intervention sub goals were formulated as follows:
- Accepting HIV and finding positive meaning in living with HIV
- Feeling empowered by having safer sex (women)
- Reducing stress of limited access to work and educational services and/or Improving access to the labor market

- Having (improved) access to treatment/health care services and professionals
- Reducing HIV-stigma in neighborhood/community and/or improving dealing with HIV-stigma in neighborhood/community

Integrating the priorities of the target group and professionals we recommend the intervention to focus on improving ‘**social participation’** SSA living with HIV on a structural societal and on an individual personal level. Social Participation is engagement in a variety of roles with others. Social roles include domestic roles of home-maintainer and caregiver, interpersonal roles of friend and family member, major life roles as student, worker and volunteer, and community roles such as participant in organizations, religious participant and hobbyist. Social participation is actively and constructively participating in informal and formal links (Walraven 2002). By this participation an independent position in society can be acquired and one can contribute to society. Two forms of social participation can be distinguished: formal and informal. *Informal participation* is relationships with family, friends, and peers. For many vulnerable groups, the lack of social informal networks form additional risks to well-being. *Formal participation* is defined as the participation in core institutes of our society such as educational and welfare systems, sports and employment. The opportunities for participation in the society are dependent on educational level, employment status, income and also housing accommodation.

Social participation is a key determinant of successful living and therefore an important emerging intervention goal for health professionals. Social participation definitions mostly focus on the person's involvement in activities providing interactions with others in society or the community. Depending on the main goal of these social activities, six proximal to distal levels of involvement of the individual with others can be distinguished: on a participation level 1) doing an activity in preparation for connecting with others, 2) being with others, 3) interacting with others without doing a specific activity with them, 4) doing an activity with others, and on a social engagement level 5) helping others, and 6) contributing to society (Levasseur et al 2010).

The goal of the intervention should be:
The promotion of social (formal and informal) participation of SSA people living with HIV.

Determinants of social participation on which the program objectives could focus, are:

- Social competence
- Empowerment
- Self-management
- Skills to function in the Dutch society and in relation to others
- Structural support from the society, opportunities to participate in informal and formal networks, e.g. employment, housing and education.

An integral multi-method, including structural societal changes, approach is recommended. To achieve (determinants of) social participation one may think of the following notions of methods on a structural level:

1. Assigning a case manager to each SSA person living with HIV as a support to refer to specific institutions, to help with disease management
2. Developing multi-scenario methods to which the case manager could refer the participants
3. Combining instruments to improve communication and evaluation (e.g. software for adequate case management)

4. Optimalising the content, presentation and implementation of existing self-help groups, support groups, and skills training
5. Creating an infrastructure of multi-sectorial networks focusing on sexual health for Sub Saharan African people living with HIV
6. Creating networks on a community level actively involving target group in activities
7. Creating an umbrella network on a societal level with medical professionals, health care, health insurance companies
8. Improving the quality and quantity of adequate possibilities of engaging in informal or formal networks
9. Providing the necessary resources to combat discrimination on for instance the job market and providing employment opportunities

Some of these ideas have been applied in the project “Integrale benadering van vrouwelijke migranten met chronische pijnklachten” (Nederlands Paramedisch Instituut) (van Vliet, de Gruijter, and Singels 2006).

In addition to the structural methods, methods focusing on individual and personal change could focus on social competence including:

1. Supportive self-help groups
2. Skills training in social competence, e.g. developing independence, relationships with others and functioning in Dutch society
3. Inauguration, initiation, and instruction in Dutch (medical) HIV related society
4. Training in responsibility, commitment and active and constructive attitude towards participation
5. Identity formation, assistance and support in the transition to a new identity, and coping strategies for living with HIV/AIDS

Social competence is the ability to integrate insights, attitudes and skills in order to perform tasks focusing on the development of the individual identity and social participation in society. Acquiring social competence as part of identity development is interrelated with social participation. A positive identity is of importance to positive participation in society, but an identity can only be developed in interaction with that same society.
In social competence several skills of tasks are distinguished:

- Social skills (self-management, communication, solution oriented behavior)
- Ability to form attitudes based on moral considerations, confidence, commitment and effort (see also Walraven 2002, Lavesseur 2010)

Regarding stigma en discrimination several recommendation could be made:

1. Risk reduction, adherence, and coping interventions should address HIV-positive patients’ concerns about stigmatization.
2. At a minimum, interventions should provide a supportive environment for discussing the ways in which stigma interferes with mood management, medication adherence, and sexual partner communication.
3. Although a more daunting challenge, a second focus for intervention research is the advancement of effective strategies for reducing stigmatization at the societal level

7 Discussion participatory approach

PEN3 was used as an analytical framework for the project to ensure cultural appropriateness and sensitivity. The PEN3 model urges researchers to use a participatory approach to gain a deep understanding of the target group culture and needs. Collaboration between researchers, representatives from key organizations, and members of the target population was regarded as essential during the needs assessment. In practice, however, engaging the target group in a successful participation process was extremely difficult. Moreover, the literature provided little guidance for involving the target population in program development (Lasker & Weiss, 2003; Wagemaker, 2008). In this project participation with the target group was ensured by employing an extensive linkage system.

7.1 Collaboration with other parties

From the onset of the project, SoaAids Nederland, HIV Vereniging Netherlands, Maastricht University, Erasmus University Rotterdam were the collaborating organizations in this research project. Representatives from those organizations formed part of the professional board.
SoaAids Nederland (SANL) and HIV Vereniging Nederland (HVN)
SANL and HVN were unique partners to this project due to their experiences with the target group. SoaAids Nederland ethnic minority program worked with migrant self-support organizations including organizations of SSA living with HIV. The HIV Vereniging, as a legitimate organization for people living with HIV in the Netherlands, has the expertise and experiences in living with HIV. It also had the diversity project that was specifically directed to address issues of migrant people living with HIV in the Netherlands. As such, they were important partners in the project especially in its process. Together with TNO, SoaAids Nederland organized the first kick-off expert sounding board meeting. TNO and HVN organized four meetings with the target groups and one expert meeting (see phase 2 of the project). The three organizations (TNO, SOAAIDS and HVN) had jointly organized two expert workshops and were intensively involved in the recruitment and execution of the individual and focus group interviews.

Dr. A. Bos is an expert in the field of HIV-related stigma. He has published various articles on this topic and is involved in different projects focusing on HIV-related stigma among people with HIV/AIDS from different ethnic backgrounds. Dr. Arjan Bos was involved in this project when he was working with Erasmus University Rotterdam. But later he moved to Maastricht University and afterwards to (Open Universiteit Heerlen)

Late Prof. dr. H. Schaalma of Maastricht University was a significant partner to the project. Prof. dr. Schaalma had expertise on the systematic development of theory- and evidence-based health promotion programs, including HIV-preventive interventions for several target groups. He also held endowed chair on HIV/STI prevention among migrants in the Netherlands and developing countries. He was a member of the expert sounding board before the tragic incident that took his life away.

The professional sounding board
The professional sounding board was comprised of a fixed number (8) of professional experts in the field of HIV/AIDS prevention and treatment and/or migrant (sexual) health, and gender issues and representatives of migrant support organizations. More specifically, members of the expert sounding board were Chantal Baziruwisabiye (Positive Africans Mutual AIDS; PAMA), Arjan Bos (expert in the field of HIV-related stigma, Maastricht University), Masego Kanis (theologian

and expert in religion and HIV, Kampen Theological University), Herman Schaalma (professor in AIDS prevention and health improvement, Maastricht University), Joshua Maiyo (program officer ethnic diversity, HIV Vereniging Netherland), Iris Shiripinda (medical anthropologist and former program manager HIV prevention ethnic minorities, SOA AIDS Nederland), Laura Nunu Siya (medical doctor and public health researcher, TNO), and Nicole van Kesteren (health scientist, TNO).

The expert sounding 1) contributed knowledge in the content of HIV prevention and living with HIV, and on the implementation of research plans. 2) They also functioned as intermediaries by informing and involving the target population in the project and creating and keeping support among parties involved.

