

## Report of the Evaluation of ShivA's Positive Sisters project



*"Feeling that HIV is not a burden on you because you are now living in a positive way" \**

November 2013

ResultsinHealth





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## List of Abbreviations

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AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-retroviral Therapy
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
MSC	Most Significant Change
PAMA	Positive Africans Mutual Aid
PLWHIV	People living with HIV
PS	Positive Sister
PWW	Positive Women of the World
SSA	Sub-Saharan Africa
SWOT	Strengths, Weaknesses, Opportunities, Threats

# Samenvatting

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## Achtergrond

In 2012 stonden 1,585 hiv-geïnfecteerde vrouwen afkomstig uit sub-Sahara Afrika (SSA) of het Caribisch gebied, wat neerkomt op 48% van alle hiv-geïnfecteerde vrouwen in Nederland, onder klinische zorg in Nederland<sup>1</sup>. Binnen deze klinische zorg bieden hiv-verpleegkundig specialisten medische en psychosociale ondersteuning. Echter, het aanpakken van gevoelens van isolatie en stigmatisering, vooral die van migrantenvrouwen, blijkt een uitdaging. Aangezien kinderen afhankelijk zijn van hun moeders, worden zij hierdoor eveneens beïnvloed.

ShivA is een Nederlandse stichting die zich richt op de kwaliteit van leven, zoals spiritualiteit, religie en zingeving voor mensen die leven met hiv/aids. Voor de specifieke doelgroep van allochtone vrouwen is ShivA in 2011 het Positive Sisters (PS) project gestart. Een 'Positive Sister' is een hiv-geïnfecteerde migrante uit SSA of het Caribisch gebied, getraind door ShivA om ondersteuning te bieden aan een andere HIV besmette migrante, die moeite heeft om met hiv als migrant in Nederland te leven. Het project heeft als doel de zelfredzaamheid van de PS, alsmede van de vrouwen die zij ondersteunen, te vergroten. Op dit moment hebben 18 PS's een intensieve zesdaagse cursus afgerond en een certificaat ontvangen van de voltooide opleiding. Sinds de start van het project zijn 45 vrouwen ondersteund door een PS.

Gezien de groei van het project wil ShivA leren van de ervaringen uit de eerste periode van de implementatie, en de project processen en resultaten documenteren en analyseren.

## Evaluatie methode en proces

De belangrijkste doelstellingen van deze evaluatie:

1. Het documenteren en analyseren van de belangrijkste veranderingen die hebben plaatsgevonden in het leven van vrouwen met hiv uit SSA of van Caribische afkomst, na aansluiting bij het PS project;
2. Het documenteren van het proces van de implementatie van het PS's project, en
3. Het identificeren van belangrijke lessen en aanbevelingen voor toekomstige implementatie.

Het evaluatie team gebruikte de Most Significant Change (MSC) techniek voor het ontwerp van de evaluatie. De MSC techniek is een kwalitatieve en participatieve vorm van monitoring en evaluatie op basis van het verzamelen en de systematische selectie van verhalen van gerapporteerde veranderingen, die teweeg worden gebracht door projectactiviteiten. Het evaluatieteam verzamelde informatie door middel van een desk review, semigestructureerde interviews en een Focus Group Discussie (FGD). De dataverzameling vond plaats van juni tot en met augustus 2013, waarbij ethische principes werden gehanteerd, en exclusieve anonimiteit, en een veilige omgeving en professionaliteit werden gegarandeerd. Nadat de verhalen waren verzameld, werd een workshop gehouden ten behoeve van de selectie van verhalen. Aan de workshop nam een diverse groep van respondenten en belanghebbenden deel om de verhalen te selecteren met betrekking tot de veranderingen die werden gezien als de meest belangrijke verhalen. De analyse van de data omvatte veranderingen in de kwaliteit van leven van de vrouwen die in het PS project betrokken zijn, veranderingen in hun naaste omgeving (familie en vrienden) en veranderingen in hun deelname aan de samenleving. Voor de project coördinator werden ook veranderingen in de organisatorische processen geanalyseerd. Hiv-verpleegkundigen werden tevens gevraagd naar veranderingen op het niveau van de therapietrouw van de vrouwen, en veranderingen in hun werk nadat ze de samenwerking met het PS project zijn gestart. Naast de analyse van de veranderingen werden gegevens over de PS opleiding, de implementatie van het project en toekomstperspectieven verzameld. Een deel van deze gegevens werd geanalyseerd in een Strengths, Weaknesses, Opportunities en Threats (SWOT) analyse van het PS project. Aan de hand van al deze gegevens formuleerde het evaluatie team de conclusies en aanbevelingen op basis van de evaluatie vragen.

## Resultaten

Gegevens van in totaal 34 respondenten zijn verzameld. Hieronder vielen zes opgeleide PS's, zeven PS's in een FGD (inclusief een overlap met een individueel interview), vier vrouwen die ondersteund worden door een PS, twee familieleden van een PS, vijf hiv-verpleegkundig specialisten, een trainer, zeven relevante belanghebbenden en één project coördinator. 18 respondenten werden geïnterviewd met behulp van een richtlijn voor MSC en semigestructureerd interview (zes PS's en de FGD, 4 vrouwen ondersteund door een PS, twee familieleden van een PS,

vier hiv-verpleegkundigen en de project coördinator). De overige respondenten werden geïnterviewd met behulp van een richtlijn voor een semigestructureerd interview.

De meeste respondenten in de groep van de PS's kozen voor de verandering in "de mogelijkheid om anderen te helpen" als de belangrijkste verandering die teweeg werd gebracht door het PS project. De belangrijkste veranderingen zoals gerapporteerd door de vrouwen die worden begeleid door een PS waren "zelfvertrouwen", "acceptatie" en "het toekomstperspectief". Familieleden van de PS rapporteerden veranderingen zoals "meer zelfvertrouwen" en "de mogelijkheid om anderen te helpen", welke ook werden genoemd als de belangrijkste veranderingen. De hiv-verpleegkundigen rapporteerden veranderingen in het leven van de vrouwen die in het PS project betrokken zijn zoals "het gevoel niet alleen te staan", "meer openheid over hiv-positieve status", "toegenomen emancipatie", "acceptatie" en "toekomstperspectief". Deze veranderingen werden ook genoemd als de meest significante veranderingen veroorzaakt door het project. De belangrijkste verandering zoals aangegeven door de project coördinator is "het toegenomen zelfvertrouwen".

Eén PS noemde een negatieve verandering teweeggebracht door de PS project: "het gevoel van druk omdat iemand afhankelijk van je is". Veranderingen gerapporteerd in het gezinsleven van de ondersteunde vrouwen waren "minder ruzies thuis" en "betere communicatie tussen de PS en haar man". Veranderingen gerapporteerd in deelname aan de samenleving worden geïllustreerd door een vrouw die wordt ondersteund door een PS die met vrijwilligerswerk is gestart. Hiv-verpleegkundigen meldden veranderingen in hun werk; al kost het hen tijd om de verbinding tussen de vrouw en de PS maken, bespaart het hen later tijd omdat psychologische problemen worden verminderd.

De PS's vinden de inhoud van de training op het gebied van kennis over hiv en vaardigheden over hoe vrouwelijke immigranten met hiv te ondersteunen nuttig. Zij hebben het gevoel dat ze door de training en extra begeleiding goed voorbereid zijn om hun taak als PS uit te voeren: ze kunnen de vragen van de vrouwen beantwoorden en kunnen handelen in bepaalde situaties door gebruik te maken van de vaardigheden uit de training. Daarnaast is de training ook nuttig in het persoonlijke leven van de PS's. De frequentie van ontmoetingen tussen de PS's en de ondersteunde vrouwen varieert, en is afhankelijk van de voorkeur van de ondersteunde vrouwen. De meeste communicatie verloopt via bellen of sms'en. Sommige PS's zijn ook begonnen met het ondersteunen van vrouwen met hiv via andere projecten of hun persoonlijke netwerk. De hiv-positieve migranten die worden ondersteund door de PS zijn blij met hun steun.

Het evaluatieteam maakte een SWOT-analyse na de verzameling van diverse data. Sterke punten (strengths) waren het zeer toegewijde professionele leiderschap, de basisprincipes van het PS project en de adequate uitvoering van de PS project. Zwakte punten (weaknesses) waren het feit dat de projectcoördinator, als individu, de drijvende factor van het project is, wat beperkingen met zich meebrengt. Ook de minimale controle en standaardisatie van processen, alsmede de kleine omvang van het project zijn zwakte punten. Mogelijkheden (opportunities) zijn de perspectieven om samen te werken met andere organisaties, een hogere diversiteit in de vorm van ondersteuning aan te bieden en het gebruik van de resultaten van de huidige evaluatie. Bedreigingen (threats) zijn de complexiteit rond de problematiek van het zijn allochtone vrouwen met hiv, het afvallen van getrainde PS's en het gebrek aan financiële en personele middelen.

## Conclusie

De belangrijkste veranderingen in de levens van vrouwen met hiv uit SSA of van Caribische afkomst na te zijn verbonden met een PS in het PS project zijn:

- Acceptatie van de hiv status
- Toekomstperspectieven
- Meer zelfvertrouwen
- Mogelijkheid om iets voor anderen te doen
- Meer openheid over hiv
- Verhoogde empowerment

Deze veranderingen laten zien dat het PS project de levenskwaliteit van zowel een PS als van de vrouwen die worden begeleid door een PS is verbeterd. Dit geeft aan dat het PS project haar doelstellingen bereikt. Naast deze bereikte doelstellingen, heeft de manier waarop het project momenteel wordt geïmplementeerd vele sterke punten. Maar er is nog ruimte voor verbeteringen. Deze verbeteringen moeten in de nabije toekomst worden aangepakt om de duurzaamheid van het PS project ten goede te komen en de uitbreiding van het project mogelijk te maken.



## Aanbevelingen

- Om de duurzaamheid van het PS project te waarborgen, is het cruciaal om alternatieve manieren van fondsenwerving te vinden, naast de traditionele financieringsbronnen en thema's. Deze fondsen kunnen gedeeltelijk worden gebruikt om de organisatie te ontwikkelen.
- Om ervoor te zorgen dat het PS project stevig geaard wordt, is het stroomlijnen en optimaliseren van de werkprocessen van de organisatie nodig om de efficiëntie te verbeteren, waarbij de sterke punten van het project moeten worden behouden.
- Er is een behoefte om de personeelscapaciteit van de organisatie te vergroten, omwille van de structurele hoge werkdruk en de anticipatie op uitbreiding.
- Voor een verdere ontwikkeling van de PS training, kunnen relevante professionals worden betrokken, en het training curriculum en de materialen worden gestandaardiseerd, en daarbij kan eventueel worden gekeken naar "certificering" door een bevoegde autoriteit.
- Creëer mogelijkheden voor PS's om ervaringen te delen en creëer ondersteunende systemen. Deze zijn belangrijk om het netwerk van PS's verder te ontwikkelen en te optimaliseren. Dit netwerk zou kunnen worden gecoördineerd door een senior PS.

# Executive Summary

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## Background

In 2012, 1.585 HIV-infected women originating from sub-Saharan Africa (SSA) or the Caribbean, representing 48% of all HIV infected women in the Netherlands, were under clinical care in the country<sup>1</sup>. Within this clinical care, HIV nurses offer medical and psychosocial support. However, addressing feelings of isolation and stigma, especially those of migrant women has proven to be challenging. Being dependent on their mothers, children are equally affected by this.

ShivA is a Dutch foundation working on quality of life including spirituality, religion and meaning of life for people living with HIV/AIDS. For the specific target group of migrant women, ShivA designed the Positive Sisters (PS) project in 2011. A 'Positive Sister' is a HIV infected migrant woman from SSA or the Caribbean trained by ShivA to provide support to another HIV infected migrant woman, who encounters difficulties in living with HIV as a migrant in the Netherlands. The project aims to empower the PS as well as the women they support. Currently, 18 PSs have completed an intensive six-day course and received a certificate of training completion. Since the start of the project, 45 women have been supported by a PS.

As the project is expanding, ShivA wished to learn from the experiences of the first period of implementation, and document and analyse the project processes and outcomes.

## Evaluation method and process

The main goals of this evaluation:

1. To document and analyse the most significant changes that have occurred within the lives of women living with HIV of SSA or Caribbean origin, after being connected to the PS project;
2. To document the process of implementation of the PSs project; and
3. To identify important lessons learnt and make recommendations for future implementation.

The evaluation team used the Most Significant Change (MSC) technique for the design of the evaluation. The MSC technique is a qualitative and participatory form of monitoring and evaluation based on the collection and systematic selection of stories of reported changes, which are caused by project activities. The evaluation team collected information employing desk review, semi-structured interviews, and Focus Group Discussion (FGD). The data collection took place from June to August 2013, adhering to ethical principles ensuring exclusive anonymity, a safe environment and professionalism. After the stories were collected, a stories selection workshop was held with a diverse group of respondents and stakeholders to select stories of change which were seen as the most significant stories. The analysis of the data included the changes occurring in the quality of life of the women involved in the PS project, changes in their close circle (family and friends) and changes in their participation in society. For the Project Coordinator changes in the organisational processes were analysed as well. HIV nurses were also asked on changes in the level of adherence of the women to their medication and changes in their work after they started their collaboration with the PS project. Besides the analysis of changes, data on the PS training, project implementation and future perspectives were collected. Some of this data fed into a Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis on the PS project. From all of this data the evaluation team formulated the conclusions and recommendations based on the evaluation questions.

