Siyakhathala
Basic Care Package Process Document

September 2008 – August 2009

September 2010 Update

South Africa Partners

Acronyms

AIDS: Acquired Immune Deficiency Syndrome
ART: Antiretroviral Treatment
ARV: Antiretroviral
ATICC: AIDS Training Information and Counseling Centre
BCP: Basic Care Package
C&T: Counseling and Testing
CBO: Community-based Organization
CDC: Centers for Disease Control and Prevention
DOH: Department of Health
ECDOH: Eastern Cape Provincial Department of Health
ECRTC: Eastern Cape Regional Training Centre
FET: Further Education and Training
GIPA: Greater Involvement of People Living with HIV and AIDS
HCT: HIV Counseling and Testing
HIV: Human Immunodeficiency Virus
HLSG: Healthy Living Support Group
HHS: Health and Human Services
ILC: Ibhayi Living Centre
JRI HEALTH: Justice Resource Institute – Health Division
MANEPHA: Masihlanganeni Network of People Living with HIV and AIDS
NAPWA: National Association of People Living with HIV and AIDS
NDOH: National Department of Health
NGO: Non-Governmental Organization
NMBM: Nelson Mandela Bay Municipality
NSP: National Strategic Plan
OVC: Orphans and Vulnerable Children
PEPFAR: United States President's Emergency Plan for AIDS Relief
PLHIV: People Living with HIV and AIDS
PLHA: People Living with HIV and AIDS
PMTCT: Prevention of Mother-to-Child Transmission
POE: Portfolio of Evidence
PTSD: Post Traumatic Stress Disorder
RTC: Regional Training Centre
SANAC: South African National AIDS Council
SA Partners: South Africa Partners
SAQA: South African Qualifications Authority
SGF: Support Group Facilitator
Siyakhathala: "I care, you care, we care".
STI: Sexually Transmitted Infection
TAC: Treatment Action Campaign
TB: Tuberculosis
TB/MDR: Multi Drug Resistant Tuberculosis
ToT: Training of Trainers
UFH: University of Fort Hare
VCT: Voluntary Counseling and Testing
WHO: World Health Organization

Acknowledgements

South Africa Partners (SA Partners) gratefully acknowledges the organizations and individuals that contributed to the development of the Basic Care Package (BCP), developed as a component of South Africa's national response to the HIV epidemic. The Basic Care Package program is a successful project due to their collective work.

We particularly thank the Centers for Disease Control and Prevention in South Africa for its leadership and guidance throughout the process of developing BCP. Africare served as a prime on the grant that made the work possible and subcontracted SA Partners to lead the effort.

SA Partners coordinated a partnership that included the Eastern Cape Province Department of Health, The Center for Training and Professional Development at Justice Resource Institute (JRI) Health, and the Eastern Cape Regional Training Centre (ECRTC) that all played significant roles in the development of the BCP. We also acknowledge and thank the Healthy Living Support Group facilitators of Masihlanganeni Network of People Living with HIV and AIDS (MANEPHA) for sharing their experience and expertise and also the People Living with HIV and AIDS (PLHIV) who participated in focus groups providing their invaluable input. It is through the collaborative efforts of this partnership that BCP was successfully developed and implemented.

We also recognize and appreciate the services of the contributors who volunteered assistance with curriculum layout and technological assistance.

Development of this publication was supported by the HHS Centers for Disease Control and Prevention (CDC), National Center for HIV, STD, and TB prevention, Global AIDS Program Cooperative Agreement 5U2GPSOO1816-02. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.

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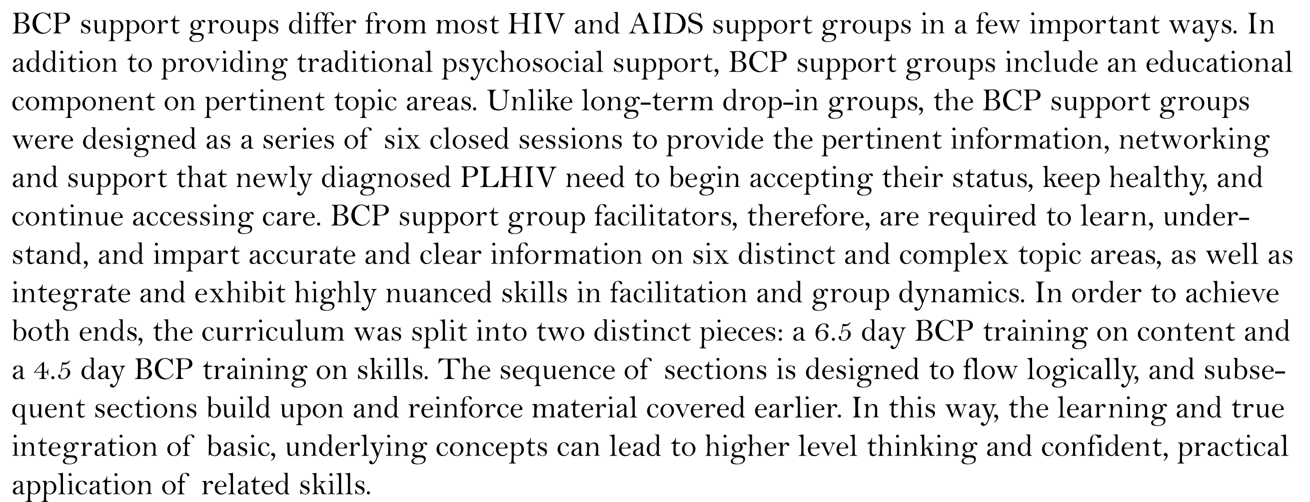
Rationale for BCP

UNAIDS (2007) estimates that 5.7 million South Africans are HIV positive, the highest number of infected people in any country in the world. Through the coordinated efforts of the public sector, non-governmental organizations, and international partners, South Africa has made significant progress in meeting the prevention, treatment, care and support needs of South Africans at risk for and living with HIV. In March of last year, the National Department of Health (NDOH) announced that 743,798 South Africans were on antiretrovirals (ARVs), between a third and a quarter of those projected to need medication.

With such a large burden of disease, services such as support groups have become a critical component in the continuum of care. Started before the availability of publicly-funded antiretrovirals in 2004, Voluntary Counseling and Testing (VCT) was first introduced in the early 1990s through city-based AIDS Training, Information, and Counseling Centres (ATICC) and then became available at select public health facilities in 2000.[1] While at first these VCT sites could offer few options after a positive diagnosis was administered, VCT has expanded to become an entry point for referrals to a range of care and support services. PLHIV organizations also began to provide support to those who tested positive, formal and informal peer support groups sprang up around the country. As the continuum of care for PLHIV has evolved, support groups have become more numerous, effective, and integrated both into health facility and community-based services.

As more is learned about how to support individuals after they receive an HIV positive test result, attention is being focused on strategies designed to lessen 'loss to follow-up.' A 2006 study examining loss to follow-up in South Africa, for example, identified three stages when vulnerable PLHIV were likely to be lost to the system: (1) patients with known HIV who need assessment and decisions on treatment, (2) patients in the first four months of ARV treatment, and (3) patients on long-term ARV therapy.[2] Lawn, et al. noted that "Stages 2 and 3 have received the most attention to date, but Stage 1 is also a major point of failure, with 46% of deaths in that study occurring prior to the start of treatment."

The Basic Care Package is intended to support PLHIV in all three stages, with an emphasis on Stages 1 and 2, as identified by Lawn, SD, et al., reaching newly diagnosed PLHIV who are not yet eligible for treatment. Through the development of a cadre of well-trained peer lay support group facilitators and a network of community-based BCP support groups, BCP focuses attention and resources on newly diagnosed individuals, providing them with psychosocial support to enable them to come to terms with their diagnosis, gain the knowledge, confidence, and support to manage their health care, live longer and healthier, and join with their peers to advocate for service delivery improvements. Equally important, BCP helps to strengthen relationships between health facilities and community-based organizations at district and sub-district level and builds the capacity of community-based NGOs to provide support services to further empower PLHIV.



BCP support groups differ from most HIV and AIDS support groups in a few important ways. In addition to providing traditional psychosocial support, BCP support groups include an educational component on pertinent topic areas. Unlike long-term drop-in groups, the BCP support groups were designed as a series of six closed sessions to provide the pertinent information, networking and support that newly diagnosed PLHIV need to begin accepting their status, keep healthy, and continue accessing care. BCP support group facilitators, therefore, are required to learn, understand, and impart accurate and clear information on six distinct and complex topic areas, as well as integrate and exhibit highly nuanced skills in facilitation and group dynamics. In order to achieve both ends, the curriculum was split into two distinct pieces: a 6.5 day BCP training on content and a 4.5 day BCP training on skills. The sequence of sections is designed to flow logically, and subsequent sections build upon and reinforce material covered earlier. In this way, the learning and true integration of basic, underlying concepts can lead to higher level thinking and confident, practical application of related skills.

Healthy Living Support Group, (HLSG)

Healthy Living Support Group, the pilot phase of the BCP, completed in August 2009 in the Eastern Cape, was developed from a partnership between SA Partners and the ECDOH. SA Partners is a non-profit organization with offices in Boston (USA), East London, and Port Elizabeth. Other important partners on the project were the ECRTC, JRI Health, and selected community-based NGOs operating in rural, peri-urban, and urban settings in five of the province's seven health districts. Funding for the BCP pilot was provided by Africare with PEPFAR funds from CDC South Africa.