The members of the expert sounding board were chosen according to experience and expertise in the research subject, the target population and the institutions they represented. Participation in the expert meetings was voluntary but participants' travelling costs were refunded and they received 50 euro honorarium for participating in the meeting unless they considered participating in the meeting as part of their professional requirement, in that case, they did not receive anything for participation.

Before every meeting, documents were sent to the experts and their feedback was collected during every meeting. For those who were not able to attend, their inputs were collected through emails and telephone calls. However, all the participants managed to attend every meeting except for Prof. dr. H. Schaalma due to his untimely death.

7.2 Collaboration with the target group

To develop an HIV-preventive intervention that “fits” with the specific needs, values and beliefs of SSA living with HIV required the participation of the target population in all phases of intervention development. As a result, a linkage system was developed.

The linkage group, which also functioned as the advisory board, was comprised of a professional sounding board and a target group sounding board. The target group sounding board was mainly composed of SSA men and women living with HIV. However, one of the members of the professional sounding board was also a representative of the target group (PAMA member). Both the professional and the target group sounding boards were consulted throughout the process of intervention development. A process of frequent group meetings, expert workshops, individual interviews, telephone and email contacts in which we moved back and forth included members of the target group to inform them about the process and outcomes of the intervention development at all phases.

Right from the beginning of the project, it was anticipated that the target group involvement would be challenging. But since SANL and HVN who were partners to this project had working experiences with the target group, there was a ‘gate of entry’ through these two organizations.

Target group participation

Participants were reached using a referral method of recruitment through migrant self-support organizations for people living with HIV. Participants were recruited via key figures of the target population. Participation in the target group sounding board, focus group discussions and the individual interviews was voluntary. However, each participant received a 50 Euros honorarium, refund of travel expenses and had refreshments in the course of the discussions.

Some of the bottleneck issues encountered during the run of this study can be summarized as follows:

Trust

Although TNO was recognized as a professional organization for research, migrant self-support organizations were critical about how the research would help solve the issues that migrant PLWHIV face in their daily lives. Their criticisms related to previous studies done by other organizations, which, according to the migrant groups, had not benefited them. Those studies had investigated 'their needs', for example, the problems of legal status and jobs but failed to produce any solutions.

Disclosure and fear of stigma

Although consent of the participants and confidentiality of the information gathered was given an important attention in this study, some individuals were hesitant to participate. They explained their hesitancy to previous negative experiences they had with other studies; but also, due to the fact that HIV/AIDS related stigma was still relevant among the SSA community in particular and the general population.

Working relationships

Working relationships between and among various group coordinators and key individuals (members of the target group) had a significant effect on the process of the study. Due to previous personal tensions in working relationships, it was not easy to bring some individuals (some coordinators and other members of the target group) together or get access to the members of certain groups. That was significant in the case of recruitment in the target group sounding board. But that was compensated by additional focus group interviews and some informal consultations with emails and telephone contacts.

Conflict of interests

There were differences between the expectation of the target group and that of the researchers. The target group was expecting an intervention that could meet its 'specific needs' while the researchers were seeking for a more cultural appropriate intervention in general. This, partially, play a role in the lack of motivation from the target group.

Irrespective of the above-mentioned bottlenecks, it is still possible to argue that the target group participation in this study was very significant. But, the study took more time than anticipated.

From this experience, a lesson can be learnt that if the target group is left to drive the purpose of a research that is directly related to their specific needs, a high level of participation from the target group is achievable, and may be, in a less time.

Challenges in future research regarding participation

Other challenges concerning a participatory approach that researchers should keep in mind are:

- What are the guarantees that the participants are representatives or true spokesmen of the target group?
- Neutrality, impartiality and objectivity of the professionals: how can you be certain that the professionals do not have a personal agenda which may not correspond with the aims of the project?
- Resources: A participatory approach is very time consuming and the logistics of setting up meetings is daunting
- There is always the issue of creating an active participation and collaboration: the mere presence of a representative at a meeting does not guarantee participation in the meeting
- Access to the target group remains very difficult and collaborations are delicate. Issues of trust not only between the researchers and the target group, but also between the representatives of the target group may obstruct a fruitful process

7.3 Changes to the original plan

Delay in project plan

In the project timeline some interruptions are apparent: between the consultation of the target group sounding board (November 2007) and the professional workshop (February 2009) and the second consultation of the professional sounding board 9june 2010). These gaps are due to difficulties to accessing the target group and the immensely complications regarding the formation of the target group sounding board.