## Results

Data from a total of 34 respondents has been collected, which included six trained PSs, seven PS in a FGD (including one overlap with the individual interview), four women supported by a PS, two relatives of a PS, five HIV nurses, one trainer, seven relevant stakeholders and one Project Coordinator. 18 respondents were being interviewed using a guideline for MSC and semi-structured interview (six PS and the FGD, four women supported by a PS two relatives of a PS, four HIV nurses and the Project Coordinator). The other respondents were interviewed using a semi-structured interview guideline.

The respondents in the group of PSs chose "the change in ability to help others" most often as the most significant change, which is induced by the PS project. The most significant changes as reported by the women supported by a PS were "self-confidence", "acceptance" and "the future perspective". Relatives of the PS reported changes such as "increased self-confidence" and "the ability to help others" which were also mentioned to be the most significant changes. The HIV

nurses reported changes in the lives of the women involved in the PS project such as “the feeling of not being alone”, “increased openness about being HIV positive”, “increased empowerment”, “acceptance” and “future perspective”. These changes were also mentioned as being the most significant changes caused by the project. The Project Coordinator reported “the increased self-confidence” as the most significant change.

One PS mentioned a negative change caused by the PS project, which is “the feeling of pressure because someone depends on you”. Changes reported in the family life of the women supported were “fewer arguments at home” and “better communication between PS and her husband”. Changes reported in participation in society are illustrated by a woman supported by a PS who started a voluntary job. HIV nurses reported changes in their work; although it takes them time to make the connection between the woman and the PS, it saves time later as physiological problems are reduced.

The PSs feel that the content of the training in terms of knowledge on HIV and skills on how to support migrant women with HIV is useful. They feel that they are well-prepared through the training and extra guidance to do their task as PS: they can answer questions of the women or handle situations by using the skills from the training. In addition, the training is also useful in the personal life of the PSs. The frequency of encounters between the PSs and the supported women varies, depending on the preference of the supported women. Most communication is done via calling or texting. Some PSs also started to support women with HIV via other projects or personal network. The HIV positive migrants who are being supported by the PS are happy with their support.

The evaluation team performed a SWOT analysis after the data collection. Strengths included the highly dedicated professional leadership, the basic principles of the PS project and the adequate implementation of the PS project. Weaknesses were the fact that the Project Coordinator, as an individual, is the driving factor of the project implying limitations, minimal monitoring and standardisation of processes, and the small project size. Opportunities include the possibilities to collaborate with other organisations, offering a higher diversity in type of support provided and using the results of the current evaluation. Threats are the complexity around the issues of being migrant women with HIV, drop-out of trained PSs and the lack of funding and human resources.

## Conclusion

The most significant changes within the lives of women living with HIV of SSA or Caribbean origin after being connected to a PS in the PS project are:

- Acceptance of being HIV positive
- Future perspectives
- Increased self-confidence
- Ability to do something for others
- Increased openness about HIV
- Increased empowerment

These changes show that the PS project has improved the quality of life of both the PS as well as the women. This indicates that the PS project is reaching its objectives. Considering these achievements, the way the project is currently implemented has much strength; however, there is still room for improvement. These need to be addressed in the near future to benefit the sustainability of the PS project and to enable expansion of the project.

## Recommendations

- To ensure sustainability of the PS project, it is crucial to seek alternative ways of fundraising, besides the traditional funding sources and themes. These funds could be partly used for cultivating the organisation.
- To ensure that the PS project is firmly grounded, streamlining and optimising the work processes of the organisation to improve efficiency is required, while maintaining the strengths of the project.
- There is a need to increase the human resource capacity of the organisation in managing the structural high workload and anticipating on expansion.
- For a continued development of the PSs training, relevant professionals could be involved and training curriculum and materials standardised, while possibly aiming at “certification” by a relevant authority.
- To enable PSs to share experiences and create support systems, it will be important to further develop and optimise the network of PSs. This network could be coordinated by a senior PS.

# The organisation ResultsinHealth

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ResultsinHealth (RiH) conducted this evaluation for Shiva. The evaluation team consisted of: Maaïke Esselink (project leader), Nur Hidayati, Rutger Top, Marieke van Dijk, Kimberley Thiel and Aryanti Radyowijati.

## ResultsinHealth

RiH is an international public health agency that has been active as an international public health agency since 1993. While based in the Netherlands, RiH now operates in more than 70 countries through a collaborative working arrangement with PricewaterhouseCoopers and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM; the 'Global Fund'). Its vision is to improve the health and development of poor and vulnerable populations, and its mission is to strengthen their access to essential health care through its innovative advisory and research activities. RiH has worked with various local, national and international agencies, such as the Dutch RIVM and Aids Fonds, UNAIDS, GFATM, World Bank, EU, USAID and UNTF, FHI- 360 and Oxfam Canada.

RiH works with government, non-government and private organisations/institutions at local, national, regional and international levels, and is part of international and national professional associations, has a network of highly qualified professionals, and actively liaises with other agencies, civil society and academic institutions. Working in many different environments, RiH has achieved an in-depth understanding of major global health issues, and established itself as a key player in international health.

RiH's work ranges from providing quality Technical Advice (project implementation, monitoring and evaluation), Capacity Building (training, education, mentoring and supervision) and Research (mapping of best practice, piloting new approaches and conducting systematic review including meta-analysis). RiH provides services through short and long term assignments in the field of international public health. Adhering to RiH's mission, RiH focusses on the three technical areas Maternal Newborn and Child Health (MNCH), Medicines Management and Operation (MMO), including issues such as access, supply chain and use of (essential) medicines, and Sexual Reproductive Health and Rights (SRHR) including Gender and HIV.

In its services, RiH is guided by three principles: it is evidence-based, innovative and practice-oriented. This is evidenced by RiH's experiences in conducting Monitoring & Evaluation and Research & Education activities, and in various technical areas within public health. In its advisory services and research activities, RiH translates results from practice into knowledge and measures the impact of interventions, generating lessons learnt. As for its M&E services, RiH is known for providing expert services, by employing quantitative and qualitative techniques, including the use of mixed methods. RiH has a highly developed expertise in applying participatory methods such as the 'Most Significant Change' (MSC) methodology, Outcome Mapping (OM) and Appreciative Inquiry (AI).

RiH has undertaken activities and assignments ranging from ensuring that life-saving medicines reach the people who need them, working on gender and HIV prevention activities, analysing policy and providing strategic guidelines for international bodies, to providing post-graduate level education on public health related topics at universities and technical colleges. RiH is seasoned in building and strengthening existing partnerships to meet fast-paced demands.

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# 1. Background

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In 2012, 16.169 persons, including 257 children, lived infected with HIV under clinical care in one of the HIV treatment centres in the Netherlands. 80% of whom are men (74% became infected through homosexual contact); 20% are women. The majority of HIV infected men under clinical care in the Netherlands originated from the Netherlands (67%). A total of 1.585 HIV-infected women originate from SSA or the Caribbean. They represent 48% of all HIV infected women in the Netherlands, compared to 29% of the female patients who are of Dutch origin. Most of all patients born in SSA became infected in that region (83%), but 15% of them were most likely infected in the Netherlands. The average age at the time of diagnosis of heterosexual women born in SSA is 31 years, which is substantially younger than their Dutch counterparts (38 years).<sup>1</sup>

In the Netherlands, 26 different health institutes across the country that are acknowledged by the Dutch Minister of Health, Welfare and Sport as HIV treatment centres or sub-centres, provide care for HIV infected patients. Care providers in these HIV treatment centres are HIV specialised medical doctors and HIV nurses. The HIV nurses offer Medical and psycho-social support. However, addressing feelings of isolation and stigma, especially those of migrant women, is often challenging.

ShivA Foundation (in Dutch: Spiritualiteit, hiv & Aids; in English: Spirituality, HIV and AIDS) is the Dutch knowledge centre on spirituality and meaning of life for people living with HIV/AIDS. ShivA aims to improve the physical and mental health of people living with HIV/AIDS, their families and others involved in the Netherlands. Breaking through isolation, developing self-esteem and promoting social participation are essential issues to improve this. ShivA works together with other stakeholders in HIV care in the Netherlands, such as Hiv Vereniging Nederland, Buddy-organisations in Den Haag and Rotterdam, the HIV treatment centres and the Dutch Aids Fund (Aids Fonds). The work of ShivA is founded on three pillars: empowerment, knowledge transfer and commemoration. Its activities include individual and group counselling and trainings in which problems caused by physical and mental health, support to questions regarding meaning of life, increase of self-reliance, care for children, and support on how to overcome obstacles in participation in society are central themes.

ShivA has a long history of working with different cultures and has experience with religious questions, which play an essential role in the lives of migrants with HIV/AIDS. Since its start, ShivA also has a special focus on the position of women with HIV/AIDS, who are a neglected group in the field of HIV/AIDS care in the Netherlands. Through its special attention to religious aspects, ShivA aims to reach the difficult to reach groups of HIV infected migrant women from SSA and the Caribbean. For this specific target group, ShivA has designed activities which work on self-empowerment. Through these activities, ShivA aims to improve the quality of life of migrant women living with HIV and their families so that they are able to find a place within the Dutch multicultural society.

The women participating in ShivA's activities for HIV infected migrant women from SSA and the Caribbean are aged between 20 and 60 years old and most of them have children. Education levels range from illiterate women to women with university degrees. Most of the women are refugees from (civil) wars; many of them have a history of experiencing gender-based violence\*. Around one third of the women has been involved in human trafficking and has been forced to prostitution. Some of the women came to the Netherlands to study or to join their Dutch partner. Most women are religious; about two third being Christian, and one third being Muslim. In addition to religion, all of them are strongly rooted in traditions and cultural beliefs. The women deal with difficult social-economic situations due to the fact that they cannot or are not allowed to work. Some of them survive by working in prostitution. Most of the women live in isolation as nobody in their social environment knows about their positive HIV status. This hampers their psychological and medical well-being, and causes depression, hampers their adherence to their (HIV) medication and healthy living. To support these women and to increase their self-esteem, to get them out of isolation and to improve their social participation, ShivA develops projects focussing on this specific group of people in the Dutch society.

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\* Gender-based violence is defined as: "all acts of gender-based violence that result in, or are likely to result in, physical, sexual, psychological or economic harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life", which includes acts such as rape, etc.

## The PS Project

The activities of ShivA in empowering women with HIV from SSA or of Caribbean origin are bundled in two projects: 'Yes, We Can!' (English) or 'Vive la Vie' (French) and 'We are Family!' (PS project). In the 'Yes, We Can!' or 'Vive la Vie!' projects, ShivA works on empowering migrant women from SSA or the Caribbean origin by breaking the silence around taboos on HIV, by providing knowledge on healthy living and the Dutch health system, and by bringing women in touch with each other. Women are introduced to ShivA by the HIV nurses and after the first counselling sessions by the ShivA counsellor, the women are invited for a counselling-weekend which includes workshops and (group-) counselling sessions. After the weekend, women receive counselling in different gatherings.

In the second project, the PS project, ShivA selects and trains empowered HIV infected women from SSA or of Caribbean origin (generally from the 'Yes, We Can!' project) to become a volunteer in the PS project. A PS is an HIV-positive migrant woman who is supporting another HIV-positive migrant woman who encounters difficulties in living with HIV, and who is isolated because she is not open about her HIV status, afraid, not well-informed or incapable to stand up for herself.<sup>2</sup> The PS functions as a role model for the woman she is supporting, not merely giving advice, but building self-confidence and have a conversation at equal level, as opposed to talking to an HIV nurse. The PS supports the woman by sharing experiences, life's wisdom, warmth and assurance that the woman will be alright. The women can talk with the PS about the judgemental or empowering role of faith from an African or Caribbean perspective, which includes the belief in spirits and ancestors. Training of the PS includes knowledge training regarding medical, psychological and social aspects of HIV, the Dutch health system and other Dutch social systems; communication and counselling skills and knowledge and skills regarding ethical behaviour and confidentiality. Currently, after the first year of implementation, 18 PS were trained in the intensive training sessions and received a certificate of completion of the training.<sup>3,4</sup> The PS signed a contract with ShivA to become a volunteer and to behave according to the ethical and confidential boundaries of the programme. Most PSs support at least one woman; some of the PSs even became a Sister for more than one woman. The request for PSs is increasing and the programme is developing a post-training course for the active PSs.

### *Training*

The training ShivA provides PSs with consists of three training days plus a full training weekend.<sup>3</sup> It is aimed at giving participants more self-confidence, providing them adequately with information on HIV/AIDS and overcoming taboos such as talking about sexuality and openness about their HIV status. The goal of the training is to train women to be able to help other women and serve as a "multiplier". The program consists of the following:

Day one: The first day is used to get to know each other and explore women's motivation to become a PS. It also focusses on spirituality; where do the women get their strength in hard times.

Day two: The second day is aimed at increasing the women's knowledge on HIV/AIDS and health care in general and at theory and practice of counselling interviews.

Day three: On the third day women are trained in counselling more extensively and a code of conduct for volunteers is designed in cooperation with the women.

Training weekend: During the weekend the training in counselling interviewing is extended. Besides this training issues like sexuality, stigma and stress associated with migration and hiv and spirituality are addressed.

### *Follow up*

After the PSs have finished training and started to support other women, ShivA will organise a follow up training. During these days, actual cases are brought in by the PSs. These will then be analysed and used to improve the skills of the PSs in counselling interviews during role plays. The days will also be used to discuss the motivation of the PSs, mutual support for personal problems and a good way of reporting to ShivA about current matches.<sup>4</sup>

### *Way of working PS project*

When an HIV-nurse thinks a patient would benefit of having a PS, the nurse contacts ShivA. Based on information she gets from the nurse, the project coordinator will then select a PS to support the woman. This selection is based on a profile of the PSs, containing information on languages the women speak, region of origin, whether she has children or not etc. The HIV nurse will then

contact the PS to make an appointment for a meeting with the PS, the woman to be supported and the HIV-nurse.