The main objectives of the BCP pilot were met and deliverables were achieved. A comprehensive curriculum covering 6 distinct content areas and support group facilitation skills was developed by JRI Health with input from PLHIV Healthy Living Support Group facilitators and Tanya Jacobs of Mbumba Development Services and with support from SA Partners, the Ibhayi Living Centre, and the ECRTC. The ECRTC is in the process of finalizing the curriculum and preparing it to be submitted for accreditation.[3] Thirty community-based peer support group facilitators were selected and partnerships established with their respective NGOs. These thirty support group facilitators received content-area and facilitation skills trainings, as well as follow-up mentoring. PEPFAR-funded NGO trainers participated in two ToTs to learn how to train their own support group facilitators. During the last six months of BCP, March to August 2009, support groups were offered at 17 NGOs and 3,175 PLHIV attended BCP support groups. The participants were roughly divided between those receiving and not receiving ART who desired the additional information offered through the BCP support groups. Eighty percent of support group participants were women.

Insight and Foresight

<u>Year one accomplishments</u>:

- Incorporation of input from stakeholders, including local PLHIV networks
- Development of a comprehensive content-area and skills-based curriculum
- Two step-by-step BCP Support Group Facilitator (SGF) Manuals and accompanying Training Leader Manuals – one focused on HIV-related content and the other on support group facilitation skills
- BCP Support Group Facilitator Training of Trainers Manual to ensure local sustainability

- Development of criteria for the recruitment of NGOs, and the establishment of partner relationships with 17 NGOs providing 30 BCP support groups.
- Development of criteria for BCP support group facilitators and the recruitment and placement of those facilitators within NGO partner organizations
- Provision of BCP training to two cohorts of community lay providers, PLHIV, and PEPFAR partners resulting in 43 individuals trained as support group facilitators
- Provision of 2 BCP ToT trainings for community-based and peer PLHIV trainers, PEPFAR partners, and RTC representatives from Mpumalanga and the Free State
- Mentoring and supervision of 30 BCP community-based support group facilitators who ran both open and six-week closed support groups
- Running of 30 BCP community-based support groups that were attended by 3,175 PLHIV who received education and support
- Year-end follow-up with SGFs was overwhelmingly positive, with SGFs reporting that the BCP project had, as one participant wrote, put their skills on "another level"

Key lessons learned:
- Meetings of stakeholders are an essential step prior to embarking on a project like BCP with many components and partners, to outline shared goals, determine how BCP will fit into or change existing systems, agree upon who BCP will target, identify roles, and delegate tasks.
- There is a great need for community-based support groups. PLHIV will seek and attend a group that respects confidentiality, offers an interactive exchange between facilitators and participants, and people gain knowledge and confidence.
- For community-based support groups to be most effective, the links between the community and the health facility need to be strong.
- PLHIV and lay community people can facilitate successful support groups with proper training and support.
- Support group facilitators experience similar levels of stigma, discrimination, poverty, gender-based violence, and other traumas as their support group members, and as such, require a strong support network, clinical supervision and support.

Finally, BCP as developed in the Eastern Cape, has the potential to address some of the major challenges identified in the South African government's Progress Report on Declaration of Commitment on HIV and AIDS for the reporting period of January 2006 - December 2007. Among the challenges it will contribute toward are:
- *Issues of inequity* – BCP can help relieve some of the inequities that continue to plague "historically disadvantaged areas such as informal settlements and rural areas that are disproportionately affected by shortages in human resources." Community and health facility BCP support groups offer immediate support for newly diagnosed PLHIV who do not need ARVs. This group is not engaged because staffing is limited and the focus is on those whose CD4 count is <200 and require immediate attention.

- *Operationalization of the HIV & AIDS & STI Strategic Plan by the South African National AIDS Council (SANAC) sectors* – BCP offers an opportunity to strengthen the Greater Involvement of People Living with HIV and AIDS (GIPA) Principle and mobilize community-based PLHIV networks to take leadership in providing support to diagnosed peers. Linking BCP support groups to local PLHIV networks creates both an ongoing support network and a group for consultation when the SANAC PLHIV Sector representatives meet and disseminate information critical for policy development.
- *Underdevelopment – Establish and Strengthen Structures for Delivery*
  - Linking the NGOs and local health facilities providing BCP will highlight service delivery gaps impeding progress.
  - The links between BCP support groups at NGOs and local PLHIV advocacy and empowerment networks will create networks to strengthen the link between communities and District HIV and AIDS Committees.
  - NGO/CBO and PLHIV sector representatives who sit on these Committees will provide a vehicle for 'voicing' service delivery gaps observed while supporting newly diagnosed PLHIV attending BCP support groups.
- *Prevention*
  - By engaging community-based NGOs to offer couseling that provides support to newly diagnosed PLHIV, BCP supports the National Strategic Plan (NSP) proposal for "new strategies for the provision of counseling and testing outside of health facilities".
  - Over time, BCP has the potential to realign some of the NGO's services from home based care to engaging PLHIV early in their diagnosis. The NGOs can also provide the knowledge and encouragement to keep them healthy longer and delay the onset of ART.
  - BCP will work with these NGOs to establish projects that reinforce messages delivered in the support groups (cooking classes on low-cost, nutritional meal preparation). Long-term, some NGOs successfully implementing BCP may expand their services to support the NSP's counseling and testing goals.

20 Good Reasons for Support Groups

1. Provide a sense of belonging.
2. Facilitate and enable expression and sharing of feelings
3. Relieve stress – by talking about particular concerns, issues or situations, or even by obtaining useful information.
4. Nurture and build members by providing emotional support.
5. Provide mutual support.
6. Facilitate and develop different and/or new ways of doing things.
7. Expose members to accurate information regarding HIV and AIDS as well as related topics.
8. Promote and serve as a space for personal development. (for example, increased assertiveness, conflict management skills)
9. Prepare members to be comfortable with disclosure beyond the support group, for example, to a spouse, family, or colleague.
10. Educate members in terms of their human and legal rights regarding living with HIV and AIDS.
11. Help prevent the increase of HIV infection.
12. Build relationships.
13. Facilitate effective communication in all aspects of a member's life.
14. Encourage a sense of hope.
15. Promote positive living.
16. Build confidence and self-esteem to deal with issues and situations.
17. A cost-effective way of providing support to many people.
18. Serve as a platform to start other activities, for example, income generating initiatives.
19. Provide a space to explore relationships with others.
20. Facilitate/promote networking and referral systems.

From the *Training Manual – Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa*, developed by the University of Pretoria for the National Department of Health.

Introduction & History

BCP is a vibrant and evolving program. Its components – support groups, curriculum, training, referral systems, healthy lifestyle programs, and advocacy – should be seen as a dynamic web of interventions. As feedback is analyzed, adjustments will continuously be made to improve upon results. BCP is in its early stages, but we can say with some confidence that once partners are fully trained and demonstrate a clear grasp of the underlying principles of BCP, they will be encouraged to find ways to adapt interventions according to their local environment. To reach its potential, BCP should be adapted according to the particular needs of a community and the ongoing local HIV-related services BCP is meant to build upon and support.

The basic principles of BCP are the:

- Intentional involvement of PLHIV at all levels
- Enhancement of PLHIV knowledge and skills
- Strengthened referral systems and complementary care services
- Connection among PLHIV and care and support structures
- Empowerment of PLHIV to be their own health advocates
- Encouragement of communities to take responsibility for health care improvement

The intentional involvement of PLHIV at all levels of policy development and service delivery is essential to reaching BCP's ultimate goal - *empowered PLHIV capable of assuming responsibility for managing their own health needs.* As one practitioner put it, "The person living with HIV and AIDS is like someone driving a bus. We, as health care providers, are on the bus and can provide assistance, but they themselves must know where the bus is going and how to get where they want to go."

BCP grew directly out of needs identified by PLHIV for more meaningful support immediately after diagnosis. Too many PLHIV are lost to the health care system between the time of diagnosis and the commencement of ART. While healthy at the time of their diagnosis, their CD count is too often very low when they return to the facility.

CDC South Africa began the process by engaging in conversations with the National Department of Health (NDOH) to ensure their full participation in the design of BCP. On September 10, 2007, NDOH and CDC co-hosted a stakeholder's meeting in Pretoria to discuss the development of BCP. The purpose was to stimulate a discussion on care and support services and to reach consensus on the composition of BCP.

Partners in the design of BCP in the Eastern Cape, and previous initiatives that contributed significantly to the development of BCP included **SA Partners,** the **ECDOH, MANEPHA, ECRTC,** and **JRI Health. Africare** provided PEPFAR funding from **CDC South Africa**, through a subcontract to SA Partners. Together, efforts were undertaken to offer Eastern Cape PLHIV leadership and advocacy training and educational opportunities. The latter were specifically designed to empower PLHIV with knowledge about HIV, its science, and how a healthy lifestyle can impact quality of life and defer onset of ART after diagnosis. With support and guidance from CDC South Africa, during 2004 and 2005 the partners identified service delivery gaps and participated in the development of programs to address those needs, including the development of HLSGs designed to address the psychosocial needs of newly diagnosed PLHIV. Implemented from April 2006 to March 2007, the HLSG program objectives were to:

- Compliment care services offered at Counseling and Testing (C&T) sites
- Add human resource capacity to increase program effectiveness
- Strengthen referral systems
- Address stigma challenges
- Increase knowledge about healthy living to delay the need for ARVs
- Ensure better prognosis once on ARVs.