As a result of the introduction of the eight focus group discussions and the anticipated delay, the project leader requested an extension of seven months on December 21 2010. The recruitment, organization, analysis, and reporting entails extra time, however no extra money.
The Aids Fonds agrees to the extension (February 4 2011) and the final date is postponed to December 1 2011. Unfortunately the project leader falls ill and the end date is postponed again to May 1 2012.

Goals and aims of the project

The central goal of the project was aimed at developing culturally appropriate HIV-preventive intervention for SSA living with HIV. Specifically, the aim will be: (a) to get insight in the behavioral and environmental factors related to HIV/STI transmission in SSA living with HIV; (b) to achieve better understanding of the socio-cultural and economic context of HIV/STI transmission within this target group; (c) to develop and pretest an HIV-preventive intervention for SSA living with HIV; (d) to conduct a small-scale process evaluation of the intervention and refine the intervention.

As stated earlier funding was offered for the first two phases) a needs assessment phase, 2) an intervention development phase.

The following project phases were out of the scope of this project.
Project phase 3. The third phase concerns the actual program design of the program. This involves organizing practical strategies, such as individual counseling or HIV support groups, into a deliverable program, taking into account the context in which the program will be used. Program structure (i.e., scope and sequence), theme, and channels for delivery will be based on the research findings emerging from the first project phase, feedback from the linkage group and pre-testing of program materials. Assuring cultural appropriateness in terms of more surface structures (so that the intervention will be attractive and salient to the target population; Krueter et al, 2003) will be a particular challenge when designing the intervention. Therefore, a group of key representatives of the target population and SSA men and women living with HIV will be assembled and consulted to determine preference for and feedback on program design.
And *Project phase 4.* Phase 4 of the project concerns piloting and refining program materials. Although the format of the final program is not known yet, a small-scale qualitative study will be carried in order to try out the intervention and make any needed changed or adjustments. For example, if the intervention consists of individual counseling sessions, these sessions will be pilot tested with 10 SSA living with HIV. The counseling sessions will be video-taped and rated for content and format fidelity, materials used, difficulties observed and group reactions. Feedback from implementers and SSA living with HIV will be incorporated in the final program (e.g., Wainberg et al., 2007).

However this project produced many useful recommendations (see chapter 6) that a follow-up of the project in terms of designing, piloting and evaluating an intervention for this target group would be more than reasonable.

Regarding the proposed activities some changes have been made during the course of the project.
Organizing, arranging and planning a target sounding board meeting with regular intervals proved to be sheer impossible. The target sounding board which was to be formed by 2 SSA men and 2 women living with HIV only met once. Also organizing the ‘lay workshops’ as a counterbalance of the professional workshops proved too difficult to achieve. Instead the focus group discussions study was conducted and in Phase 2, five feedback meetings were organized.

Despite the difficulties in accessing the target group and organizing the meetings the project DID succeed in involving the target population.

Expected outcome of the project

As the title of the project “Development of a culturally appropriate HIV-preventive intervention for HIV-positive Sub-Saharan Africans in the Netherlands” suggests the expected outcome of the project would have been an intervention program with the aim to increase safe sex among SSA living with HIV.

As it turns out the recommended objectives emphasize structural environmental factors much more than the personal behavioral determinants. Applying a participatory approach automatically means that the researcher has to truly ‘listen’ to and understand the context and reality of the target group. The needs of the target group do not necessarily coincide with the predetermined objectives of health professionals. In this project it has become apparent that the target group is not so much concerned with prevention of STI/HIV transmission but that their needs lie in the realm of well-being of living and dealing with HIV. Utilizing this knowledge in designing an intervention will not only create an intervention that is culturally appropriate but also is much more acceptable to the audience, probable leading to a coherent intervention and commitment from the target group.