During this first meeting the woman and her possible PS will get to know each other. They will also sign a privacy statement during this meeting. After this initial contact the project coordinator will discuss with the PS and the HIV nurse with her patient the decision whether or not they both want to proceed with this match. When both decide to proceed, they will be matched for 6 months after which the match will be evaluated for a possible extension.<sup>5,6</sup>

#### *Expansion*

As the PS Project is expanding to train more PSs, and connects more Sisters to migrant women living with HIV, ShivA intends to learn from the experiences of the first period of implementation, to document and analyse the project processes and outcomes. Evaluating the PS project would help ShivA to expand the project effectively. In addition, it would be an opportunity to show effect caused by an intervention in a complex population addressing a multifaceted problem.



## 2. Methodology

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In this section the evaluation methodology is outlined. The methodology includes the evaluation objective, evaluation strategy, timing and ethical considerations.

### 1. Evaluation Objectives

The objectives of this evaluation are:

1. To document and analyse the most significant changes that have occurred within the lives of women living with HIV from African or Caribbean origin after being connected to a PS in the PS project;
2. To document and analyse the changes that have occurred within the lives of women involved as PSs in the PS project, as well as the changes within the lives of relatives of women living with HIV from African or Caribbean origin and in the professional lives of HIV nurses;
1. To document the process of implementation of the PSs programme including identifying challenges and supporting factors that have been encountered during the implementation of the PS project;
2. To identify important lessons learnt and make recommendations for the implementation of the PS project in the future.

### 2. Evaluation Strategy

In order to reach the objectives of this evaluation and considering the nature of the intervention, the following evaluation strategy is employed:

#### *Document review*

The process of implementation of the PS project, the early development and actual implementation of the project will be documented. This activity enabled the evaluation team to obtain information on the development and implementation of the project.

#### *The 'Most Significant Change' (MSC) Technique*

The evaluation team applied the Most Significant Change (MSC) Technique to analyse the changes observed by the PSs, Women supported by a PS, relatives, and by HIV nurses after being involved in the PS project.

The MSC technique "is a qualitative and participatory form of monitoring and evaluation based on the collection and systematic selection of stories of reported changes from development activities"<sup>7</sup>. This technique develops stakeholder skills<sup>8</sup> in observation and analysis; identifies what needs changing and how to measure the changes; identify what should be publicized as good practices and evidence-based findings from the PS project; improve accountability of the project; and identifies strategic direction on where to go in the future. It should be noted that MSC is not a prescribed methodology, rather an evolving one that is adapted to suit the context in which it operates. The focus is on the unexpected instead of predetermined indicators; information about change is documented in text instead of numbers; major attention is given to explicit value judgements; and information is analysed through a structured social process.<sup>9</sup>

The MSC technique is a monitoring and evaluation tool that is useful in monitoring intermediate outcomes and impact in complex programmes. It measures change through the stories of who did what, when and why, and highlights reasons why the event was important by asking the question: "From your point of view, looking back over the last year, when the PS project started to be implemented, what was the most significant change that occurred as a result of this programme?"

The postulated advantages of using MSC for the evaluation of this project are the following:

- The telling and the collection of the stories would offer the PS, Women supported by a PS, relatives and HIV nurses the opportunity to reflect on the knowledge gained and their personal development with regard to the programme to empower HIV positive women from SSA or of Caribbean origin in the Netherlands. This self-reflection process can enhance a sense of commitment and participation amongst the PSs, their relatives and HIV nurses.
- Analysing stories would offer HIV nurses and the project coordinator the opportunity to gain insight into the impact of the programme on HIV positive women from SSA or of Caribbean origin.
- The data collected through the Most Significant Change stories from PSs, Women supported by a PS, relatives and HIV nurses is rich as it allows room for the unexpected rather than the



predetermined, and it gives attention to explicit value judgements. Furthermore, the data analysis occurs through a social process in which PSs, Women supported by a PS, relatives and HIV nurses are included.

In practice, the MSC Technique starts with a preparatory phase in which the MSC guideline for interviewers and focus group discussion leaders are created, and appointments with interviewees will be made. This will be followed by the actual step of story collection, in which interviewers meet interviewees, individually or in FGD, and collect their stories of change. The stories will be written after collection and verified if needed.

The strength of the MSC method is how the methodology allows key informants to participate fully in data analysis, unlike other methods. In MSC, true involvement of the key informants in selecting the most significant change stories is part of the data analysis. This involvement is realised in the form of a story selection workshop. In this workshop respondents analyse the collected stories of change, discuss within their group the most significant stories and reach agreement on which story/stories represent the most significant changes attributed to the project.

The MSC Technique also includes a final step of meta- and secondary-analysis in which changes from all collected stories are being analysed in depth.

#### *Semi-structured interviews*

Semi-structured interviews with the PSs, women supported by a PS, HIV nurses, relatives of the PSs, Project Coordinator, PSs trainer(s) and other relevant stakeholders were performed to obtain additional information on challenges encountered during the project implementation, next to supporting factors and recommendations.

#### *Focus group discussions (FGDs)*

One FGD with PSs was performed to obtain information on changes caused by the PSs project, challenges encountered, and supporting factors identified during the project implementation.

#### *Dissemination Workshop*

One dissemination workshop was conducted towards the end of this evaluation. In this workshop preliminary results and recommendations of the evaluation were presented. This workshop is meant to elicit comments and concrete suggestions, which can be used to improve the PS project implementation and for Shiva as an organisation.

### 3. Timing

The initial meetings for the preparation of the evaluation started in February 2013. The interviews started in June 2013 and the MSC workshop took place in October 2013. The dissemination workshop and finalisation of the report were conducted in November 2013.

### 4. Ethical considerations

The following measures have been taken to uphold ethical standards:

- Due to sensitivity of the HIV status among migrant women, we only employed female researchers to interview the PSs and the Women supported by a PS;
- Children under 16 years old were not included in the data collection;
- Informed consent and respondents' assent were sought from all respondents to record interviews and focus group discussions where applicable;
- Respondents were provided with full anonymity, they could stop their participation at any time.
- Information given by the participants will not be shared with others in such way that the information can be linked back to the participant.

### 3. Process of Evaluation

This chapter describes the process of the evaluation. The evaluation was performed in four phases: 1) Preparatory phase, 2) Interview and FGD phase, 3) Data Analysis phase and 4) Report writing phase. The process of each of the four phases is described separately in the sections below.

#### 1. Preparatory phase

In the preparatory phase, several activities were performed: the evaluation team conducted the review of project documents, developing a list of groups of respondents, developing the data collection tools, and finalising the evaluation design and its logistics.

##### 1.1. Document review

Several documents related to ShivA and the PS project were reviewed, extracted and used as a reference in developing data collection tools and the background of the project. The documents reviewed are listed in Annex 1. Each document was extracted based on the data on the process of the project development and implementation, challenges, supporting factors, success stories, partnerships/collaboration, sustainability planning, and other issues.

##### 1.2. Development of list of respondent groups

Using the information collected in the document review and information from discussions with the Project Coordinator, the evaluation team developed a list of tentative groups of respondents. Respondents were classified into 'respondents directly involved in the PS project': this group included PSs themselves, women supported by a PS, relatives of PSs and relatives of the women supported by a PS, the HIV nurses and the Project Coordinator. This group was expected to have most insight in the effect of the project itself. In addition, a group of other stakeholders was created, which was classified as the 'respondents indirectly involved in the PS project' to the project. This group included staff from partner organisations, donors, trainers in the PS project and people working in other projects with the HIV positive women involved in the PS project.

##### 1.3. Development of data collection tools

The data collection tools were developed using the information from the document review and discussions with the PS project's Coordinator. Before preparing the guideline for the interviews using the MSC Technique, several domains of changes were defined. The domains of changes were based on the changes that may occur as identified by the different stakeholders in this project. Domains of changes were only identified for the respondent groups of 'respondents directly involved to the PS project' as they were expected to be able to explain the changes caused by the PS project. For this evaluation, the following domains of changes were defined (Table 1):

Domain of changes	PS	Women	Relatives	HIV Nurses	Project Coordinator
Quality of Life	x	x	x	x	x
Change in your close circle (friends, family, neighbours)	x	x	x		
Participation in society	x	x	x		
Organisational Practices					x
Adherence to ART				x	
Change in your work				x	x

**Table 1. Domain of changes for each group of respondents in the respondents directly involved to the PS project**

For the respondents directly involved in the PS project, as well as for the group of respondents indirectly involved in the PS project (trainers and others stakeholders), interview themes were defined on topics not directly covered by the MSC Technique. The themes were connected to the position of the respondent, the evaluation objectives and themes derived from data reviewed in the document review. Themes included the support received by HIV-positive migrant women, the PS training, effects of the project observed, challenges and supporting factors in implementation, lessons learnt, recommendations, and position of the project in the future. Based on the interview themes, questions were made for the semi-structured interview guideline.

All tools were developed in both English and Dutch, except for the tools for the HIV nurses and Project Coordinator which were only developed in Dutch, as the respondents would be Dutch-speaking. The MSC tools were piloted before being used for collecting the data. Based on the input during the pilot process, the evaluation team revised the tools to make them ready for use.

Based on the domains of changes and the interview themes, and covering both the Dutch and English language, 13 data collection tools were developed and can be found in Annex 2.

#### 1.4. Finalise the evaluation design and logistics

In order to prepare the interviews and FGDs, a list of potential interviewees was made to cover respondents from each group (both directly and indirectly involved stakeholders). The evaluation team approached all respondents and made appointments for the individual interviews. The evaluation team travelled to the interviewees to meet them at an agreed place identified as 'safe' and easy for them. These places were in the office of ResultsinHealth in Leiderdorp, at the office of ShivA in Amsterdam, homes and offices of the interviewees, and the office of Buddy Netwerk in Den Haag (for the interviewees living in or close to Den Haag).

#### 1.5. Process and criteria for inclusion and exclusion

Selection of the PSs was based on their responsiveness for participating in this evaluation. The first selection of the PSs was done by the Project Coordinator, who introduced this activity to the active PSs and asked them whether the evaluation team could get in touch with them. Once the evaluation team could reach a PS, an appointment was made for an interview. Some PS could not be reached for an appointment. After six interviews and the FGD, the evaluation team agreed that data became repetitive ('saturation'), hence no further interviews with PSs were planned. Selections for the relatives were based on information of the Project Coordinator and the PS interviewed.

Interviews with the women supported by PSs were conducted after all interviews with PS were finalised. Selection of the women supported by a PS was done based on information from interviews with the PS and information from the Project Coordinator on the willingness of some women to talk to someone about their situation and the PS project. All women were reached through the PS. Relatives were also selected on their responsiveness for participating in this evaluation and were all reached through the PSs.

For the other respondents (trainers, HIV nurses and 'other stakeholders') only English or Dutch speaking respondents were included. Respondents were selected based upon the knowledge of the evaluation team and ShivA's Project Coordinator, as well as recommendations of other respondents during interviews. Respondents were contacted by email or telephone.

#### 1.6. Description of respondents

For this evaluation a total of 34 respondents were interviewed. PSs were HIV positive migrant women from Sub-Saharan Africa (SSA) or the Caribbean, living in the Netherlands, who have been trained as PS: they had all completed the training of ShivA and signed a contract with ShivA to be PS. In total six PSs were interviewed; seven PSs were included in the FGD. No detailed information about them is available.

Women supported by PSs are HIV positive migrant women from SSA or the Caribbean living in the Netherlands who are connected by their HIV nurse to a PS. At the time of the interview, these women have been in touch with their PS already for at least two months. Some of them had already concluded the period of support from the PS (which is generally six months) and are still in touch with the PS (see Table 2).

Characteristics	Category	PS	Women supported by a PS
Total		6	4
Age	<b>20-29</b>	0	1
	<b>30-39</b>	1	0
	<b>40-49</b>	4	3
	<b>Unknown</b>	1	0
Region of origin	<b>SSA</b>	5	3
	<b>Caribbean</b>	1	1
Women Supported	<b>1-2</b>	4	NA
	<b>3-4</b>	2	NA
Marital Status	<b>Married</b>	4	1
	<b>Not married</b>	2	3
Children	<b>0</b>	0	2
	<b>1-2</b>	4	1
	<b>3-4</b>	2	1

**Table 2: PS and women supported by a PS interviewed (excluding FGD)**

Relatives are people close to a HIV positive migrant woman from SSA or the Caribbean living in the Netherlands. The relatives included in this evaluation were all family members of the PSs. HIV nurses (Dutch: verpleegkundig consulent HIV) are nurses who specialised in HIV care and support of patients with HIV. Some HIV nurses and other stakeholders call these nurses 'consulent'; this term is used in some Stories of Change to refer to the HIV nurses. Trainers are professionals who gave at least one training session during the PS training. The Project Coordinator of the PS project also has been interviewed.

Other stakeholders were people working in a field related to the working area of Shiva. This includes people working with migrants, on HIV, or both. Also funding organisations in the field of migrants and/or HIV were included. Eight "Other stakeholders" were interviewed. These stakeholders work or have worked at organisations active in the field of HIV in the Netherlands, and are directly or indirectly involved with Shiva and its activities. These organisations are SOA AIDS Nederland, Aids Fonds, HIV Vereniging, Buddy Network, the AMC and Shiva itself (see Table 3)

Characteristics	Category	Relatives	HIV Nurses	Trainers	Other Stakeholders
N Total		2	5	1	8
Sex	<b>Men</b>	2	1	0	3
	<b>Women</b>	0	4	1	5
Age	<b>30-39</b>	0	2	1	1
	<b>40-49</b>	1	3	0	4
	<b>50&lt;</b>	1	0	0	3
Profession	<b>HIV Professional</b>	0	5	1	7
	<b>HIV Volunteer</b>	0	0	0	1
	<b>Other</b>	2	0	0	0

**Table 3. Summary of the characteristics of the HIV nurses, trainers, relatives and other stakeholders**

## 2. Interview and FGD Phase

The Interview and FGD Phase includes the data collection through interviews and FGD using the tools prepared in Phase 1. Phase 2 is divided in 2 parts; data collection using the MSC Technique and data collection using semi-structured interviews.