Fifteen MANEPHA members were trained by JRI Health to run HLSGs formed at fourteen ART sites in the province over the course of a year. SA Partners staff worked with the facilitators to ensure their support group's smooth integration into C&T sites, while providing mentoring and 'care for the care-giver' support. The HLSG facilitators offered both open and closed groups.[4] The closed groups ran for six sessions, each focused on a different issue (e.g. disclosure, opportunistic infection, and nutrition), and participants signed a contract outlining a code of conduct within the group that included confidentiality. Once a group started, no new members were admitted. A process evaluation of HLSGs conducted after six months determined that:

Without exception, each stakeholder and participant of the HLSGs was in favor of the HLSGs and of providing people who are newly diagnosed with information and support to better manage HIV in their lives.

As a result of the lessons learned from the HLSGs, SA Partners was able to transition smoothly from the HLSGs to the BCP program. We will continue to improve BCP and identify additional interventions firmly grounded in meeting the practical needs of PLHIV and the services dedicated to supporting individuals newly diagnosed as HIV positive.

This BCP Process Document is a guide for understanding, designing and implementing BCP in other settings, using the first year of implementation as a starting point.

Project Description

Purpose

The goal of BCP is to promote early recruitment and retention of newly diagnosed PLHIV into care and support programs. In addition, BCP strives to reduce the high rate of loss to follow-up from the time of HIV diagnosis to successful commencement of ART. Although BCP primarily focuses on newly diagnosed HIV positive individuals, it was designed to include HIV positive individuals in general and individuals who are affected by HIV and need a support group.

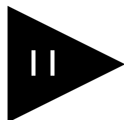
As defined at the beginning of the BCP pilot project, the basic principles of BCP are to:

- Increase PLHIV knowledge and skills;
- Strengthen referral systems and complement care services;
- Keep PLHIV connected to care and support structures;
- Empower PLHIV to be their own health advocates; and
- Encourage communities to take responsibility for health care improvement.

The intentional involvement of PLHIV at all levels of policy development and service delivery is essential to reaching the ultimate goal - *empowered PLHIV capable of assuming responsibility for managing their health needs.* BCP was envisioned as a national standard for the support of PLHIV prior to the need for ART. The BCP demonstration pilot developed in the Eastern Cape is meant to serve as a 'laboratory' for BCP, testing new strategies and disseminating findings, as BCP is scaled-up in other provinces.

Key Players and Products

SA Partners, in collaboration with the **ECDOH**, **ECRTC**, **JRI Health**, **MANEPHA**, and **Tanya Jacobs** of Mbumba Development Services, led the implementation of the BCP program. **Melanie Preddy**, an independent consultant, helped refine the supervision and mentoring component of the program.



The **ECRTC's** role was to collaborate with JRI Health to develop the *BCP support group facilitator curriculum*, particularly the alignment of BCP with SAQA standards. ECRTC also worked with SA Partners to monitor BCP support group facilitators.

The BCP Curriculum

The purpose of the BCP curriculum is to train high quality facilitators of PLHIV Support Groups. To achieve this outcome, participants are required to learn and understand accurate and clear information on six distinct and complex HIV-related topics, as well as integrate and exhibit highly nuanced skills in facilitation and group dynamics. The sequence of sections is designed to flow logically, and subsequent sections build on and reinforce material covered earlier. In this way, the learning and true integration of basic, underlying concepts can lead to higher level thinking and confident, practical application of related skills.

In order to achieve both ends, the curriculum is split into two distinct pieces: a 6.5 day Content training and a 4.5 day Skills training.

In the **BCP Content training**, participants are versed in the content area and skills so that they can speak accurately, confidently and consistently on all BCP topics. These topics are technical and meant to equip the facilitator with facts and information that will challenge misinformation when it surfaces. Because they are not only learning for their own sakes but also to teach others, participants must have ample time to integrate the material and practice delivering it.

In **BCP Skills training**, participants build on their content knowledge and acquire the knowledge and skills to facilitate, organize, and maintain effective and sustainable support groups. Emphasis is placed on appropriate use of self, including boundaries and self-care, managing challenging behaviors, and understanding key clinical issues facing PLHIV including disclosure, stigma, and acceptance of status.

With the assistance and support of the ECRTC, **JRI Health** developed two step-by-step BCP Community-based *Support Group Facilitator Manuals* and accompanying *Training Leader Manuals*, one focused on HIV-related content and the other on support group facilitation skills, and a BCP Community-based Support Group Facilitator *Training of Trainers Manual* to ensure local sustainability. In addition, a 6-session support group Toolkit was developed for the facilitators during the 6-session closed groups for newly diagnosed PLHIV. JRI Health also conducted several trainings.

MANEPHA members worked with SA Partners to conduct an *assessment* in the Nelson Mandela Bay Municipality (NMBM) that identified non-governmental, community-based and faith organizations that offered or wanted to offer support groups. MANEPHA also provided invaluable consultation to the ECRTC and JRI Health on areas of the BCP curriculum, and technical support to ongoing community-based support groups.

Tanya Jacobs of **Mbumba Development Services** was responsible for reviewing the curriculum and ensuring that it addressed the broader contexts of risk in South Africa, including gender dynamics and gender-based violence.

SA Partners provided overall coordination, including oversight of curriculum development, NGO selection, support group formation, mentoring and supervision of support group facilitators, data collection, and reporting to funders and the ECDOH.

The **ECDOH** provided guidance on placement of the support groups within communities, rather than facilities, as a way to overcome some of the challenges of the HLSGs.[5] To ensure that health facilities were aware of the establishment of BCP support groups within their catchment area, the ECDOH informed District Health offices that SA Partners would be introducing BCP as a continuation of HLSGs. When invited, SA Partners met with District Health office staff.

Africare served as the prime during the pilot, subcontracting with SA Partners to design and implement BCP. Funding came from PEPFAR provided by the Centers for Disease Control and Prevention South Africa.

BCP Pilot Program Overview

As noted, to achieve its desired outcomes, the BCP program engaged multiple partners to design, implement and assess its various components. Overall, the BCP's underlying structural goal is to create a web of services available in the community and in local health facilities that empower recently diagnosed PLHIV as they come to terms with their diagnosis and take on the management of their health care. The steps involved in creating the BCP pilot were:

1. Curriculum Development
2. Identification of NGO Partners
3. Selection of Facilitators
4. Training
5. Support Group Formation
6. Supervision and Mentoring of Facilitators
7. Referral Systems
8. Links to PLHIV Networks

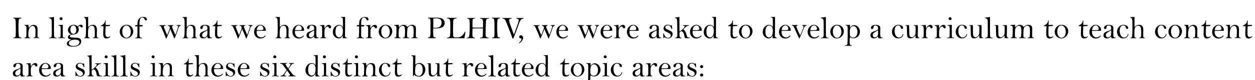
BCP Pilot Program Steps

1. Curriculum Development

From the beginning, the BCP curriculum was intended to serve as a national standard. The curriculum breaks new ground, both in terms of content and pedagogy. It is designed to highlight the key aspects of HIV and AIDS that are essential to the wellbeing of PLHIV in such a way that they are assisted in maintaining their health and are empowered to join with their peers to take action for service delivery improvement. In order to achieve this outcome, the development of the BCP curriculum included five essential elements:

- Inclusion of PLHIV
- Accreditation for Career Growth
- Knowledge and Skills Building
- Broader Context of Risk - Address Retraumatization
- Tools for Capacity Building and Sustainability

- **Inclusion of PLHIV, the target audience, "Nothing about us, without us":** Topic areas for the BCP were decided by and with PLHIV at Eastern Cape PLHIV summits, through questionnaires administered to focus groups and existing support groups in Eastern, Northern, and Western Capes and the Free State. It was agreed there was little point in creating a program unless it met the needs of those who were to benefit and be its advocates. To be effective, the BCP curriculum and its accompanying support group programs should address the reasons that PLHIV were being lost to care, including: stigma, acceptance of status and disclosure, and lack of information about what it means to be HIV positive. PLHIV said there should be more community-based support groups to provide alternatives for those who fear stigma or discrimination from the clinic staff, have access barriers due to a lack of transportation, or will hear the messages more clearly or powerfully from a from a peer who is also living with HIV.



In light of what we heard from PLHIV, we were asked to develop a curriculum to teach content area skills in these six distinct but related topic areas:

1. HIV, AIDS and Opportunistic Infections (including TB)
2. Treatment Literacy and Adherence Counseling
3. Acceptance of Status
4. Disclosure
5. Nutritional Assessment and Counseling
6. Prevention with Positives

All agreed that there was a great deal of misinformation circulating among the general South African public, and thus imperative that support group facilitators have an accurate, consistent foundation of basic information. Learning support group facilitation skills, including how to manage challenging group dynamics and how to address issues of recruitment and retention plaguing support groups across the four identified Provinces,[6] were also seen as key. PLHIV concerns and ensuring that the training is a career path were also prioritized.

- **Accreditation for Career Development:** To increase motivation among support group facilitators, and address PLHIV's real concerns regarding career development opportunities, it was determined that the curriculum should be submitted to SAQA for accreditation. Once the topic areas were chosen, the ECRTC helped scan all of the relevant SAQA standards and determined that the curriculum be at a level 4,[7] similar to other community health worker curricula, based on our intended training audience of PLHIV and affected lay people.

The SAQA unit standards shown in Table 1 were chosen as the core. The ECRTC included the facilitators already trained in BCP in the 10-day VCT training, in order to complete their learning and earn additional credits. Thus, support group facilitators who successfully completed the curriculum requirements can receive up of 150 credits for use toward other certificate and degree programs.