The objectives formulated from the research conducted in this project are largely aimed improving or increasing social participation. There is extensive evidence in international literature claiming that social participation, mobility and social contacts and networks are extremely important to the well-being of individuals. Informal social capital or social participation might be of particular important for those in circumstances which make them more vulnerable to marginalization, exclusion and poverty. In a large scale study in the UK among chronically ill (Platt 2006) they found that Black Africans and Black Caribbeans, especially women, are notable for their lack of opportunities for social engagement and are particularly at risk of social isolation with severe consequences for their welfare. The authors suggest a strategy of direct support for social activity to increase social welfare (Platt 2006). Long-term illness in itself did not increase social isolation, but associated factors such as low incomes and fewer qualifications did. Therefore they suggest to support social engagement of the long-term chronically ill focusing on increasing qualifications and improving their incomes. The overall welfare is likely to benefit most from interventions focusing directly another forms of deprivation (e.g. low employment rates and high rates of poverty) (Platt 2006). The individual cannot be separated from the context of daily life.

8 Project Deliverables

Presentations/workshops
van Kesteren N, Nunu Siya L, Shiripinda I, Maiyo J, Bos A, Schaalma H. Increasing cultural fit with the target population: Applying the PEN-3 model in the development of HIV prevention for HIV-positive sub-Saharan Africans. 3rd Conference of Migrant and Ethnic Minority Health in Europe, Pécs, Hungary, 27-29 May, 2010

Airhihenbuwa CO, van Kesteren N. Quality of interventions development. Positive cultural elements as a tool for change. The PEN 3 Model. 5th National Ethnic Minorities Conference. Mobilising Support in Challenging Times Sexual Health and STI/HIV Prevention amongst Ethnic Minorities in the Netherlands. Den Haag, 8 October 2010

van Kesteren N, Maiyo J, Nunu Siya L, Shiripinda I, Bos A, Schaalma H† (2010) Developing HIV-prevention for HIV- positive sub-Saharan Africans in the Netherlands. How are we doing? 5th National Ethnic Minorities Conference. Mobilising Support in Challenging Times Sexual Health and STI/HIV Prevention amongst Ethnic Minorities in the Netherlands. Den Haag, 8 October 2010

van Kesteren NMC, Martens MK, Cense M (ism ResCon, RIVM en RNG). Soa/hiv preventie verkoopt zich niet vanzelf! 14e Nationaal Congres SOA HIV Aids, Amsterdam, WAD, 1 december 2010

Bertens M, Westmaas A, Vriens P, Watzeels A, Meijer S, van Kesteren N. De kracht van cultuur: het bevestigen van positieve culturele elementen in soa/hiv preventie. 15e Nationaal Congres SOA HIV Aids, Amsterdam, WAD, 1 december 2011

Publication
Westmaas A, Bertens M, Vriens P, Watzeels A, Meijer S, van Kesteren N. PEN-3: oplossing voor een cultuurspecifieke aanpak? Soa/hiv-preventie in Nederland, Seksoa, 2012: 3(1)

Publication in preparation
Maiyo J, Nunu Siya L, Shiripinda I, Bos A, van Kesteren NMC (in preparation) A study of factors influencing sexual risk among HIV-positive Sub-Saharan Africans in the Netherlands: Applying a culturally sensitive approach using the PEN-3 theoretical model

Publication in preparation
Maiyo J, van Kesteren NCM, Nunu Siya L (in preparation) Africans don’t love, it’s money: HIV, gender identity and safer sex among HIV positive heterosexual men and women of Sub-Saharan African origin in the Netherlands.

9 References

Airhihenbuwa CO. Health and Culture: Beyond the Western paradigm. Thousand Oaks, Calif.: Sage Publishers, 1995.

Airhihenbuwa CO. 2007 SOPHE Presidential Address: On Being Comfortable With Being Uncomfortable: Centering an Africanist Vision in Our Gateway to Global Health. Health Educ Behav 2007; 34: 31-42.