The selection of the guideline depended on the types of respondents (see Table 4) and their involvement in the PS project. Respondents who were directly involved in the PS project were interviewed using MSC interview questions for the changes caused by the PS project; and semi-

structured interview guideline to gather other relevant information. Respondents who were not directly involved in the PS project were interviewed using the semi-structured guideline.

Type of respondent	Type of data collection method		
	Semi-structured interview and MSC	Semi-structured interview only	FGD
PSs	6	0	1 with 7 PS
Women supported by a PS	4	0	0
Relatives of the PSs	2	0	0
HIV nurses	4	1	0
Trainers	0	1	0
Relevant stakeholders	0	6	0
Project Management	1	1	0

**Table 4: Type of data collection method used per type of respondent**

### 2.1. Data collection using the Most Significant Change Technique

In collecting the stories of changes using the MSC Technique, the following steps were taken:

1. Interviews were conducted using the prepared MSC guidelines for several different groups of respondents (PSs, women supported by a PS, relatives of PSs, HIV nurse, and Project Coordinator); in total 17 MSC interviews were performed (Table 4);
2. Conducted FGD with PSs in which seven women participated;
3. Data transcribing and writing: of each interview one Story of Change was produced and from the FGD also one Story of Change was produced, resulting in 18 Stories of Change in total (for all stories please be referred to Annex 3).

### 2.2. Data collection using semi-structured interviews

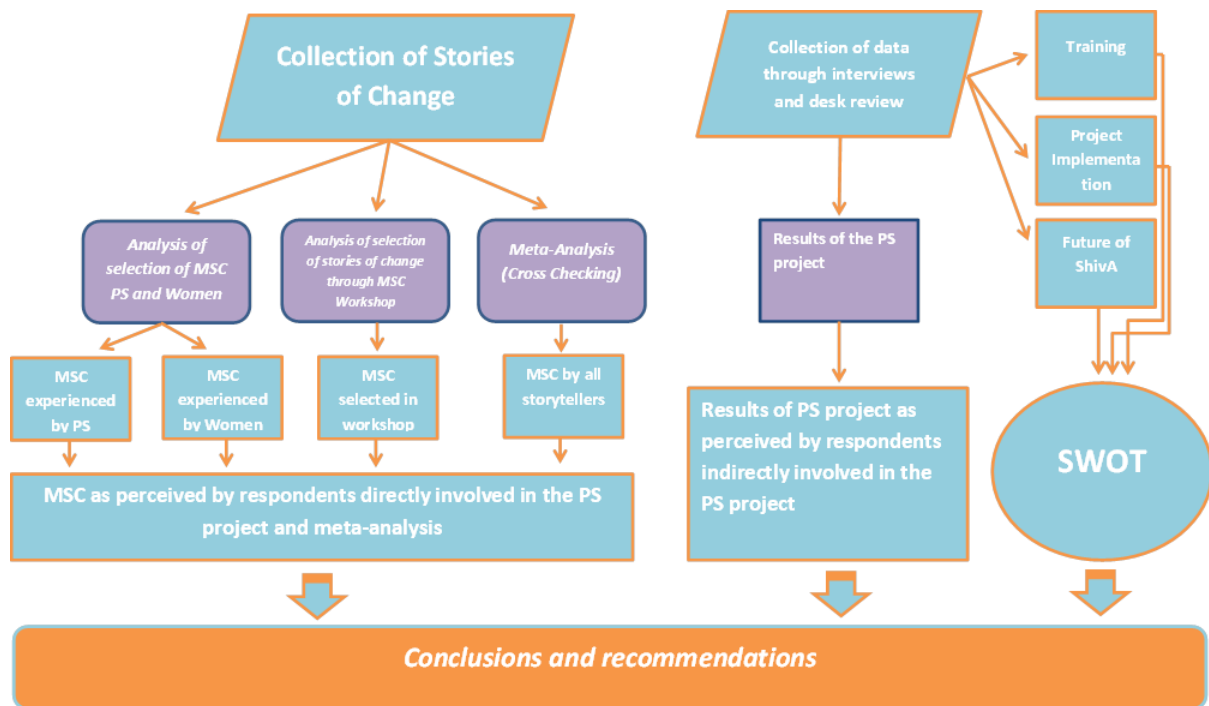
In conducting the semi-structured interviews, the following steps were followed:

1. Semi-structured interviews were conducted by using the prepared guidelines for different groups of respondents (PSs, women supported by a PS, relatives of PSs, HIV nurse, Project Coordinator, donors and persons from partner organisations). If possible, the semi-structured interview was combined with the MSC interview to save time. In total 26 semi-structured interviews were conducted (Table 4).
2. Data transcribing and writing: of each interview the recorded data was transcribed.

Most of the interviews and the FGD using the MSC and/or the semi-structured interview guidelines were carried out by two researchers, 12 interviews were done by one person due to timing of the interviews and other priorities of the members of the evaluation team. All but one interview has been recorded with a voice-recorder to facilitate transcription of the interview. Interviews were conducted in the language of choice of the respondents, either in English or in Dutch.

## 3. Data Analysis Phase

Phase 3, the Data Analysis Phase, includes the analysis of the data collected using the MSC technique including the stories selection workshop, and the process of analysis of the data collected in the desk review and semi-structured interviews. The analysis phase is illustrated in Figure 1 below.



**Figure 1. Flow-chart of analysis of data**

### 3.1. Analysis of data collected using the MSC technique

After the collection of the Stories of Change, and the writing of the Stories, the data was split in three phases of analysis; 1) the MSC selected by the respondents and singling out the MSC of the PS and women supported by a PS, as they are the principle beneficiary of the PS project, 2) selection of the Stories of Change through the story selection workshop, and 3) the advanced analysis including cross checking of the changes mentioned in all Stories of Change collected.

#### 3.1.1. Selection of the MSC of the PS and Women

Key in the MSC Technique is the question to explain which of the changes caused by the PS project is the most significant change (the MSC), as perceived by the respondents. This information was taken from all Stories of Change, and described separately. The changes mentioned by the PS and women supported by a PS were separated to be compared with the other data later in the analysis. These changes were separated because the PS project has the objective to cause changes for the PS and women supported by a PS as its principle goal.

#### 3.1.2. Selection of Stories of Change in the MSC workshop

The purpose of the workshop was to involve respondents in selecting the most significant stories that can be perceived as a result of the PS project and explaining the reasons why this story was selected. This process adds to the strengths of the analysis through providing a contrast of stories of changes, thus area of changes, as selected by an individual and by groups. This contrast can provide insights on how the group and the group process may cause shifts or changes in the selection of the most significant change stories.

Due to the limitations in time and ability for participation of the key informants for the workshop, the evaluation team did a pre-selection of the collected stories to fit the available time and participation of the participants of the workshop (stage 1). During the workshop, participants conducted the stories selection out of the nine stories pre-selected in stage 1: stage 2. These processes are described in detail below:

##### 3.1.2.1. Story Selection - Stage 1:

In total 18 stories of changes were written. Due to the large number of stories and the limited time available for the stories selection workshop, the evaluation team decided to pre-select nine stories (three stories from the group of PSs, three from the HIV nurses and three from the group of the

women supported by a PS) before the stories selection workshop. These stories were selected as follows:

1. The evaluation team developed criteria to assess the strength of the stories of changes based on the description of the information in the story. The criteria included: i) clarity of the description of the changes occurred, ii) clarity of the description of the process of change, and iii) clarity of description of the reasons why the changes are important. For each criteria a score was applied; 1 (poor), 2 (average), and 3 (good);
2. All members of the evaluation team selected the stories using the agreed selection criteria individually;
3. Results of individual selection were discussed in a group session, and a group agreement was made on selecting nine stories;
4. The nine stories were prepared in two languages (Dutch and English) to anticipate language of preference of the participants in the stories selection workshop.

### 3.1.2.2. Story Selection - Stage 2:

The second part of the story selection took place in a workshop setting at the office of ShivA. In total 13 participants including nine PSs, one relative of a PS, one HIV nurse and two other stakeholders participated in this workshop. All except for one participant were female. The evaluation team divided the participants into three groups of three or four people. Each group consisted of various types of key informants (PS, relative, nurse and stakeholders). The nine selected stories were distributed over the three groups (one group discussing the three selected HIV nurse stories, one group discussing the three PS stories, and one group discussing the three stories from the women supported by PS). Each group was facilitated by one of the members of the evaluation team to guide the discussion in selecting, and analysing the content of the stories.

In general the processes implemented by the three groups were similar: 1) the facilitator explained the purpose of the small group discussion; 2) group members read the stories in their preferred language (Dutch or English); 3) the facilitator guided the discussion of the content of each stories by focussing on what kind of changes happened/mentioned in each story, what the most significant change was mentioned by the story teller, and for which reason(s), etc.; 4) the group discussed which factors/considerations and changes should be considered as important to guide them in selecting the stories and 5) the group decided on which story should be selected as the most significant change story.

Of the three groups, the groups discussing the stories of the PS and of the women supported by a PS could not come to an agreement to select one most significant change story. These groups reported that the difficulty in selecting the stories was due to the fact that all were similarly important and reflected the same process from a different angle. Within the group discussing the stories of the women supported by a PS, two group members (out of four) selected the story of W2 as the most significant change story. But the other two group members did not support this selection. Therefore, the agreement was not to select any story out of the stories of W1, W2 and W3. The PS' stories group could exclude one story and ended up with two stories (story of PS2 and PS3) as a final result of selection. Also this group found that both stories illustrated an equally important change. The HIV nurse group selected the story of N3 as the most significant change story, as in their opinion this story reflects all important changes caused by the PS project.

Each group presented their selection process and findings in the plenary session, and discussions regarding the group's agreement were held and facilitated.

#### *Evaluation of the process by workshop participants*

At the end of the workshop, the evaluation team facilitated a short evaluation of the MSC workshop itself. The workshop participants were asked to agree, disagree, or neither agree nor disagree with a statement. Two statements were presented for individual opinions: 1) the process and organisation of the workshop was clear and 2) the workshop was useful. None of the participants disagreed with any statement. More than half of the participants agreed with the first statement, the rest did not agree, but also did not disagree. On the second statement, almost all participants agreed for different reasons: some stated that it was useful to know that the project is useful for the women involved; others found it useful to see people involved in the project. Participants agreeing with the second statement also mentioned that they agreed because it is useful to do this for ShivA, and ShivA is helping them, so therefore the workshop was useful for them as well.



### 3.1.3. Meta-analysis

In the meta-analysis, the evaluation team worked on the results of all 18 Stories of Change collected in this evaluation, including the stories not selected for and in the story selection workshop. The team identified areas of changes within the domains of change to group all changes identified by the respondents. In addition, the most significant changes as defined by the respondents were analysed according to the areas of change. The areas of change related to the domains of change (Table 5):

Domains of changes	Areas of change:
Quality of Life	Increased knowledge on HIV
	Feeling of not being alone
	Increased happiness in life
	Increased openness about being HIV positive
	Increased self-confidence
	Better physical health
	Increased empowerment
	Role of spirituality and being HIV positive
	Ability to help others
	Increased interpersonal skills
	Acceptance
	Improved family relations
	Future perspective
	Adherence
	Influence on work of HIV consultant
Negative Changes	
Change in your close circle (friends, family, neighbours)	Change in your close circle (friends, family, neighbours)
Participation in society	Participation in society
Organisational Practices	Organisational Practices
Adherence to ART	Adherence to ART
Change in your work	Change in your work

**Table 5: Areas of changes related to the pre-defined domains of change**

The meta-analysis of the MSC data included analysing the changes mentioned by different respondents. Overlap and differences were identified. An analysis on the changes identified by one group about another were analysed by comparing them with the changes identified by the group itself.

### 3.1.4. Data analysis from desk review and analysis of data collected by semi-structured interviews

The data of the desk review has been used for the preparation phase, as well as to feed into the SWOT analysis and recommendations of the evaluation.

In addition to the MSC data and information from the desk review, also the data collected by the semi-structured interviews was analysed. All data was grouped according to the pre-defined themes. Most data of the semi-structured interviews was used for the SWOT analysis and some of the data has been described separately in the results section of this report.

## 4. Report writing Phase

After the analysis of all data, the evaluation team prepared the evaluation report with the preliminary results of the evaluation. The preliminary findings were presented in a dissemination workshop on 11 November 2013 for stakeholders from the field, including PSs, partner organisations, donors, and other parties interested. Comments or additions were included in the final report of the evaluation.



## 4. Findings: Changes due to the PS project

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In this chapter the results attributed to the PS project are described. The results are described in terms of changes, reported by individuals and groups of respondents. Within this chapter, those changes are also further analysed to show the connection of these changes across the different groups of respondents.

### 1. Changes reported by groups of respondents

The first section of this chapter describes the changes as reported by the different groups interviewed using the MSC Technique. The changes are summarised in Figure 2.