- **Knowledge and Skills Building:** BCP support groups differ from most HIV and AIDS support groups in a few important ways. In addition to providing traditional psychosocial support, BCP support groups include an educational component on pertinent topic areas. Unlike long-term drop-in groups, the BCP support groups are designed as a series of six closed sessions providing pertinent information, networking and support that newly diagnosed PLHIV need to begin accepting their status, keep healthy, and continue accessing care. BCP support group facilitators, therefore, are required to learn, understand, and impart accurate and clear information on six distinct and complex topic areas, as well as integrate and exhibit highly nuanced skills in group facilitation and dynamics. In order to achieve both ends, the training curriculum is split into two distinct parts: a 6.5 day BCP Content training and a 4.5 day BCP Skills training. The sequence of sections was designed to flow logically, and subsequent sections build upon and reinforce material covered earlier. In this way, the learning and true integration of basic, underlying concepts leads to higher level thinking and confident, practical application of related skills.

In the **BCP Content** participants receive the content-area information and skills to speak accurately, confidently and consistently on all BCP topics. These topics are technical because a great deal of misinformation exists. Because they are not only learning for their own information but also to teach others, participants must have ample time to integrate the material and practice delivering it.

In the **BCP Skills** participants build on their content knowledge and acquire the knowledge and skills to facilitate, organize, and maintain effective and sustainable support group programs. Emphasis is placed on appropriate use of self, including boundaries and self-care, managing challenging behaviors, and understanding key clinical issues facing PLHIV including disclosure, stigma, and acceptance of status.

Table 1: Overview of South Africa Qualifications Authority standards addressed by BCP Curriculum

SA QA ID	*Credits*	*Unit Standard Title (Levels 4 and 3)*
114491	10	Educate and work closely with the community with regard to sexually transmitted infections (STIs) including Human Immune Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS)
252513	3	Apply established strategies and procedures to deal with risk behaviour and promote personal wellbeing
117490	12	Plan and promote nutritional programmes to improve community health
117507	6	Develop and implement a client ARV treatment plan
252510	3	Demonstrate knowledge and understanding of HIV and AIDS, other Sexually Transmitted Infections (STIs) and Tuberculosis (TB) for counselling purposes
7384	16	Facilitate an adult learning event
114478	15	Conduct basic lay counseling in a structured environment
119471	5	Use language and communication in occupational learning programmes
116987	6	Apply active listening skills in the care and support environment
119469	5	Read/view, analyse and respond to a variety of texts
119465	5	Write/present/sign texts for a range of communicative contexts
8612	4	Demonstrate an understanding of societal values and ethics
117498	10	Demonstrate knowledge of the provision and implementation of primary health care within the community
8968	5	Accommodate audience and context needs in oral communication
8976	5	Write for a wide range of contexts
10231	8	Plan a learning event
10136	4	Plan, organise and support project meetings and workshops

- **Broader Context of Risk – Addressing Retraumatization:** The curriculum is designed to be relevant and contextualized in the realities that support group members and facilitators live and the HIV epidemic thrives. As such, the BCP discusses many taboo or difficult topics, including sexual behaviors, sexual orientation, and gender-based violence. Merely lecturing on these topics causes participants to tune out and ignore any area that is uncomfortable. The interactive activities used throughout the BCP Content and BCP Skills curricula invite participants (and trainers) to lean into their discomfort and begin to feel comfortable and let go of the discomfort.

Support group facilitators, like the support group members they serve, may have suffered severely traumatic events in their lives (death of loved ones, deteriorating health, extreme ostracism, sexual assault, gender-based violence, community violence, etc.). The training topics, including those discussed in the support groups and participant discussions, may trigger painful memories and Post Traumatic Stress Disorder (PTSD). Creating a safe environment for the trainings not only reduces the risk of retraumatization for the support group facilitators, it also models how they can similarly create a safe environment for their support groups. Because few resources exist for the support group facilitators to receive support, relationship

building and peer networking are important aspects explicitly built into the training. This takes time but is vitally important for the sustainability of support groups. It is essential that support group facilitators have an opportunity to explore these issues themselves in order to provide an optimal experience for their support group members.

- **Tools for Capacity Building and Sustainability:** The BCP Content and Skills Facilitator Manuals were designed with several objectives in mind, not only a guide to content. The facilitator manual serves as an in-depth resource on what might be a new training modality for trainers. Detailed descriptions of activities, time allotments, and copious trainer notes provide, in essence, a training of trainers on how to deliver the material using participatory education methods rather than the customary didactic lectures. Our goal was to facilitate the development of a local cadre of educated, motivated and competent trainers that are ultimately needed to sustain a program.

- **Participant Manuals; 6-session Toolkit –** The BCP Content and Skills Participant Manuals include reference material, in-class activities and homework, and a six-session Toolkit from which Support Group Facilitators can draw to run their groups. Many of the Toolkit activities are modeled during BCP Content training, allowing trainees to observe and experience them as engaged participants before practicing facilitation in the BCP Skills training and in their actual groups.

2. Identification of NGO Partners

Essential Elements of BCP NGO Partner Identification Selection

Based on the analysis of a questionnaire survey, in-depth interviews and our experiences implementing BCP:

- Consultation with the ECDOH
- Design and implementation of a transparent identification process
- Existing community care workers who can be redeployed to BCP
- Have existing support groups of PLHIV
- Strong commnity support for the organizations ongoing problems
- Dynamic and positive contact with local health facilities
- Demonstrate strong leadership for inclusion of BCP within the organization

In consultation with the ECDOH, it was decided that the support groups be based within communities rather than health facilities, and that BCP support groups would be conducted in five of the seven health districts in the province, with a concentration of groups in the Nelson Mandela Bay Municipality (NMBM). Since we are providing training and a stipend to the BCP support group facilitators, it was important to ensure transparency in selecting NGO partners. To minimize any sense of favoritism, we embarked on a process that included prioritizing NGOs for consideration that were already working with ECDOH,[8] and had therefore previously been screened on a range of criteria, and also conducting a situational analysis within the NMBM where there would be the

largest concentration of support groups. The situational analysis identified the most effective and respected NGOs in which to place BCP support groups.

NGO Situational Analysis Process

The purpose of the NGO Situational Analysis was to provide insight and understanding into community based NGOs within NMBM, with special attention to the existing support groups and how they operate. From this analysis, NGOs were selected to host BCP support groups and recommend facilitators for BCP training.

A dual process of a questionnaire survey and a few in-depth interviews were conducted to elicit information to develop an understanding of the NGOs and their support groups within NMBM. A group of six MANEPHA fieldworkers from the three sub districts of NMBM were selected to conduct the survey. This ensured the geographic spread of the interviews throughout NMBM was comprehensive. To improve data collection results, SA Partners held a training session for the field workers to guarantee a thorough understanding of the process.

In a meeting, the fieldworkers helped identify a list of twelve larger "umbrella" institutions[9] and 36 local NGOs working with HIV and AIDS. In addition to these organizations, the Departments of Social Development and Health and the local ATICC were approached to provide input on organizations operating within NMBM. The 48 organizations originally considerated were local organizations known to the fieldworkers for their work with HIV and AIDS. From the 48 organizations, the fieldworkers selected 32 to interview. The criteria used to refine the list were as follows:

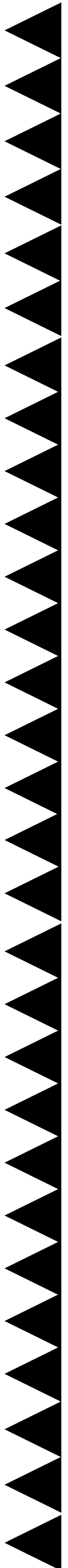
- Organizations that work in the field of HIV broadly speaking - focus on awareness; treatment, care and support; OVCs and their care givers; soup kitchens; etc.
- Must ensure geographic spread and not be confined to one area within a sub district
- Must ensure sector spread through NGOs, CBOs, Faith based organizations, grant makers, etc.

Fieldworkers met with senior management of organizations and over the course of two weeks went out to 32 organizations and completed questionnaires. Fieldworkers were reimbursed for transport fares and lunches and received R50 per completed questionnaire. The responses to the questionnaires provided a graphic view of the 32 organizations. Eight organizations participated in more in-depth interviews, which provided a richer understanding of support group complexities and filled gaps that were outstanding from the organizational questionnaire.

Selection of NGO Partners

After analyzing the results of the survey and interviews, ten NMBM NGOs were invited to a meeting to learn more about BCP and the benefits of hosting BCP support groups. These ten NGOs submitted written proposals to participate in BCP and ultimately seven of these organizations were selected as partners based on a number of factors, including their geographic spread within the NMBM.

In the other 4 health districts (Alfred Nzo, Cacadu, Chris Hani, and Ukhahlamba), where MANEPHA facilitators were transitioning from HLSGs to BCP, NGO partners were approached based on the location of the MANEPHA facilitator and the organization's reputation within the community. We used the criteria and process developed in the NMBM as a starting point, but in these four districts, the facilitators were already identified when we selected NGO partners.[10] The NGOs that were considered as partners were located within the general geographic area where the facilitators resided.