Banner RO, DeCambra H, Enos R, Gotay C et al. A breast and cervical cancer project in a native Hawaiian community: Wai'anae Cancer Research Project. Preventive Medicine 1995; 24: 447-453.

Bartholomew LK, Parcel GS, Kok G et al. Planning health promotion programs: An intervention mapping approach. Jossey-Bass, 2011.

Campbell J. Intimate partner violence: Issues for the health care system. Women's Health Issues 2001; 11(4): 381-385.

DiClemente RJ. Peterson JL. Preventing AIDS: Theories and methods of behavioral interventions. Plenum Press: New York, 1994.

Erwin DO, Spatz TS, Stotts RC et al. Increasing mammography and breast self-examination in African American women using the Witness Project model. Journal of Cancer Education; 1996.

Green LW, Kreuter MW, Green LW. Health program planning: an educational and ecological approach. New York: McGraw-Hill, 2005.

Guidry JJ, Fagan P, Walker V. Cultural sensitivity and readability of breast and prostate printed cancer education materials targeting African Americans. Journal of the National Medical Association, 1998;90(3): 165-9.

Heus L. There is no love here anyway. Sexuality, identity and HIV prevention in an African sub-culture in Amsterdam, the Netherlands. Sex. Health Sexual Health, 2010; 7(2): 129-134.

Kreuter MW, Lukwago SN, Bucholtz DC et al. Achieving cultural appropriateness in helath promotion programs: targeted and tailored approaches. Health Education Behavior 2003; 30:133-46.

Levasseur M, Richard L, Gauvin L, Raymond E. Inventory and analysis of definitions of social participation found in the aging literature: proposed taxonomy of social activities. Soc Sci Med. 2010; 71(12): 2141-9.

NIZW, Schema sociale processen, Opgehaald in http://www.nizw.nl/thesaurus/socialeparticipatie.htm

Navarro et al. Por al Vida model intervention enhances cancer screening tests among Latinas. American Journam, Preventive Medicine, 1998; 15: 32-41.

Platt L. Social participation: How does it vary with illness, caring and ethnic group? ISER Working Paper 2006-18. Colchester: University of Essex, 2006.

Smith JA, Flowers P, Larkin M. Interpretative phenomenological analysis : theory, method and research. Los Angeles: SAGE, 2009.

Smith JA, Osborn M. Interpretive phenomenological analysis. In JA Smith (Eds) Qualitative psychology: A practical guide to research methods. Pp 51-80. London: Sage Publication, 2003.

Tanjasiri SP, Kagawa-Singer M, Foo MA et al. Designing culturally and linguistically appropriate health interventions: The 'Life is precious' Hmong breast cancer study. Helath Education & Behavior 2007; 34:140-153.

Türmen T. Gender and HIV/Aids. International Journal of Gynecology & Obstetrics, 2003; 82(3): 411-418.

van Vliet, de Gruijter, Singels. Diversiteit in participatie in gezondheidsbevordering. Verkennende studie doelgroep participatie allochtonen voor het programma Gezond leven van ZonMw. Rapport Verweij Jonkers Instituut en NIGZ, 2006.

Wainberg ML, McKinnon K, Mattoes PE et al. A model for adapting evidence-based behavioral intervention to a new culture: HIV prevention for psychiatric patients in Rio de Janeiro, Brazil. Aids and Behavior, 2007.

Wagemakers A, Corstjens R, Koelen M, Vaandrager L, Van 't Riet H, Dijkshoorn H. Participatory approaches to promote healthy lifestyles among Turkish and Moroccan women in Amsterdam Promotion & Education, 2008; 15(4): pp. 17–23.

Walraven M, Appelhof P. Sociale competentie ter bevordering van sociale participatie, Utrecht: Oberon, 2002.

Wiggers LCW, de Wit JBF, Gras MJ, Coutinho RA, Hoek A. Risk Behavior and Social-cognitive Determinants of Condom use among Ethnic Minority Communities in Amsterdam. AIDS Education and Prevention, 2003;15(5): 430.