#### 1.1. Changes occurred in the life of the PS due to the PS project

The changes described by the PSs were changes in their personal life and changes in the life of the women they have supported. Five of the six PSs, as well as the PS in the FGD experienced "increased empowerment" in their personal life. This was described as becoming stronger as a person or the feeling of being able to fight stigma: *"ShivA has brought this strong woman out of me, to care for other people."* Another important change that was mentioned by five PSs and the PS in the FGD was that "they are now able to do something for others". This is translated into the ability to give hope to the women they support, make real changes in the lives of these women or even save their lives: *"I have never experienced so much joy of doing what I really love without being paid. I feel successful. It is priceless, honestly. Making somebody has hope."* Four PSs also indicated that by being a PS "they are now more open about being HIV positive and able to open their heart". The same number and the PS in the FGD indicated to have an increased knowledge on HIV from the training ShivA provides to PS and also because they decided to look for information themselves. Three PSs and the PS in the FGD feel that "they have more self-confidence" due to the role they now play in other women's lives: *"[...] having the confidence to coming out to help other people. To be there for somebody, it is priceless."* Besides this, these three PSs also feel that "their physical health has improved; they feel good and have more energy". This was explained as a direct result of either being a PS as it gives the women energy, or because the PS feels the need to take extra good care of herself to be a good role model for the women they are supporting.

Two PSs also reported "increased happiness in life" as a noticeable change. One PS mentioned that since she is working as a PS, she feels good and happier: *"I feel good; I feel that I am somebody, somebody important."* Similarly, two PSs and the PS in the FGD mentioned that "they now feel they are not alone as being an HIV positive migrant woman". Through their involvement with ShivA, they met other women in similar situations and made friends with women who understand their situation. Through similar mechanisms, two PSs mentioned about "having learnt a lot on the role of spirituality in their lives; and on how their spirituality can play a role in their life as an HIV positive woman". One PS also mentioned that "her interpersonal skills have improved" since the start of this project, as she explained that she uses the skills she learned in the PS project also on other occasions and feels strengthened by this. "Acceptance" was another change mentioned by one PS. The PS project helps people to be able to tell their story and accept it: *"I am free; I know who I am and now I can give everything a place, accept it."*

The PS project also induced a negative change. Although PSs generally felt good about the project, one PS mentioned that "being a PS also gives her lot of pressure": *"Someone is waiting behind you. Someone is leaning on you."*

Changes that occurred in the domain of their close circle (e.g. whether the relationships with their family at home changed) and the domain of participation in the society were also probed in the interviews (e.g. whether the PSs are able to find a job after being involved in the PS project), but no changes were reported.

The PSs (four of six and the PS in the FGD) mentioned "the ability to do something for someone else" as the Most Significant Change due to the PS project. In the end helping another person is the main reason why these women join the PS project: *"Then after a few weeks, you meet her and you see a changed person."* And that makes them feel happy: *"You saved somebody's life."* "Increased openness about being HIV positive", "increased empowerment" and "acceptance" have also been mentioned as Most Significant Changes by a lesser number of PS individually and in the FGD.

## 1.2. Changes occurred in the life of the women supported by the PS

Changes for the women supported by a PS mostly occurred in the domain of the quality of life. One woman (out of four) explained that "her knowledge on HIV has increased due to the support of the PS through provision of printed materials". One woman explained that she "became more self-confident after meeting her PS". Two women mentioned that "being connected to a PS helps them to adhere to their medication", as the PS motivates them to take their medication as part of a healthy lifestyle and next to eating healthy food and exercising. Three women mentioned that "the PS helps them to have a future perspective by being their role model": "[...] when W2 was waiting in the waiting room of the hospital to meet each other, she saw a lady coming and W2 thought; "it cannot be her". In W2's mind she was expecting to see someone who is very blown off, really skinny."

Three women mentioned "Increased happiness in life". They feel happy and feel calm, start to enjoy life, do fun things and change their lifestyle. According to them this happiness is due to their acceptance of being HIV positive: *"I'm glad I have accepted it (HIV positive), I just feel different now! I know that things don't always go your way, but now I just think: that's life. I dare to face the facts."* The latest is also mentioned by the PSs: *"There is life after HIV. You can still have children, you can still do a lot of things anybody else, a normal person, can do. It does really give them hope."* Three women mentioned that the PS helped them in accepting their HIV status: *"I used to worry a lot. I thought, does this happen because I am in a foreign land? Far away from home and have nobody? Now, I don't panic like I was years ago. With her [the PS] I am comfortable. Now I know myself, and it [her HIV status] is slowly getting a place in my heart. She [the PS] makes that I can talk about it."* In the case of one woman, accepting the HIV status also resulted in forgiving the person who infected her. The PS suggested her to let it go *"So it is forgiving, letting go. She [the PS] was my inspiration for that."*

The PS also helped the women to disclose their HIV status, showed them that they are not the only one with HIV, and helped them overcome the fear of being confronted with HIV in daily talks and media. The PSs helped three women to be open on their being HIV positive; in sharing her status with close family of one woman, and convincing another woman to join a weekend-event and to meet others from her own community: *"I thought, if she [her PS] asks me to come, it must be ok."* Three women mentioned that talking to the PS helps them to talk about their HIV status, which helps them further in talking to their health care providers. However, two women did not disclose their HIV status with others in their close circle up to now. All women mentioned that being connected to a PS makes them feel that they are not alone. They feel that the PS is someone with good understanding on what they go through, as the PS has been in the same situation. With the PS they can discuss everything, and the PS is able to answer all their questions. For three women, being connected to the PS gives them a feeling of having somebody who cares: *"like having a person that doesn't want me to feel bad, this person is trying to do her best for me"*.

One woman mentioned that her family relations improved after meeting her PS, and had fewer tensions at home as she does not accuse her partner of infecting her in every small argument. This change can be positioned in the domain of changes in her close circle. One of the women started voluntary work to provide counselling to others who are feeling down: *"it all started with being confident and say OK now I'm standing up and go out"*. This change can be attributed to the domain of participation in society. There are no negative changes reported by the women supported by a PS.

According to one of the women supported by a PS, increased self-confidence is the most significant change. As soon as she felt confident, it enabled her to stand up, go out, and bring about other changes. Two other women mentioned acceptance of their HIV status as the most significant change. Acceptance was needed to have a future for herself and her family: *"that I have finally accepted it."* *"I think otherwise I would have collapsed, after all, I didn't have a choice."* One woman felt that the future perspective is most important: *"I used to think that I would die soon", but now she knows that she could probably live for another 25 years!*

## 1.3. Changes occurred in the life of the relatives of the PS due to PS project

Two relatives of a PS were interviewed on changes that occurred in their own life and in the life of the PS. Both relatives mentioned the ability to help others as an important change. Considering that the majority of PS are migrant, being able to help other migrants give them a sense of purpose in life. Both relatives also noticed that their wives have more self-confidence after being involved as a PS. According to one relative, this may be due to the fact that his wife now has a

responsibility, does something useful and that she can manage herself in the new country. Consecutively, he also noticed that his relationship with his wife improved. Helping others helps them to reflect on how they addressed certain issues themselves and not automatically assuming that others have no problems with it: *"It puts your own situation in perspective."*

One relative thought that "increased self-confidence" was the Most Significant Change. The other relative mentioned that both the "increased self-confidence" and "the ability to do something for someone else" are equally important.

#### 1.4. Changes reported by the HIV Nurses

For the HIV nurses, changes due to the PS project occur in two domains; changes in the lives of the women involved in the project and changes in their work as a HIV nurse. In the lives of the women, several changes were mentioned. Better physical health (less stress and a less bad experience of being HIV positive) is mentioned by two HIV nurses. Two HIV nurses mentioned "increased acceptance of being HIV positive" as another change: *"Because of the PS project, some women say: 'I have HIV, but I'm no longer HIV'".* This increased acceptance lead to more openness, translated into the feeling of liberation or relief: *"The last patient who was connected to a PS was immediately very positive: 'She was so relieved of that burden.'" HIV nurses described that the silence is broken, women start disclosing their status. Not only to the PS but also to other people and they become more open also in their contact with their HIV nurse. Three HIV nurses mentioned a change in terms of increased feeling of not being alone. The PS has a full understanding on what patients go through and how to handle issues related to their situations. In addition, for the patients, being connected to the PS project opens opportunities for other contacts, e.g. weekend-events with other HIV positive people which reduce the feeling of being alone. Three HIV nurses observed how their patients are being empowered by participating in the PS project. They take control and responsibility of their own life, start actively looking for solutions when they have problems and be a role model for their own communities. All HIV nurses mentioned that the PS project helped patients to have a future perspective. *After her first conversation with her PS this woman said: "Now I am re-born again."**

One nurse mentioned improved adherence to HIV medication as such, as the medication is no longer seen as a daily confrontation with HIV but rather as something positive: *"One can say that the medications remind me that I have that terrible disease. But one can also say that the medications remind you that you can still live for a long time with HIV."* All HIV nurses explained that the indirect link to increased adherence because of increased acceptance of the HIV status and decreased feeling of not being alone can be made. If the psychosocial state of the women improves, which they all see is clearly happening because of the support of a PS, and women start to care for themselves again, the adherence tends to get better. *"Instead of the medicines reminding me of having HIV; it is said that the medicines reminds me that I am still alive and that I can have children."*

After working with the PS project, all HIV nurses experience changes in their work as HIV nurse. Two HIV nurses mentioned that the PS project serves as a welcome option for referral for their patients, next to the already existing groups for HIV positive migrant women, due to the individual focus of the project. The PS project makes the work of the HIV nurses easier as it enables them to have more time to discuss medical issues with their patients, instead of dealing with psychological issues. Three HIV nurses mentioned that it does take them quite some time to arrange the first meeting between the patients and the PS. However, they did not see this as a negative change, as it is perceived as having more benefit for their patients, knowing all the positive changes the PS are bringing in the lives of the women.

When asking about the most significant change, one nurse mentioned "the increased openness on being HIV positive", specifically the feeling of liberation. Another HIV nurse mentioned the fact that "the women become empowered" as the most important change; specifically, the combined empowerment: being a PS and the feeling of having someone who fully understands you. One HIV nurse mentioned that "acceptance" is the most important change: *"When acceptance occurs, the rest can follow".* And one HIV nurse indicates that the future perspective given by the PS project is the most significant change: *"The confidence in a life with HIV, that is an enormous positive change: 'seeing that another woman who is HIV positive and has gone through a lot; leads her life, active, seeing where she is, and does all sorts of things."*

### 1.5. Changes reported by the Project Coordinator

For the coordinator of ShivA, the changes due to the PS project occur in the domain on changes in the lives of the PS. "The role of spirituality in relation to being HIV positive" is reported as a change, specifically in having less problems in accepting HIV status in relation with their being religious and having a meaningful religious life: *"In some cases, they are able to turn the relationship between their religion and their HIV status into a positive thing; instead of something bad or connected with punishment."* Other changes are "the increased self-confidence", specified by growing self-awareness and self-esteem and happiness in life. The Project Coordinator sees that women "become more empowered by being a PS". This is reflected in the change on their awareness of their abilities and boundaries: *"At the beginning the PS always says "yes" to me. Lately they started saying no to me when I asked whether they can support a (new) woman, with good explanation on their reason to say no. For me, this means that they are very much aware of their boundaries, in what they can and cannot do."* These women become strong persons who need less support.

There are changes within the organisation of ShivA mentioned by the Project Coordinator which are due to the PS project. Because of the target group of migrant HIV positive women, ShivA is now also giving broader support instead of only the spiritual support it provides in its other projects. This support includes contact with social workers and other organisations involved in housing, health care, etc. to get the lives of the women back on track so they can start working on their spiritual well-being: *"You should not talk about God and emotion if you have nothing to eat."* These activities take a lot of time, which is not directly paid by the donors of the PS project as this is not officially part of the project. Therefore a lot of non-earmarked money is going to the PS project instead of to other projects of ShivA. The extra support ShivA is giving to HIV positive migrant women also created tensions between donor organisations and ShivA, as they become involved with the donors not only for funding of their projects, but also as a partner organisation to deal with the target group of HIV positive migrant women.

According to the ShivA coordinator, the most significant change is "the increased self-confidence including the growth of self-esteem of the PSs": *"When the self-esteem is improved, the rest will come."*

## 2. Changes across the different group of respondents

The domains of change across the different groups of respondents have been classified in different areas of change. The table below summarises the number of changes reported within the different areas of change per respondent group. Changes reported in the FGD are counted as one change (Figure 2).

Domain of change	Area of change	Positive Sister	Woman supported by PS	Relative of PS	HIV Nurse	ShivA Project Coordinator	Total
Quality of Life	Increased knowledge on HIV						
	Feeling of not being alone						
	Increased happiness in life						
	Increased openness about being HIV positive						
	Increased self-confidence						
	Better physical health						
	Increased empowerment						
	Role of spirituality and being HIV positive						
	Ability to help others						
	Increased interpersonal skills						
	Acceptance						
	Future perspective						
	Adherence						
	Negative Changes						
Change in your close circle	Change in your close circle (friends, family, neighbours)						
Participation in society	Participation in society						
Organisational Practice	Organisational Practices						
Adherence to ART	Adherence to ART						
Change in your work	Change in your work						
	Represents one respondent in whom change was present						
	Represents one respondent in whom change was not present						

**Figure 2. Summary of changes reported across the different groups of respondents**

Most changes were observed in the domain of change of quality of life of the women involved in the PS project, including the PS and the women supported by the PS. This can be explained by the fact that the PS is the primary target group of this project, and because the number of interviewees in this group is highest. Similarly, many changes are also reported to occur in the life of the women supported by the PS, as they link directly to the activities of the PS.

Changes attributed to the PS project that are mentioned by three groups of respondents are increased knowledge on HIV, feeling of not being alone, increased openness about HIV, increased empowerment, acceptance of being HIV positive and improved family relations (highlighted in orange in Figure 2). This suggests that the PS project contributes to the increased knowledge on HIV, feeling of not being alone, increased openness about HIV, increased empowerment, acceptance of being HIV positive and improved family relations of the PS or the women supported by the PS.