3. Selection of Facilitators

Essential Elements of BCP Facilitator Selection

- Identify needs within the community and develop a clear set of criteria that is incorporated into the BCP facilitator job description
- Circulate the job description and instructions for applying broadly among area PLHIV networks
- Establish a transparent and fair recruitment and hiring process
- Announce the selection of successful candidates to all partners as soon as decisions are made[11]

Due to the available funding, it was determined that a maximum of 30 facilitators could be selected for the BCP pilot phase. BCP support group facilitators were identifited to build on the work of HLSG. These support groups were led by 15 HIV positive individuals active in MANEPHA with training in leadership, advocacy, the basics of HIV, and support group formation and maintenance. Conscious that BCP was a more advanced and focused continuation of HLSG, the 15 HLSG facilitators were invited to apply to be BCP support group facilitators. All applied and were accepted.

To complete the group of BCP facilitators, criteria and a job description were developed based on the qualities of a successful HLSG facilitator. The criteria and job description were distributed to our NGO partner organizations and each NGO partner organization was invited to nominate up to three candidates for consideration. After interviewing the 30 candidates recommended by the NGOs, SA Partners selected 15.[12]

The priorities identified for successful facilitators were:

1. Ability to read and write; do simple calculations
2. Maturity and experience
3. Fluency in local language and ability to understand English
4. Prior involvement with community care program
5. Good interpersonal skills
6. Respect for others and commitment to maintain confidentiality
7. Enthusiasm for the work involved
8. Physically fit to carry out the work
9. Seeking opportunities to advance career
10. Must be from the same community he or she is serving
11. PLHIV preferred

As stated earlier, BCP support groups are intended to be safe, supportive environments that offer a newly diagnosed individual a strong base of knowledge, assistance, and the encouragement needed to make important changes in lifestyle that will promote future health and wellbeing. It is therefore very important that BCP support group facilitators are selected meticulously. Investment in the individuals trained as BCP support group facilitators is seen as long-term and linked to a broader strategy to support newly diagnosed PLHIV. They are a critical element in the web of activities that constitute BCP.

Since SA Partners has several years experience working with PLHIV advocacy and empowerment networks in the Eastern Cape, we began the process of BCP facilitator selection with an advantage. Our 15 HLSG facilitators were from MANEPHA, whose

members were in turn from TAC, NAPWA, and affiliated and unaffiliated support groups across the province. As a result, our original core of 15 BCP facilitators was a mix of these various PL-HIV networks. Working with NGOs to identify possible candidates, membership in a PLHIV network was an advantage. By the completion of the selection process for the pilot phase, BCP had links to all the major PLHIV networks in the province.

During the pilot phase of BCP, we were fortunate to have had a high number of motivated and talented support group facilitators. While some were more skilled than others in their ability to guide participants through a complex and often wrenching learning process, all offered important information and support that benefited those who attended.

4. Training

Essential Elements of BCP Training

- Led by trainers who are knowledgeable about and comfortable with the BCP Content and Skills Curriculum
- Adequate capacity for translation during key sections
- Sufficient time for participants to practice and absorb information

Two Cohorts:

As noted earlier, due to the funding, the overall goal was to identify and train 30 community-based (placed in selected NGOs) facilitators. Thirty-seven support group facilitators were actually trained (as well as six participant observers from various organizations, including DOH and RTC representatives from other Provinces). Trainees were divided into two separate and distinct cohorts for the 6.5 day BCP Content training: in Port Elizabeth in February and in East London in May. Both groups had a joint BCP Skills training in East London.

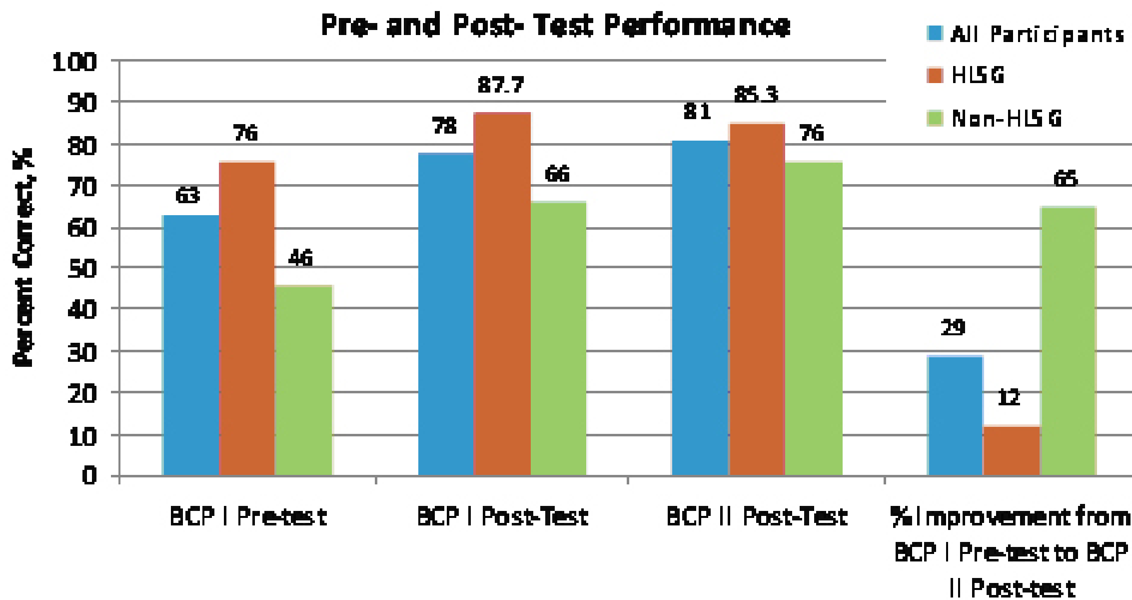
The Port Elizabeth cohort was comprised of 15 NGO support group facilitators, mostly new to the field. Many had never facilitated a group, though some had without prior training. Thirteen out of the fifteen disclosed that they were living with HIV. The East London cohort was a group of 15 more seasoned facilitators with prior training experience, trained to run 'Healthy Living Support Groups'. All disclosed living with HIV.

The facilitators' comfort level with English varied greatly, for most their first language was Xhosa. Three spoke Afrikaans and one spoke Sesotho. While English was the bridge language for the participants, participants were invited and encouraged to communicate in the language(s) in which they felt comfortable expressing themselves.

Pre and Post-Tests:

Participants were required to take written pre and post-training tests assessing their content knowledge. The tests were administered in English which posed a challenge to a number of participants. That being said participant test scores indicate significant learning. Overall, the average improvement was 29% from pre to post-tests for all 37 participants. Not surprisingly, those for whom the training was completely new (the Port Elizabeth cohort) had an average improvement of 65% while those in the East London cohort who knew some of the material showed a more modest, though not insignificant, 12% improvement.

The following graph lists participants' scores on pre and post-tests:



Training Evaluations:

On three of the seven days (days 1, 3, & 6) participants were asked to write or share what went well, what they thought needed improvement or could be changed. On days 2, 4, and 5 participants were asked to fill out more elaborate daily evaluations to assess the day's work. On the final day, participants filled out a more comprehensive evaluation encompassing the entire training.

According to the participants, the central strength of BCP is the use of participatory education methodologies, engaging participants in their own and each others' learning, and understanding that there is a great deal of knowledge and experience in the room that can be used and built on. Although a few of their final class presentations were didactic, the majority were able to incorporate the more participatory methodologies.

Feedback on the methodologies was overwhelmingly positive.

Some examples of comments:

- "Group activities were wonderful because we learnt from others."
- "I learned how to express myself in front of a group of people I don't know and get to know their ideas. It showed me another way of putting words into action."
- "I acquire the information and I'm getting new points. I think this training is very helpful. And I would apply it to my community."

Training of Trainers:

JRI Health also delivered two two-day ToTs on BCP Content and Skills. Fourteen people who were previously trainers attended. The ToTs were designed to walk the participants through facilitating the actual training.

5. Support Group Formation

Essential Elements of Support Group Formation

- Support group must understand the nature or type of support group they want to form
- Members must be willing to form the group and should agree on the group rules or norms to govern the activities of the group members
- Open groups are ideal for support group members who will not attend the six-week group and are knowledgeable in other topics

To maximize the opportunity for PLHIV to feel safe and supported, the partners agreed that BCP support groups should be closed groups. In this case "closed" has two meanings: after the first session no new members are allowed to join, and all members should be newly diagnosed PLHIV[13] who have not started on ARVs and have a CD4 count of 200+. Groups were open to both men and women, married or single. While anyone of any age could join, the main target age was age 18 and above. Although the group was available to anyone, regardless of employment status, some members probably had work schedules that interfered with attendance. Generally speaking, those who were unemployed or self-employed found it easier to attend groups held during daytime hours.

Most facilitators found the best place to recruit group members was from clinic waiting rooms. Facilitators did an open presentation on a relevant topic, and then told listeners about the group. Some members heard about the groups through word-of-mouth. Facilitators stated that family members of PLHIV were often a good source for potential members because they told the PLHIV about the group and encouraged them to attend.

Open Sessions

SGFs were expected to present BCP topics in already existing support groups within NGOs or CBOs. Here, members of the support group were mixed (e.g. PLHIV on ARVs and newly diagnosed attended the same support group), and had no obligation to attend subsequent sessions. This helped address gaps in knowledge or information for support group members who felt they had information on other topics but needed more information in a specific area. As a result, the facilitator consulted with the group on what topic they wanted to learn about before presenting the information.

Closed Sessions

Closed support group sessions were formed with the intention of exclusively serving newly diagnosed PLHIV whose CD4 count is above 200 and were not on ARVs. This type of support group remained closed for six weeks with the same members attending all the six BCP topics. The closed group members were properly briefed on the type of support group and gave consent to attend all 6 sessions. They also signed registration forms as a

commitment to attend the group. The registration forms collected information such as CD4 count, date of diagnosis and medication.