Changes that are mentioned by at least four of the five groups of respondents are increased happiness in life, increased self-confidence and having a future perspective (highlighted in blue in Figure 2). This suggests that the PS project has successfully changed the level of happiness of PSs and of women supported by the PS, built their self-confidence and gave them a future perspective in being a migrant woman living with HIV in the Netherlands.

Changes in the domain of close circle (close family or friends) were mentioned by one woman supported by a PS and one relative of a PS. Changes in the domain of participation in the society was only mentioned by one of the women supported by a PS. The Project Coordinator mentioned changes in the organisational practices. One HIV nurse mentioned changes in the adherence to HIV medication and all HIV nurses mentioned changes in their work caused by the PS project.

## 2.1. Cross-check of changes occurred in the life of the PS and women supported by the PS with other group of respondents

To document confirmation of changes which occurred within a group of respondents, changes mentioned by one group of respondents was cross-checked with similar changes mentioned by another group of respondents. Considering that the PS and the women supported by the PS are the primary target for the PS project, changes occurred in their quality of life that can be attributed to the PS project were cross-checked.

### 2.1.1. Changes in the quality of life of the women supported by a PS: reported changes by the women supported by a PS, the PS and the HIV Nurses

Changes in the quality of life of the women supported by the PS, as defined earlier in the analysis, were cross-checked with changes in the quality of life of these women as reported by the PS and the HIV nurse (see Table 6). The decision to select the PS and the HIV nurse for cross-checking the statements of the women supported by a PS is based on the fact that they are the ones who are regularly in touch with each other; for the PS it is their task to support these women, and the HIV nurses see these women regularly.



Area of change	Women supported by a PS	PS about the women supported by a PS	HIV Nurse about women supported by a PS
Increased knowledge on HIV	1		
Feeling of not being alone	4	1	3
Increased happiness in life	3	2	
Increased openness about being HIV positive	3	1	3
Increased self-confidence	1	1	
Better physical health		1	2
Increased empowerment		1	3
Role of spirituality and being HIV positive			
Ability to help others			
Increased interpersonal skills			
Acceptance	3	2	2
Improved family relations	1	2	
Future perspective	3	4	4
Adherence	2		1
Negative Changes			

**Table 6. Changes mentioned by women supported by the PS cross-checked with these changes as mentioned by the PS and HIV nurse**

For the women supported by the PS, “the feeling of not being alone”, “increased openness about being HIV positive”, “acceptance of HIV status”, and “having a future perspective” are mentioned by the women, the PS and the HIV nurse, implying that those changes are strongly associated with the PS project.

“Increased happiness in life” and “improved family relations” were mentioned by the women and the PS, but not by the HIV nurse. “Adherence to HIV medication” is mentioned by the women and the HIV nurse, but not by the PS. “Better physical health and empowerment” were mentioned by the PS and the HIV nurse; but not by the women. And “increased knowledge on HIV” was mentioned by the women, but not by the PS or the HIV nurse. Not all changes were confirmed by different groups. This might partially be explained by the fact that the sample size of the evaluation is low, or can also be explained by the different perceptions of changes that can be attributed to the PS project among the different respondents:

- “Increased knowledge on HIV” is perceived as important change by the women supported by a PSs, but not by the PSs or the HIV nurse, as the PSs and the HIV nurse see their role as care supporter and not as knowledge providers;
- “Increased happiness in life” and “improved family relations” were mentioned by the women and the PSs, but not by the HIV nurse. This may be due to the fact that the relationship between the women and the HIV nurse is a professional relationship and that the HIV nurses only spend a limited amount of time with the women (only during consultation hours); while the PSs spend more time with the women they support. Thus, the HIV nurse may not have noticed all changes, particularly the ones which occur in the women’s private sphere.
- Due to the private nature of taking pills and the fact that the women meet their PS in a defined time, the issue of adherence to medication may not be mentioned in the discussions between the PS and the women she supports. Two women mentioned that the PS helped them in adhering to their medication which might be due to indirect support given by the PS.
- “Increases in physical health” were not mentioned by the women supported by the PS, but by the HIV nurses and the PS as an important change, which may be due to the fact that the PS can observe the changes on physical health over time; and the HIV nurse may have more focus on this regarding her professional role as care provider. While the women may perceive the better physical health into the broader picture of well-being such as happiness in life and future perspective.
- “Being empowered” was perceived as an important change by the PS and the HIV nurse, and not by the women supported by a PS themselves. This may be due to the fact that the PS and the HIV nurse can see and experience the changes on empowerment over time, while it may be difficult for the women to recognise this. This may also be due the fact that empowerment can

be translated into different parameters, that makes it less defined, thus tends to be subjective and less clear to observe.

### 2.1.2. Changes in the quality of life of the PS: reported changes by the PS, the relatives of the PS and the Project Coordinator

Changes in the life of the PS are being cross-checked with the same changes reported by the Project Coordinator and the relatives of the PS, due to the nature of the PS project, in which the PS has intensive contact with the Project Coordinator through provision of support and guidance, and the relatives of the PS will be able to provide information on changes that occur in the private lives of the PSs (see Table 7).

Areas of change	PS	Project Coordinator about PS	Relatives of a PS about PS
Increased knowledge on HIV	5		1
Feeling of not being alone	3		
Increased happiness in life	2	1	1
Increased openness about being HIV positive	4		
Increased self-confidence	4	1	2
Better physical health	3		
Increased empowerment	6	1	
Role of spirituality and being HIV positive	2	1	
Ability to help others	6		2
Increased interpersonal skills	1		
Acceptance	1		
Improved family relations			1
Future perspective		1	
Adherence			
Negative Changes	1		

**Table 7. Changes mentioned by the PS cross-checked with similar changes as mentioned by the Project Coordinator and the relatives of the PS**

Increased happiness in life and increased self-confidence are mentioned by the PS, as well as the Project Coordinator and the relatives of the PS, implying that those changes are strongly associated with the PS project.

Changes such as “increased knowledge on HIV” and “ability to help others” were mentioned by both the PS and the relatives of the PS, but not by the Project Coordinator. “Increased empowerment”, “role of spirituality and being HIV positive” were mentioned by the PS and the Project Coordinator, but not by the relatives of the PS. Changes like “the feeling of not being alone”, “increased openness about being HIV positive”, “better physical health”, “increased empowerment”, “role of spirituality and being HIV positive”, “increased interpersonal skills”, “acceptance” and “negative changes” due to the PS project were mentioned by the PS, but not by the Project Coordinator nor by the relatives of the PS. Not all changes were confirmed by different groups. As mentioned earlier, this might partially be explained by the fact that the sample size of the evaluation is low, or can also be explained by the different perceptions of changes that can be attributed to the PS project among the different respondents:

- The Project Coordinator mentioned “having a future perspective” as an important change for the PSs, but the PSs themselves did not mention it as an important change. This may be due to the fact that the PSs perceived “having future perspectives” as an ability to help others or as a consequence of the increased empowerment.
- Similarly with “improved family relations”, this change was perceived as important by the relatives of the PSs, as they can see the changes; but not by the PS themselves, as it may be difficult to capture.
- Being part of the PS private sphere, the relatives of the PS reported “the increased knowledge on HIV” and “ability to help others” as important changes for the PS, while it is not mentioned by the Project Coordinator. This may be due to the fact that for the Project Coordinator the increase knowledge on HIV is somehow expected, as this subject was provided during the PS



training. Similarly with “ability to help others”, the sole purpose of being a PS is to help others; therefore, the Project Coordinator may not perceive this as an important change.

- “Increased empowerment” and “the role of spirituality and being HIV positive” are mentioned by the PS and the Project Coordinator as important changes; but not by the relatives of the PS. This is somehow understandable as the relatives may not be aware and therefore not recognise the content of the training that has been received by the PS from Shiva.
- “Feeling of not being alone”, “increased openness about being HIV positive”, “better physical health”, “increased interpersonal skills” and “acceptance of HIV status” are considered as important changes by the PS, and not confirmed by their relatives and the Project Coordinator. The relatives may not be focussing on these types of changes, as it may not concern the relationship between the PS and themselves directly. As for the Project Coordinator, these changes may be seen as a consequence of increased self-confidence and the ability to relate their HIV status with their spirituality; rather than as separate changes as such.

### 3. Selection of stories of change selected by groups of respondents in the stories selection workshop

As part of the data analysis, a workshop to select the most significant stories of change was conducted.

The workshop was attended by 13 respondents, and they were divided into three groups. Each group analysed three stories of change; one group analysed three stories from the PS, one group analysed three from the women supported by a PS, and one group analysed three from the HIV nurse.

The group analysing the stories from the PSs selected two stories: the story of PS2 *“They should know that there is life with HIV”* and the story of PS3: *“When I hear a story I think “I am even better than these other people.”* These stories were found equally important and were therefore both selected. The other story of PS6 was discarded as the PS seemed to struggle with her own acceptance of the HIV diagnosis. The group thought that a typical PS *“needs to have gone through this process of acceptance before being able to support other women”*. One of the selected PS stories sounded very familiar to the PSs participating in the group, clearly illustrating how she aims to reach a step beyond hope in the women she supports. She works *towards “the women’s acceptance of HIV; spiritually, mentally and physically”*. The other selected story was perceived stronger in the sense of providing a clear description of the internal process of the PS when giving support and hope to other women, with regard to feeling rewarded as a PS.

The group analysing the stories of the women supported by the PS did not select any story, as all stories were found to be a reflection of the same process but from a different angle. In all stories the power of the PS was used as an example by the women supported by them. It showed “the possibilities of a life with HIV”: this was agreed to be the important factor which was shared by all stories. The group members concluded that “acceptance of HIV status” was the most important result of the PS project.

Of the group that selected the story of the HIV nurse, the story of Nurse 3 (*“It is not the HIV that makes you sick, but it is the secret”*) was selected as the most significant story. Reasons for selecting this story were because it covers different types of changes (of a patient, HIV nurse and the health system), whereas the other two stories only included some of them. Based on this story of change, “acceptance of HIV” (*“Acceptance is the most important; you can only go on with your life if the HIV is not bothering you every moment of the day”*) is the most important change for the women supported by the PS, followed by “ability to share”, “having future perspective”, “improve medication use”, “empowerment”, and “active search for solutions”. For the HIV nurses, the most important changes were “the ability to work more efficient” and “to have more time to deal with medical issues”: *“For me the HIV nurse was also the only person I could talk to and we were always limited in time when I visited her”*. As for the system, the group agreed that if women (patients) stay in the system and take her medication, it will save the system time and money.

### 4. Results attributed to the PS project by respondents indirectly involved in the PS Project

Within this evaluation, respondents indirectly involved were asked to give their opinion on the PS project based on the results they could have observed from their indirect position regarding the PS project. The general opinion on the PS project was overall positive. Most indirectly involved respondents mentioned that the project is useful, ‘real’ (plans are realised and results can be

observed) and professionally implemented: “ShivA does good work; the project is real and useful. And Shiva is professionally managed.” In addition, most indirectly involved respondents appreciate the fact that the PS project shows real results after being active for a couple of years.

When asked about results of the PS project, indirectly involved respondents reported that they see a lot of positive results, namely: the PS project makes women feel relieved as they are able to talk about their problems to someone in a similar situation; the project makes it easier for women to accept HIV and to disclose their status; this project enables women to get their lives on track, find a job, and have a healthy family relation; the project helps women to anchor the faith in God, in themselves and overcome the feeling of being punished due to their being HIV positive. At the society level, the PS project empowers women and enables them to start adding to the cultural diversity of the Dutch HIV movement through participating in meetings and conferences and give voice to the migrants within the HIV activities in the Netherlands.

When comparing the results as mentioned by the indirectly involved respondents with the ones reported by the respondents directly involved in the PS project (see Table 8), the majority, except for one, are overlapping, which suggests that the results are observable from outside the direct project influence, and can be attributed to the PS project. The effect mentioned by one of the indirectly involved respondents regarding the fact that the women start adding to the cultural diversity of the Dutch HIV movement is not being cross-checked, as this was not measured as such for the respondents directly involved in the PS project.

Respondents indirectly involved	Respondents directly involved
The PS project makes women feel relieved as they are able to talk about their problems to someone in a similar situation	Increased openness about being HIV positive; increased self-confidence
The project makes it easier for women to accept HIV and to disclose their status	Acceptance of being HIV positive; increased empowerment
This project enables women to get their lives on track, find a job, and have a healthy family relation	Feeling of not being alone; improved family relations; future perspectives; increased empowerment
The project helps women to anchor the faith in God (which is very important to many migrants) in themselves, and overcome the feeling of being punished due to their being HIV positive	Role of spirituality and being HIV positive; increased happiness in life
The PS project empowers women and enables them to start adding to the cultural diversity of the Dutch HIV movement, through participating in meetings and conferences, and give voice to the migrants within the HIV activities in the Netherlands	Increased empowerment, ability to help others; increased interpersonal skills

**Table 8. Comparison of changes reported by respondents directly and indirectly involved in the PS project**

## 5. The Most Significant Change

Based on the above analysis, the most significant changes that can be attributed to the PS project based on different angles of the analysis are outlined below in Table 9:

The most significant changes for women involved in the PS project			
Selected by the PSs	Selected by women supported by the PS	Selected by all groups of respondents during the data analysis workshops	Mostly selected by different groups of respondents
Ability to do something for others		Ability to do something for others	
Increased openness about HIV		Increased openness about HIV	
Increased empowerment		Increased empowerment	
Acceptance of being HIV positive	Acceptance of being HIV positive	Acceptance of being HIV positive	
	Increased self-confidence		Increased self-confidence
	Future perspectives	Future perspectives	Future perspectives
			Increased happiness in life
		Adherence	

**Table 9: The most significant changes selected by groups and individuals**

The above table shows the overview of areas of changes selected as the most significant change attributed to the PS project by individuals and groups of respondents. The MSC as reported by the PSs and by the women supported by a PS were listed separately as these groups are the main beneficiaries of the PS project. The most significant changes as reported in the stories selection workshop are also listed separately as this describes the changes reported as most significant as reported, and agreed upon by the participants of the workshop. After cross-checking between different groups of respondents, three changes were listed by at least four out of five groups of respondents: increased self-confidence, future perspectives, and increased happiness in life. The table also shows the overlap between the results from the different sources of selection.

The overlap suggests that these changes are perceived as the most significant by individuals and is strengthened through the changes selected at the group level. These changes are:

- Acceptance of being HIV positive
- Future perspectives
- Increased self-confidence
- Ability to do something for others
- Increased openness about HIV
- Increased empowerment

The fact remains that changes are an event that is subjectively experienced and may be differently worded by each individual or group. For instance, the ability to do something for others and increased openness about HIV can be important parts of increased happiness in life. In this light, all of these changes should be considered as equally important.

## 5. Findings: Results of the semi-structured interview questions

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Besides the data on the changes caused by the PS project, other relevant information on the PS project is also collected from all respondents through semi-structured interviews. The information is organised according to topics and presented below.

### 1. Support received as a HIV positive migrant woman in the Netherlands

Living as HIV positive migrant women in the Netherlands can be complex. Legal issues such as a permit to stay and permit to work can be present, in addition to issues such as housing, issues related to children or partner and psychosocial related problems. For instance, one PS mentioned difficulties in opening a bank account for her children due to her HIV status. In the Netherlands, formal and informal support is available for HIV positive migrant women; however, it is not always accessible for the intended target group.

The PSs feel that they are very much supported by the HIV nurses and the social workers. Some of them mentioned their HIV nurse is their "engine". Most PSs reported that they do not receive support from their friends, as they do not disclose their HIV status to them and hence they are not able to understand their situation. Some PSs receive support from their family, such as their husband or in-laws, by giving an extra hand with daily work and showing an interest in her medical results. Other PSs do not receive support from their family members due to similar reasons with their friends. According to the relatives of the PSs, the PSs receive support from the professionals involved in the PS project on how to talk about their HIV status with the HIV nurse, their partners and their family. The biggest support for the PSs, according to their relatives, is by not acting differently towards women with HIV.

For the women supported by a PS, support is received from the PS, HIV nurse, internist, psychologist, family members or friends (e.g. at the church). For them, the PS is the most supportive at the moment. In most situations, the number of people knowing about their HIV status is very limited, as some of them have bad experiences (e.g. betrayal) by sharing their HIV status with others.

### 2. First contact with Shiva

For most of the PSs, their first contact with Shiva was via their HIV nurse. Other ways of being connected to Shiva: via internet, social worker, through meetings such as the PAMA, Humanitas Rotterdam and activities around World AIDS Day. As for all the women supported by a PS, they got in touch with Shiva through their HIV nurse. And as for the HIV Nurses, their first contact with Shiva was through a meeting of the professional association of HIV Nurses.

For the trainer and other relevant stakeholders, their first contact with Shiva was through work relations (e.g. for the trainer) or work-related events (meetings on HIV and or migrant).

### 3. Experience of working and being with Shiva

As mentioned earlier, Shiva is an organisation that bases its work on HIV and spirituality. The PSs reported only positive experiences in working and being with Shiva. The PSs claimed that they learned a lot from attending meetings at Shiva, and that the knowledge gained can be used in other projects or activities. Similarly, through Shiva they got to know other people in the same situation (being HIV positive), which contributes to the experience of being with close friends. The close relationship with the Project Coordinator is of high value to many of the PSs; they feel that they can always call her, talk to her and share everything.

Some PSs reported that they are also active in other support groups than the one organised by Shiva. Some PSs participate in groups such as Tam-Tam, Positive Africans Mutual Aid (PAMA), Positive Women of the World (PWW) and *Volle Maan*.

The PSs described that meeting other HIV women/people at Shiva ('terugkomdagen') and these different groups, was very motivating and helpful. They can talk with people who have similar issues during these meetings and therefore have a full understanding: "*When I go to Shiva or to PAMA, I feel like home. I can talk everything just without to feel afraid. It feels like meeting with old friends*".

Some PSs prefer to be and work with Shiva, rather than with other organisations. They feel that Shiva is honest and transparent, as opposed to some other organisations which were felt to be struggling and arguing about money. The PSs also highly value their relationship with the Project Coordinator. Some PSs also mentioned that it is difficult to go to the meetings of other organisations, as they often give very late notice.

A positive experience of being with Shiva is also reported by the relatives of the PSs; they very much welcome an organisation which specifically focusses on HIV positive, migrant women. Although not directly being or working with Shiva, the women supported by a PS also mentioned their experience with Shiva as positive, based on their experience in receiving support from the PS.

#### 4. Working as a PS

PSs usually meet the women they support for the first time at the hospital. After the first meeting, the PS stays in touch with these women through meeting them in person (to drink a cup of coffee) or through telephone or text messages.

The frequency of contact varies from a telephone call once per two days, texting once a week (to find out how the woman is doing and to let her know the PS is thinking of her), to only communicating when needed (with no defined frequency), depending on the need of the woman. As calling via telephone can be quite costly, texting was considered as the best option.

In many cases the PS reported that the woman she supports can contact her directly, by picking up the phone and talk to her *"Just being there"*. The PS is also available for a talk when the woman feels that there is nobody else to talk to, when they go for their medical check (the PS will then say *'hope that your CD4 counts are good, viral load is undetectable'*). The conversation between the PS and the woman they support may be on issues such as healthy nutrition, live a good life, thinking positively, and thinking about the future. They also talk about sharing the HIV status with others. Most PSs mention that they are not there to give advice. The work of the PS is to listen and let the women whom they support share their feelings and experiences. The women may ask a lot of questions and it is experienced as positive to be able to answer questions about things the PS knows. *"The women are not curious about HIV but they are curious to know what happens when you have HIV. It is nice for them to hear that from somebody who has it, who has the experience."*

PSs also mentioned that sometimes when a meeting was arranged, the woman did not show up. This is mostly clarified in the next meeting, e.g. the women had another meeting or something else came up. Some PSs also support women with HIV via another way, e.g. via the social worker, than via Shiva's PS project. *"Sometimes you meet someone who likes you and wants to be in touch with you."*

#### 5. Training of the PS

The information on the training of the PS is mainly collected from the project coordinator. Some of the PSs interviewed participated in the training in 2011 and others in 2012. The training consists of several sessions and was implemented as group training.

The training is mostly given by the Project Coordinator, and sometimes by the involvement of other professionals, including some PSs on specific topics. For the one trainer who is being interviewed, she has focussed on subjects such as: safe sex, relationships for people living with HIV (PLWHIV), and the Dutch health care system. She has done it more than five times, and the subject changes depending on the need.

During the training, the PSs learned about HIV, sexuality, nutrition, spirituality, how to talk with their family about HIV and how to live healthy with HIV. The PSs also learned that they can just be themselves, letting things out and there is space for people to tell their story, good and bad stories. They also learned how to approach issues step-by-step; not talk too much as *"the door might close again"*. *"To be there, just to hear, to give the ear, until everything comes out."* They learned how to talk to other people who are also positive, and have problems to deal with it. They practice with role-plays. *"For example, I am a Positive Sister and you are the Sister who is Positive and we are talking to each other. Now you tell me, you know, 'I live with this man and I know now for 5 years that I am positive and I am having sex with him without a condom.' If you say: Hè! How can you do that?!". Then you are pushing her away and will never see her again. These are the things that are taught: on how to talk to people; be patient."* The Project Coordinator tells

them "you cannot solve the problems of the others and you do not have to tell them how they can solve it themselves."

They learned how to use a method for asking questions on how and why, and to put the problem back to the person to solve it herself. They learned how to protect themselves, but still help the others and solve their problems. These skills are put as most important by some PSs.

The information received during the training is perceived as useful. The PSs mentioned that they can answer questions of the women or handle situations by using the skills from the *training* "What you hear you can relate it to what you have learned; you can see like 'this one is leading to depression'". The PSs feel that they are well-prepared for their work as a PS.

The knowledge on HIV that the PSs gather from the training is also used in their family life; e.g. one PS explained to her family member that if you have HIV you do not directly have AIDS. One PS explained that she likes the training from ShivA better than of the other organisation, because they are given the opportunity to talk about their own story and share it with everybody during the training. In many of the trainings of other organisations they get together, share food and go home; no information is provided on topics such as the importance of taking the medication or the meaning of CD4 counts. In addition, some PSs explained that meeting other people during the training is equally important. Considering all these benefits, some of the PSs suggested to offer these trainings more often.

One PS explained that she feels she knew a lot already before attending the training, but that she still learns new things during the training. However, sometimes she feels that the level can be a bit higher and with more detailed information.

## 6. SWOT analysis

One of the objectives of this evaluation is to document the implementation of the PS project, to identify challenges and supporting factors in its implementation, and to take out the lessons that can be learned so far. For this purpose, the evaluation team analysed the data on project implementation of the PS project that has been collected through the document review and interviews by using the Strength, Weakness, Opportunities and Threats (SWOT) matrix. In this matrix, data and information on the project implementation is presented as Strength, Weaknesses, Opportunities and Threats:

- Strengths: aspects that are working well in the PS project;
- Weaknesses: aspects that have not worked so well in the PS project;
- Opportunities: elements in the environment that the project could exploit to its advantage;
- Threats: elements in the environment that could cause trouble for the project.

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• Highly dedicated professional, female Project Coordinator</li> <li>• Basic principles of the PS project:               <ul style="list-style-type: none"> <li>◦ Specific to target group</li> <li>◦ Flexibility in timing for support provision</li> <li>◦ Individual approach and spirituality-based</li> </ul> </li> <li>• Implementation of PS project:               <ul style="list-style-type: none"> <li>◦ Diversity of PSs</li> <li>◦ Defined time of support provision</li> <li>◦ The project has a low threshold</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• The Project Coordinator, as an individual, is the driving factor of the project implying limitations</li> <li>• Factors hampering future implementation:               <ul style="list-style-type: none"> <li>◦ Minimal monitoring, follow up and standardisation of processes</li> <li>◦ Current project size is small and not well connected with other HIV prevention activities</li> </ul> </li> </ul>
Opportunities	Threats
<ul style="list-style-type: none"> <li>• Possibility for collaboration and structurally “join forces” with other organisations</li> <li>• Offer diversity in type of support provided</li> <li>• Using the current project results to attract funding</li> </ul>	<ul style="list-style-type: none"> <li>• Complexity around the issues of being migrant women with HIV</li> <li>• Drop-out of trained PS</li> <li>• Lack of funding and human resources within the organisation</li> <li>• Priority of donors regarding target group</li> </ul>

### Strengths

The PS project has several strengths that explain its success in improving the lives of migrant women living with HIV in the Netherlands. The strengths can be divided into three main categories: the PS project coordinator, the basic principles of the PS project, and the way the PS project is implemented. The most important strength of the PS project is its manager. The PS project coordinator is described by several respondents as a person with an enormous passion and dedication for her work. She gets things done because she is persuasive, intuitive and charismatic. She leads the PS project in a professional manner, while at the same time she offers such warmth and confidence to the people she works with, that they are inspired to move ahead. She is not working on a volunteer basis, which was also seen as a strength. In addition, she is a woman; for a man it would be harder to reach the same effect.

The basic principles that were made when setting up the PS project make it unique in its kind. It focusses on one specific target group (migrant HIV positive women). The “care-givers” are HIV positive themselves, which is a key factor for the PS project’s success. This, in addition to the fact that PS have more time and are not bound to appointment schedules, makes the programme truly complementary to formal care. And in contrast to other organisations that mostly organise group meetings, they do this on an individual basis; one PS is coupled with one patient. Finally, but equally important: the PS works from a spiritual perspective which for migrant women is often an instrument to acceptance and self-confidence. They are enabled to connect with God or their own spirituality, and by doing so they can reconnect with themselves.

Some other, more practical factors also contribute to the strength of the PS project. For example, the PS form a network of volunteers, offering diversity which can facilitate adequate matches with women served (based on factors like language, ethnicity, and place of residence), and offering a back-up system if one of the PSs drops out. In principle, the PS supports the women basically for a defined time (6 months), which was also mentioned as a strength, as to not overburden them. Even though the duration of the support is often extended, the basic principle that the first contact



is for 6 months is mentioned as a strong factor. Furthermore, for the HIV nurses the threshold to refer to the PS project is very low, as well as for women to access the programme.

## Weaknesses

Interestingly, the main strength of the PS project was at the same time identified as the main weakness. The PS project coordinator was the pioneer and she built her programme "around herself". This makes it fragile; everything depends on her availability to take care of the project. With the programme having more and more success, she is on the edge of not having sufficient time and being able to deal with all aspects of it. Due to her boundless dedication and very high standards, it is not always easy to collaborate with her at an equal level, or replace her if needed. If the programme grows, it cannot all depend on the current project coordinator. Another aspect mentioned was that she is too protective of her PSs and the women supported, for understandable reasons. However, a few respondents thought that this can withhold the PSs from further empowerment and initiative. They could, for example, enhance the programme's visibility and attract more funding.

An important weakness mentioned was related to the future of the PS project. Several respondents would like to see the programme grow to the national level. However, currently there are not enough PSs to support all the women who would like to receive support, and the project coordinator has insufficient time and work pressure to invest in expansion; the project is growing (too) fast. Monitoring and follow-up of processes is therefore difficult. Procedures are not fully standardised yet, it would need to be streamlined and optimised first and funding sought to do so. But as the warmth and direct and close contact of the project coordinator with the people served is the key success factor of the programme, it should be safeguarded that streamlining and optimisation will not undermine this success.