Topic Areas for 6-week Closed BCP Support Groups

1. HIV Transmission and Lifecycle
2. Acceptance of Status
3. Positive Prevention
4. Opportunistic Infections
5. Treatment Adherence Counseling
6. Nutritional Assessment and Counseling

Facilitators are encouraged to plan the six-weeks according to the needs of the particular group of attendees; emphasizing those topic areas that are most relevant.

6. Supervision & Mentoring of Facilitators

Essential Elements of BCP Facilitator Supervision and Mentoring

- Coordinators must participate in BCP training to be effective supervisors/mentors
- Observation of facilitators running groups is essential
- Ongoing one-on-one meetings needed for individualized feedback and support

Ongoing supervision and mentoring of SGFs is key to their effectiveness and to ensuring quality delivery of BCP content. Since 30 facilitators were hired and their geographic spread was across 5 health districts, two Project Coordinators were hired to supervise and mentor. Each was assigned health districts, one was responsible for NMBM and Cacadu health districts, and the other for Alfred Nzo, Chris Hani, and Ukahlamba. In addition to their experience in supervision, one coordinator had experience in project management, and the other in mentoring.

These coordinators provided post-training coaching, mentoring, debriefing and technical assistance; supervised SGFs in the development of their POE demonstrating their mastery of the various components of BCP (required by the assessment process and the issuing of educational credits); and managed the relationship between the SGFs and their associated NGOs. Specifically, the Coordinators:

- *Observed at least two BCP presentations conducted by SGF*
  To obtain SAQA accreditation the SGFs had to be observed giving two presentations. The Coordinators assessed their presentation skills, knowledge of BCP content, planning and preparation for sessions, and ability to connect support group members to local resources.

- *Supported SGF in creating appropriate and relevant learner development plans*
  After each observation Coordinators met individually with SGF to discuss what they had observed. The Coordinator and SGF developed a plan to address any observed gaps or challenges in the application of BCP content and skills.

- *Compiled monthly reports detailing observations and learner development plans*
  The Coordinators provided monthly written reports to management including a report on their observed session with SGF and the development plans created with the SGF.

- *Ensured that SAQA unit standards and requirements were met for learner accreditation*
  Coordinators reviewed SGF POE for completeness and thoroughness.

- *Assisted in the translation, tailoring, and adapting of any needed training materials*[14]
  The BCP training and materials are in English, while a majority of the support groups are conducted in the local languages. Coordinators assisted SGFs to translate BCP concepts into local languages.

- *Held quarterly staff meetings with all SGFs in the region.*
  Staff meetings allowed the Coordinators to provide project updates, address issues that SGFs were having in a global way and for SGFs to debrief and share strategies.

Acquiring Credits

The long-term goal is to offer BCP SGFs the opportunity to acquire credits toward further education. This will happen when the BCP curriculum is certified by SAQA and the assessment criteria is established for the unit standards. At that point, the SGFs will present their POE to a SAQA assessor. If successful the SGF will receive credits that can be used to access further education.

7. Referral Systems

Essential Elements of BCP Referral Systems

- Good working relationship between the facilitator and the health facility
- Ongoing activities led by the facilitator at the health facility that support existing programs
- Health facility staff have an understanding of BCP and demonstrate support
- Broad understanding of BCP and the availability of BCP support groups within the community and all clinics and CHCs in the area

BCP support groups are intended to be an effective new link in the continuum of care for PLHIV. Ideally, BCP support group facilitators in both communities and facilities in a given catchment area should be in regular contact with each other, sharing information and arranging for referrals as needed – either from the facility to the NGO or NGO to the facility. In addition, all BCP facilitators should know about other social services available in the community to refer support group participants (i.e. Alcoholics Anonymous chapter).[15]

During the BCP pilot phase, support groups were based solely in selected NGOs. For that reason, BCP support group success was highly dependent upon the establishment of a good working relationship between the BCP support group facilitator, NGO, and stakeholders in the community, particularly the health facilities (e.g. Counseling and Testing sites, ARV sites, etc). In South Africa, health facilities, accessed through VCT services, are the point of entry into the continuum of care for HIV and AIDS treatment, care, and support for newly diagnosed PLHIV. Thus, a facilitator who has a good relationship with health facility staff and who knows about BCP is important for improving referrals to and from the support groups. In cases where referrals have worked well, the clinic staff (nurses and lay counselors) knew about the BCP support group and understood its aims and objectives, as well as the needs of the newly diagnosed PLHIV.

Referrals are often made by a lay counselor to the support group. However, referrals were also received from other NGOs or CBOs working on HIV and AIDS in the community, as well as from the Faith-Based organizations and churches. We also found that over time, people in the community who knew of the BCP support group referred individuals.

In turn our facilitators were able to refer clients or support group participants who needed clinical interventions to the health facilities. To help them with this, they were required to map out the various social and medical services within their communities as part of their POE. The exercise was meant to assist facilitators in understanding the services helpful for their clients. This can be developed into a community service directory for facilitators to use for referral purposes.

8. Links to PLHIV Networks

Essential Elements of BCP PLHIV Networks

- Demonstrated involvement of local PLHIV Networks in the promotion of BCP
- Active consultation by local PLHIV Networks on the improvement of BCP outcomes
- Active recruitment of local PLHIV Network members to serve as BCP facilitators

As stated in the introduction, BCP is based on the principle that through the **intentional** involvement of PLHIV at all levels of policy development and service delivery, the ultimate goal of *empowered PLHIV capable of assuming responsibility for managing their own health needs* can be achieved.

To achieve that goal, the BCP program is both education and advocacy oriented. The HIV-related content provided through the support groups is only the first step in empowering PLHIV to better manage their health care. As one practitioner said to SA Partners, "The person living with HIV and AIDS is like someone driving a bus. We, as health care providers, are on the bus and can provide assistance, but they themselves must know where the bus is going and how to get where they want to go."

To ensure that support group members have the opportunity for continued peer support after they leave the group, it is essential that local PLHIV networks connect to and engage with supporting BCP support groups. We met with the leadership of TAC, NAPWA, and MANEPHA to ensure that Eastern Cape networks were engaged. The three organizations were engaged early in the conversations about the HLSG program and later BCP. Their input was invaluable in the shaping of content and support group design.

It is envisioned that these and other networks will provide an opportunity for PLHIV who have completed a BCP support group to connect with their peers, continue learning about HIV, know what to expect as the disease progresses, and also join with others to advocate for service delivery improvements.

Summary of Challenges and Lessons Learned

Notes from Project Coordinators' mentoring sessions with SGFs and a final focus group with SGFs in August 2009 highlighted some challenges to overcome in the rollout of the BCP. These challenges are outlined below by general topic area:

1. Curriculum and Professional Development

- *Need for ongoing support and strengthening of BCP learning for the SGFs:* The learning acquired through the BCP training, while comprehensive and fundamental, requires ongoing reinforcement and support.
  - o After the training, BCP Project Coordinators provided one-on-one coaching to each SGF. In addition, the Coordinators paired up SGFs so those with less training could learn from those who had more. The following areas needed follow-up:
    - Increasing confidence in their skills
    - Making support groups more interactive (i.e. not lecturing)
    - Effectively managing time and preparing for sessions
    - Acknowledging, capturing and summarizing participants' thoughts
    - Effectively setting and adhering to the ground rules
    - Dealing effectively with difficult behaviors that emerge during sessions

- *Accreditation:* ECRTC aligned the curriculum with SAQA requirements and plans to submit it for accreditation.
  - o Upon review of the curriculum, SAQA responded that based on the curriculum's target group, another entity, like FET, is a more appropriate venue for accreditation.
  - o The ECRTC is in dialogue with the FET in Mthatha about the accreditation process. Further information about the process is needed.

- *Portfolios of Evidence (POE):* The process of receiving credits for training was new to SGFs. The Coordinators had several meeting with the SGFs to outline the information to be collected for the POE, to ensure an assessor's successful review, and to award credits.
  - o SGFs had the most trouble completing their POE requirements in the sections on Counseling and Facilitation Skills and the Behavior Change Case Study.
  - o The process of completing the POE required the Coordinators to hold individual sessions with SGFs to further review and explain instructions and/or questions about specific POE requirements that were not adequately understood.

- *Length:* The ECRTC suggested that an eleven-day training is too long.
  - o The length of the training is under review.

2. Group Formation and Logistics

- *Closed group model can be challenging:*
  - o There was a major concern around stigma of the closed groups. Many attending the support groups had not publicly disclosed their status. And therefore, a concern that the BCP support groups might become known as the "HIV/AIDS" support group and deter people from attending the sessions.
  - o It is important to find an appropriate venue for the groups, especially for the closed groups. They need to be easily accessible and offer privacy for maintenance of confidentiality.

- *Fundamentally difficult to recruit newly diagnosed PLHIV:*
  - o It often takes 9-12 months for a newly diagnosed individual to feel ready for a support group.
  - o BCP should recognize and allow people to enter the group when they are ready. Anyone who is HIV positive, but not yet ready for ARVs, should be allowed to join a BCP support group, regardless of when they received their original diagnosis.
  - o Stigma & discrimination remains a factor – newly diagnosed individuals sometimes choose to attend a group in a different community to maintain anonymity. In these cases, a strong BCP referral system becomes essential.

- *Scheduling can be challenging:*
  - o It is important to be thoughtful and deliberate about when groups meet as scheduling im pacts attendance.
  - o The group meeting time should not conflict with ongoing meetings held in the same space.
  - o Schedulers should be aware of community and seasonal events, such as initiation ceremo nies, that might impact attendance and participation.
  - o Winter (when BCP was started) often means lower attendance.

- *Because of U.S. government funding restrictions, BCP support groups did not offer food to participants at their meetings:*
  - o Other support groups do offer food at their meetings, and were more likely to be recommended by facilities.
  - o People weigh their options and due to need, often choose support groups that provide food over BCP, even though BCP provides more information than those groups.
  - o BCP content prioritizes nutrition and healthy eating practices and so the expectation was that a BCP support group should model how to provide healthy food in a cost-effective manner.

- *Need for more linkages:*
  - o SGFs reported needing assistance with creative ideas on how to market the groups in facilities and communities.

- *Need for translation of key tools and concepts:*
  - o Key scientific phrases and concepts are not easily translated into local languages. Without a standardized translation, however, descriptions will vary from group to group by the SGF and may not convey the information accurately.[16]

- *Other issues:*
  - o It can be challenging for an individual to attend groups each week due to a range of issues such as cost and/or availability of transport, employment, or being away from family duties.

3. NGO-Facilitator Relationship

- *Volunteers from NGOs were trained as facilitators:*
  - o BCP's intention was to identify facilitators already offering groups within an NGO and providing the facilitator with additional skills that would concurrently benefit the NGO & its clients.
  - o BCP facilitators receive a stipend and in some cases this created tension in the relationship between the facilitator and the NGO. Some SGFs had challenges in their work relationship after starting BCP support groups.
  - o A better feedback loop between the NGO, facilitator, and SA Partners would be helpful.
    - Community meeting with NGOs was held in August (with facilitators and NGOs, then only NGOs) to address this issue.

4. Further Training

- Some facilitators were experienced lay counselors, but those without counseling experience struggled in the first round of support groups.[17]

- Advocacy training was identified as important so that facilitators could be advocates for their community and support group members.

Accomplishments

Final Focus Group with BCP Support Group Facilitators

SA Partners convened the BCP support group facilitators in August of 2009 to conduct a focus group and capture their first hand accounts of the project, groups, and lessons that might be incorporated into the project going forward.

The facilitators commented that the BCP pilot project put their skills on "another level". They asserted that in spite of previous training for support group implementation they learned a lot from the BCP training. They commented that they also used their new skills and knowledge in their relative settings and support groups. They reported that clients (support group members and recipients of the BCP services) value the information. One facilitator in Ukhahlamba shared that so many clients were attending the support groups and overwhelming some of the facilitators.

In Ukhahlamba, one of the underserved districts in the Eastern Cape, a demand for BCP has been created and an opportunity exists for expansion to more sites.

Participating NGOs are interested in retaining BCP and other NGOs want to participate as well. NGOs are also interested to offer BCP training to home based care givers and lay counselors.

Key Quantitative Indicators (September '08 to August '09)

The key quantitative indicators for the BCP project are outlined below:

Table 2: Project Outputs for Pilot Year 1

INDICATOR	PERFORMANCE
Total number of people reached	3175
Total number of NGOs established relationship with	18
Total number of facilitators trained	30
Total number of PEPFAR facilitators trained	8
Total number of support group sessions conducted	239
Total number of closed sessions conducted	110
Total number of open sessions conducted	129

Table 3: Session Participants by Month and Gender (March - August 2009)

MONTH	# SESSIONS CONDUCTED	# INDIVIDUALS REACHED	MALE	FEMALE
March	16	241	48	193
April/May	34	587	177	410
June	43	657	159	498
July/August	146	1690	366	1324
TOTAL	**239**	**3175**	**750**	**2425**

72% of the NGOs interviewed in August 2009 had good impressions of the BCP pilot project. They noted most impressive was the knowledge and information that is shared in the support groups, the skills of the facilitators, and BCP's ability to strengthen support groups. The remaining 27% appreciated the project however they stated that they were not well briefed on BCP and its objectives and would have appreciated more visits from SA Partners.

BCP Pilot Program Timeline

The timeline of BCP program and development and implementation in the Eastern Cape highlights important steps in setting up an HIV and AIDS support group.

- **September 2008**
  - Consultation with the Department of Health
- **September – December**
  - JRI Health and ECRTC work on development of BCP curriculum via internet, confer ence calls, and face-to-face meetings (held in Mthatha during November)
- **January 2009**
  - NGO situational analysis in NMBM conducted by MANEPHA
    - 51 organizations working with HIV/AIDS, including with Orphaned & Vulnerable Children, 32 were surveyed and 6 were interviewed in-depth

- SA Partners received the report on the NGO situational analysis
- The following NGOs signed a memorandum of understanding
  - Good Samaritan
  - Living Waters HBC
  - Masithembe Action group
  - House of Restoration Community Center
  - Olive Leaf Foundation
  - Tswaranang HBC
  - Malibongwe Home Based Care
  - Jabez AIDS Health Center
  - Ubuntu Hospital
  - Masangane HIV/AIDS program
  - Pilani support group

- **February**
  - SA Partners held consultations with NGOs and shortlisted them
  - Facilitator selection - breakdown:
    - 8 PEPFAR partner facilitators
    - 15 Healthy Living Support Group facilitators
    - 19 metro facilitators
    - 11 from community-based organizations
    - 7 facilitators from MANEPHA
  - Facilitator training started: 1st group of 15 trained on BCP content (6.5 day training)
- **March**
  - Healthy Living Support Groups ended
  - BCP support groups started
- **March/April**
  - BCP facilitators from 1st group offer informational sessions at existing community-based support groups and health facilities to educate and recruit participants for BCP 6 week closed groups
  - Mentoring and supervision continues
- **May**
  - 2nd group trained on BCP content (6.5 day training)
- **June**
  - Facilitators from 1st and 2nd group trained on facilitation skills as a group
  - Closed support groups started
  - Mentoring and supervision of facilitators begins
- **July**
  - First six-week closed support group cycle completed
- **August 2009**
  - Closed support group cycles continue

Looking Forward

The BCP program has shown promise in its potential to contribute to the overall effort of reducing PLHIV loss to follow-up. As the program is scaled-up, there is reason to believe it will increase coordination between community based and facility based interventions. With the active engagement of PLHIV, BCP is expected to identify effective and efficient strategies to improve service delivery. Overall, BCP should contribute to the reduc-

tion of high rate of loss to follow-up from HIV diagnosis to commencement of ART, ultimately reducing morbidity and mortality amongst PLHIV. It will also delay the start of ART and increase the positive prognosis when on medication.

Several areas of BCP are being strengthened during scale-up, including:

- Strengthening Monitoring & Evaluation
- More effective supervision and mentoring
- Capacity development with NGOs
- Transferring skills and knowledge to other provinces

1.Strengthening Monitoring & Evaluation

In order to collect evidence on BCP's effectiveness in reducing loss to follow-up, four indicators have been developed. The indicators are for data collected by health facilities as part of the District Health Information System. The four indicators are:

1. Number of HIV+ patients who adhered to scheduled clinical assessment
2. Number of eligible HIV+ patients receiving Cotrimoxazole
3. Number of eligible HIV+ patients initiated on IPT
4. Average CD4 count of HIV+ patients who started ART

2. More Effective Supervision and Mentoring

During the pilot phase of BCP (HLSG), we recognized the need for more professional supervision of the SGFs, particularly if the support groups were to provide participants with adequate psychosocial support. As a result, when developing the scale-up of BCP, we invited the UFH Psychological Services Centre to join us a partner. UFH contributed to the improvement of the supervision and mentoring system. Each month SGFs will meet with a psychologist and/or master's fellow working with the Centre. During these monthly meetings, SGFs will discuss both their challenges and successes in leading groups. It will be an opportunity to ask questions, get advice about how to handle difficult issues they are facing in leading the group, and process their feelings about the group and its members. Each quarter, the meeting will be devoted to skill building, and twice per year, the SGF will be observed by a Master's fellow.

3. Capacity Development with NGOs

BCP support groups are an important first step for newly diagnosed PLHIV as they come to terms with their diagnosis and acquire the knowledge needed to maintain their health. To move from discussion to action, PLHIV need ongoing opportunities to connect with their peers, stay current on issues that impact their health and wellbeing, and learn new approaches to maintaining their health. The NGO where a BCP support group is held is a logical place to develop services that will enhance a PLHIV's ability to manage their health and keep them connected to the health system while monitoring their CD4 count and eventually prepare for ARV treatment.

To encourage NGOs to make this transition in service delivery, we developed a Small Grants Program. It will provide funds to partner NGOs to develop and implement a new program to offer PLHIV continued support when leaving BCP support groups.

4. Transferring Skills and Knowledge to Other Provinces

Interest in BCP is growing and there are indications that other provinces will introduce BCP locally. Lessons learned from the Eastern Cape experience will be shared with other provinces and a system to coordinate a national scale-up will be developed to ensure the basics of BCP are consistent from province to province.

End Notes

1. Karen Birdsall, Helen Hajiyiannis, Zinhle Nkosi, & Warren Parker, Voluntary Counselling and Testing (VCT) in South Africa: Analysis of Calls to the National AIDS Helpline, Centre for AIDS Development, Research and Evaluation, 2004

2. Lawn SD, Myer L, Harling G, Orrell C, Bekker L, Wood R. Determinants of mortality and non-death losses from an anti-retroviral treatment service in South Africa: implications for program evaluation. Clin Infect Dis 2006 Sep 15;43 (6):770-776.