Another weakness mentioned by one respondent was that the PS project does not really engage prevention of HIV and healthy sexual behaviour from a public health perspective.

There are some other, minor weaknesses in the implementation of the PS project: sometimes, the follow-up after the first meeting is not very clear; the next contact moment between the PS and the woman can be too late, or too soon. In relation to this, it is not very clear what is to be done if the match between the PS and the woman did not work out ("no click"). The language can also be a complicating issue, as some women do not speak Dutch or English. When the PS and the woman supported meet or are in touch by phone, it is sometimes hard for the PS to advance the money for phone-costs or drinks (they normally meet at a "neutral" place).

## Opportunities

Among the opportunities, respondents mentioned potential collaboration with other organisations (such as the hiv vereniging) and medical professionals working in the field of HIV. Jointly they can really improve the wellbeing of the target group, and ensure the sustainability of the PS project. An example of such a collaboration is to organise the first meeting between the PS and woman supported in the hospital; while this currently happens on an occasional basis and is adopted as a standard by some HIV nurses, it could be offered as an option for all cases. Furthermore, the PS project creates champions. Most of the PSs go through a strong process of empowerment, and they can act as the advocates for the group they represent. Another opportunity for the PS is that the life expectancy of HIV positive women is becoming longer, offering options to continue providing appropriate support for HIV positive women reaching older ages. Through this evaluation exercise, the results can be used by the PS project to attract more funding for their project.

## Threats

Concerning the basic principles of the PS's work, a few respondents identified that there are complications with setting up a meeting between a PS and a woman, because they are both HIV positive, or because they are both migrants. The fear of being stigmatised, for example by the communities from their home countries living in the Netherlands, is very strong. This threat is immediately converted to a strength once the contact is established, so all said, it was worth the process and because of the fact that both women are HIV positive and migrant the understanding between them is leading. Other threats include the complexity of the problems faced by migrant women living with HIV, which can overburden the PS and should be left to professional care-givers. Furthermore, sometimes it happens that the project invests a lot in PSs to train and empower them, and they stop working with the PS project and are "lost" to other organisations.



The main threat for the PS project is without a doubt, the lack of funding. If more donors could be interested in supporting the PS project, the process of professionalization and potentially, expansion, could be initiated. More staff could be hired to support the project coordinator with this process. However, migrant women living with HIV are not seen as a priority by (potential) donors. A related complicating factor mentioned was that much distrust exists between organisations working with HIV.

## 7. Lessons Learnt. Strengths and limitations of this evaluation

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By performing this evaluation, there were factors that influenced the way this evaluation was conducted. These factors are outlined below as strengths and limitations of this evaluation. Consequently, the results of this evaluation should be seen in this light.

### Strengths

- Evaluation team: the evaluation team consists of professionals of various backgrounds, they are well-trained in the methodology employed, and the majority of them is bilingual (Dutch and English). This allows for flexibility in terms of languages and time, and facilitates an advanced level of discussion during the development of the methodology and data analysis.
- Collaboration: full support from the Project Coordinator and the participants in organising and carrying out this evaluation has contributed in the successful fulfilment of this assignment.
- Evaluation method: the methods chosen for this evaluation were successful in retrieving the information to answer the research objectives. The participatory focus of the MSC Technique has proven to be work in this evaluation to be able to show effect caused by an intervention in a complex population addressing a multifaceted problem. In addition, the MSC technique helped the respondents to analyse their own situation, using language and styles that are familiar for them, which empowered the respondents themselves.
- Evaluation design:
  - Interviews with the women supported by a PS were done in the last month of the interviewing period, which resulted in recent data on the project, and their relation with the PS and the support being received was included in the evaluation report.
  - This evaluation has been designed as such to allow full anonymity and time to build trust; this resulted in the creation of a safe environment for the respondents.
  - PSs and women supported by a PS received a telephone card of €10 after the interview, and the other respondents received chocolate to thank them for their time and efforts to meet the evaluation team. This was only told to them at the moment of the interview; the evaluation team did not inform them about this incentive at the time the appointment was made, to avoid influencing their reason to participate in the evaluation.

### Limitations

- Inclusion of respondents: selection of the PSs and stakeholders was based on input from the Project Coordinator. This may introduce a bias in only including respondents who are preferred by the Project Coordinator. Unfortunately, no relatives of women supported by a PS were included in this evaluation, as no relatives were found to be willing to participate in this evaluation.
- Timing: due to time limitations, interviews with some groups of respondents were not exhaustive, which might have resulted in missing opinions and views.
- Number of respondents: the number of respondents interviewed within a specific group is low due to low response to the request for interview; this evaluation may have missed (negative) opinions and views about the project.
- Language of interviews: not all respondents could be interviewed in their mother tongue due to the limited language capacity of the evaluation team. Therefore, the evaluation might have missed information due to the fact that respondents could not express themselves in languages different from their mother tongue.

## 8. Conclusion and recommendations

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The goal of this evaluation was to answer the evaluation objectives set at the beginning of this evaluation. These goals aimed to describe the most significant changes the PS project has caused to different stakeholders in the project, as well as to document the process of implementation of the PS project, including identifying challenges and supporting factors that have been encountered during the implementation of the PS project. The last objective aimed at identifying important lessons learnt and recommendations for the implementation of the PS project in the future.

From the data collected in this evaluation, it can be concluded that the most significant changes within the lives of women involved as a PS in the PS project are “the ability to do something for others”, “increased openness about HIV”, “increased empowerment and acceptance of being HIV positive”. The most significant changes within the lives of women living with HIV from African or of Caribbean origin after being connected to a PS in the PS project are “acceptance of being HIV positive”, “increased self-confidence”, “future perspectives”.

In this evaluation we were not able to interview the relatives of women supported by a PS to collect their stories of changes. However, the most significant changes within the lives of relatives of the PS after being connected to a PS in the PS project were documented. These changes were reported to be “the ability to do something for others” and “increased self-confidence”.

The changes in the professional lives of the HIV nurses caused by the PS project were “having an extra option for referral for their patients” and “having more time to discuss medical issues with their patients, instead of dealing with psychological issues”. None of these changes caused by the PS project in the professional lives of the HIV nurses were acknowledged as the most significant changes; all HIV nurses reported “a change in the lives of the women involved in the PS project” as the most significant one.

Based on the collected information during the stories selection workshop, and the analysis of all changes as reported in the different stories of change, a conclusion on the changes which are overall found to be the most significant can be drawn. The most significant changes caused by the PS project are “acceptance of being HIV positive”; “better future perspectives”; “increased self-confidence”; “ability to do something for others”; “increased openness about HIV”; and “increased empowerment”. These most significant changes identified are all within the lives of women living with HIV from African or Caribbean origin after being connected to a PS in the PS project. From this it can be concluded that the PS project has improved the quality of life of both the PS as well as the women supported by a PS. This indicates that the PS project is reaching its objectives.

Factors supporting the implementation of the PS project are the highly dedicated professional, female Project Coordinator; the basic principles of the PS project, including the specificity of the project to the target group, flexibility in timing for support provision and individual approach and spirituality-based. Also, the implementation of PS project, including the diversity of the PSs and the pre-defined period of support provision was found to be supportive to the implementation of the PS project.

Considering the above mentioned factors, the way the project is currently implemented has many strengths, however weaknesses also exist. Challenges factors that have been encountered during the implementation of the PS project are the circumstance that the Project Coordinator, as an individual, is the driving factor of the project implying limitations and factors as minimal monitoring, follow up and standardisation of processes, and the fact that the current project size is small and not well connected with other HIV prevention activities were identified as factors hampering future implementation.

Lessons learnt from this evaluation include strong points and limitations. Strong points were the professional, flexible and well-trained evaluation team; a strong collaboration with the Project Coordinator of the Project, the chosen evaluation methods; and the design of the evaluation. Limitations include the selection and availability of respondents, time available for the evaluation, and the language of interviews.

Having analysed the achievements, strengths, weaknesses, opportunities and threats of the PS project, the following recommendations were developed and discussed in the dissemination

workshop. The following recommendations could be made for the implementation of the PS project in de future.

#### *Alternative fundraising*

To ensure sustainability of the PS project, it is crucial to seek alternative ways of fundraising, besides the traditional funding sources and themes. These funds could be partly used for cultivating the organisation. Concrete examples of themes could be a focus on the right-based approach and connecting people. Examples of funding sources could be the 'leefbaarheidsbudgetten' from local municipalities, or trying to connect to other European projects on HIV positive migrants to apply for funding together and to share lessons learnt. A funding source could also be found from commercial stakeholders such as health-insurance companies or pharmaceutical companies. Key would be to show the economic model of the project; why it is interesting for these companies to get involved. Health-insurance companies might be interested as the PS project saves costs from the health system. Pharmaceutical companies might be interested in the concept of treatment as prevention and adherence to medication in which the PSs play an important role for the target group of migrant, HIV positive women.

#### *Streamlining and optimising the work processes*

To ensure that the PS project is firmly grounded, streamlining and optimising the work processes of the organisation to improve efficiency is required, while maintaining the strengths of the project. By strengthening the connection to other organisations and similar initiatives, the PS project might be able to learn from others and strengthen its project even further. Concrete examples are connecting and learning from the 'ROAD' project from the Erasmus MC in Rotterdam and to learn from the way the hospital chaplains are doing their work in building trust but maintaining interchangeable.

#### *Human Resource capacity*

There is a need to increase the human resource capacity of the organisation in managing the structural high workload and anticipating on expansion.

#### *PS training*

Continued development of the PS training through the involvement of relevant professionals, and the standardisation of training curriculum and materials, while possibly aiming at "certification" by a relevant authority, is recommended.

#### *Network of PSs*

To enable PSs to share experiences and create support systems, it will be important to further develop and optimise the network of PSs. This network could include an extra layer to create smaller support groups of PSs, which can be coordinated by a senior PS. The newly developed internet forum of ShivA could be a good medium to connect the PSs and support each other on a regular basis by sharing experiences and ideas.

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3. ShivA, 2011. Verslag zelfredzaamheid Nuts Ohra
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## Annex 1. List of documents reviewed in the desk review

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1. Ontwikkeling plannen door de jaren heen
2. 2006, 2008, 2009, 2010, 2011 Jaarverslag
3. 2008 Aanvraag Gemengd Afrikanenweekend bij Aids Fonds
4. 2008 Plannen voor basisweekend (gemengd) voor PAMA en andere zelfhulpgroepen
5. 2008 Plannen voor vrijwilligerstraining (gemengd) voor PAMA en andere zelfhulpgroepen
6. 2009 - 2010 Brief aan Fonds Nuts Ohra
7. 2009 - 2010 Project plan Zelfredzaamheid voor Fonds Nuts Ohra
8. 2009 - 2010 Verslag Project Zelfredzaamheid
9. 2010 - 2011 Projectplan 3 jaren Zelfredzaamheid voor Nuts Ohra
10. 2010 - 2011 Verslag Zelfredzaamheid voor Nuts Ohra
11. 2012 Aanvraag implementatie We are Family voor Nuts Ohra
12. 2012 Verslag resultaten Implementatie Zelfredzaamheid migrantenvrouwen met hiv/AIDS
13. 2012 Projectplan Doorontwikkeling Zelfredzaamheid voor Oranjefonds
14. 2012 Intentieverklaring - Vereniging van Hiv-consulente
15. 2012 Intentieverklaring - AMC
16. 2012 Intentieverklaring - Medisch Centrum Haaglanden
17. 2012 Evaluatie Zelfredzaamheid voor christelijke fondsen
18. 2013 - 2014 Projectplan Zelfredzaamheid met gesprekspunten voor Aids Fonds

## Annex 2. Data collection tools developed

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This annex includes all data collection tools:

1. Document review data extraction form
2. MSC and FGD Guide for Positive Sisters
3. MSC en FGD richtlijn - Positive Sisters
4. MSC and FDG Guide - Women supported by Positive Sisters
5. MSC en FGD richtlijn – Vrouwen die ondersteund worden door een Positive Sister
6. Interview guideline – Other stakeholders
7. Interview richtlijn – Andere betrokkenen
8. MSC Guide and Semi-Structured Interview – Positive Sisters
9. MSC en Semi-gestructureerde Interview richtlijn – Positive Sisters
10. MSC Guide and Semi-Structured Interview – Relatives of Positive Sisters/Women supported by Positive Sisters
11. MSC and Semi-gestructureerd Interview richtlijn– Familieleden van Positive Sister/vrouw gesteund door Positive Sister
12. Interview guideline – Trainers
13. Interview richtlijn Trainer
14. MSC Guide and Semi-Structured Interview– Women living with HIV supported by Positive Sisters
15. MSC en Semi-gestructureerd Interview richtlijn– Vrouwen gesteund door een Positive Sister

Annex 2 of this report is, together with Annex 3, provided in a separate document.



## Annex 3: Stories of change in English and Dutch

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This annex includes the following stories in both English and Dutch:

1. Story of Change PS1
2. Story of Change PS2
3. Story of Change PS3
4. Story of Change PS4
5. Story of Change PS5
6. Story of Change PS6
7. Story of Change Group of PSs
8. Story of Change W1
9. Story of Change W2
10. Story of Change W3
11. Story of Change W4
12. Story of Change R1
13. Story of Change R2
14. Story of Change N1
15. Story of Change N2
16. Story of Change N3
17. Story of Change N4
18. Story of Change Project Coordinator

Annex 3 of this report is, together with Annex 2, provided in a separate document.