3. As this document goes to print, the SAQA Health and Welfare SETA recommended that an institution with expertise in community education (levels 1 to 4) such as the technical colleges or FET are best suited to house the curriculum.

4. Open groups were held for informational and educational purposes and often took place in the waiting room of the clinic. Anyone present was invited to listen and ask questions. Open groups were also used to recruit for the closed groups. These closed groups were structured as a six-part series of discussions on essential topics. Members attending the first session agreed to attend all six and maintain group confidentiality. Once a closed group started, no one else was allowed to join.

5. HLSG facilitators were placed within health facilities to offer groups. This generated unintended tension between the HLSG facilitators and the health facility lay-counselors who felt they were being excluded or potentially replaced. To avoid this, as we move ahead with scale-up, the ECRTC is working with ECDOH to train two lay-counselors in BCP from each health facility in the province.

6. PLHIV recommendations used in the development of the curriculum were from focus groups and questionnaires conducted in the Eastern Cape, Free State, Northern Cape, and Western Cape CDC grant.

7. National Qualification Framework Level 4 - Further Education and Training (levels 2 – 4: grade 10 – 12)

8. These were NGOs that previously received contracts from the ECDOH.

9. The umbrella organizations were comprised of larger well established organizations which mostly provide a range of services, and relevant government and local government departments. It was anticipated that all would assist in the further identification of organizations and potentially to provide more in-depth understanding of support groups.

10. The BCP SFGs in these four districts were all former HLSG facilitators.

11. We missed this step in our pilot phase. While there was no significant 'fallout' from not announcing the selection of facilitators publicly, we became aware that it would have helped smooth the way for the facilitators if we had made a public announcement about who was serving as a BCP facilitators and their scope of work.

12. We felt it was important to have the flexibility to decline a person recommended by the NGO, if they did not have the essential qualities to serve as a BCP facilitator or that personal issues made it difficult for them to provide high-quality support to group participants.

13. During the pilot phase we noted that 50% of participants were newly diagnosed and 50% were PLHIV on ARVs and looking for additional information to help them manage their wellbeing.

14. SA Partners held focus groups among its staff and support group facilitators to identify which key scientific phrases remain a challenge to ensure the concepts are properly understood in the local context and are consistently defined by all the support groups.

15. BCP support group facilitators are required to conduct a mapping exercise of the PLHIV support services available in their area. It becomes part of the POE and serves as a resource when questions come up in a group.

16. Translation to a particular language may not be enough. Various regions of the Eastern Cape use different isiXhosa words to translate the same concept.

17. This issue is being addressed through the inclusion of the University of Fort Hare Community Center for Psychological Support in the scale-up of BCP. UFH is providing monthly mentoring and supervision sessions for facilitators to address psychosocial challenges that arise during the groups.

Appendix One

Name:______________________________ Date:____________

BCP CONTENT TRAINING PRE- & POST-TEST

Multiple Choice (Please choose only one response for each question)

HIV/AIDS

1. HIV can be transmitted:

    a. If a mosquito stings an HIV-positive person, and then stings someone who is HIV-neg ative

    b. By using a toothbrush used by a person living with HIV

    c. If an HIV+ woman breastfeeds a baby

    d. By kissing

2. If someone has unprotected anal sex with a person who is HIV-positive, he or she will definitely become infected:

    a. True

    b. False

    c. Not sure

3. Which bodily fluids can transmit HIV?

    a. Blood, vaginal secretions, semen, pre-ejaculate, breast milk and saliva

    b. Blood, semen, urine, vaginal secretions and breast milk

    c. Blood, semen , vaginal secretions, pre-ejaculate and breast milk

    d. Blood, semen, breast milk and tears

4. A person who has PCP and extra pulmonary TB is in:

    a. Stage 1 HIV disease

    b. Stage 7 HIV disease

    c. Stage 3 HIV disease

    d. Stage 4 HIV disease

5. PEP is:

    a. An opportunistic infection

    b. Medications that can be taken after possible exposure as a result of a sexual assault to decrease the risk of HIV infection.

    c. An anti-TB medication

    d. WHO Stage 3

STIs, TB and opportunistic infections

1. Which of the following statements is true:
    a. Many people who have a sexually transmitted infection show no symptoms at all and do not think they have an STI.
    b. Most sexually transmitted infections are transmitted by using a toilet that has been used by a person with an STI.
    c. People who have a sexually transmitted infection always have some symptoms.
    d. Condoms do not offer protection again sexually transmitted infections.

2. Having another sexually transmitted infection increases the risk of HIV transmission infection:
    a. True
    b. False
    c. Not sure

3. Co-trimoxazole is taken to:
    a. Reduce viral load
    b. Treat shingles
    c. To prevent PCP
    d. Deal with medication side effects

4. TB is transmitted by:
    a. Shaking hands
    b. Sharing eating utensils
    c. Kissing
    d. Breathing-in the TB bacteria

5. If a person has Stage 4 HIV disease and TB:
    a. The person will always start ARVs and anti-TB treatment at the same time.
    b. TB treatment is usually started first, and then the person can go on ARVs.
    c. The person usually goes on ARVs, and then starts anti-TB treatment.
    d. The best thing to do is always start taking ARVs and anti-TB medications at the same time.

Counselling Skills

1. Which of the following is a closed-ended question:
    a. How did you decided to be tested for HIV?
    b. What are your thoughts about using condoms?
    c. Do you know your HIV status?
    d. What can I help you with today?
    e. Not sure

2. Reflective listening is:
    a. Having the client listen to the counsellor
    b. Listening to someone without saying anything
    c. Paraphrasing what a client says to be sure you understand
    d. Not sure

3. A counsellor's role is to:
   a. Be non-judgemental
   b. Give advice
   c. Warn clients about their behavior
   d. All of the above
   e. Not sure

4. Which of the following is an open-ended question:
   a. Do you use condoms?
   b. Are you aware of how HIV is transmitted?
   c. Have you ever used drugs?
   d. How has it been for you to be on ARVs?

5. A client tells you that he is nervous about disclosing his HIV status to his family. Which of the following is an appropriate response?
   a. You shouldn't tell them. It would be too much for them to handle.
   b. Lots of people tell their families and they feel much better.
   c. What are some of your concerns about telling them?
   d. I'm nervous about telling my family too.
   e. Don't know

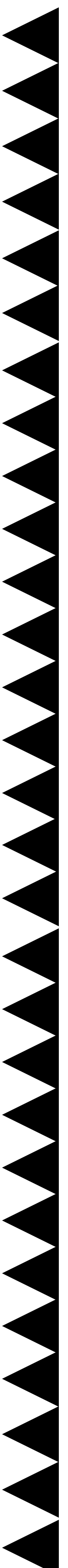
Risk Behavior Strategies

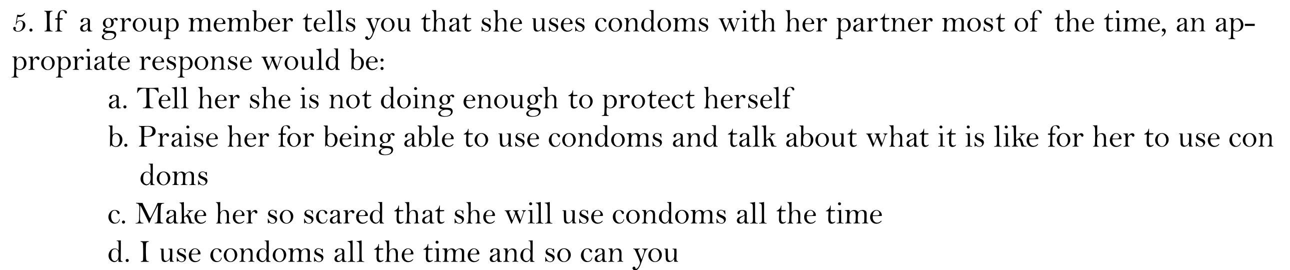
1. Being client-centered means:
   a. Doing whatever the client asks you to do
   b. Telling the client exactly what he or she should do
   c. Letting the client make decisions about what concerns she or he wants to focus on in a conversation.
   d. Not sure

2. Harm reduction means:
   a. Allowing the client to choose his or her own goals
   b. Any change made by a client that lowers risk
   c. Supporting a client regardless of what changes they make – or don't make
   d. All of the above
   e. Not sure

3. Which of the following NOT an example of harm reduction:
   a. Wearing a seatbelt in the car
   b. Eating less fatty foods
   c. Having a sex partner pull out before ejaculating during sex
   d. Taking ARVs 5 days per week
   e. Not sure

4. If you don't know the answer to a question asked by a client it is better to make something up than say you don't know.
   a. True
   b. False
   c. Not sure





5. If a group member tells you that she uses condoms with her partner most of the time, an appropriate response would be:
   a. Tell her she is not doing enough to protect herself
   b. Praise her for being able to use condoms and talk about what it is like for her to use con doms
   c. Make her so scared that she will use condoms all the time
   d. I use condoms all the time and so can you

Treatment Literacy

1. The goal of ARV treatment is:
   a. To cure HIV
   b. To increase the CD4 count and the viral load
   c. To keep the person in Stage 3 of HIV disease
   d. To increase the CD4 count, decrease the viral load, and improve overall health

2. In South Africa, a person living with HIV can start taking ARVs when:
   a. The person is diagnosed with HIV
   b. The CD4 count is blow 200 or in WHO Stage 4 of HIV disease
   c. The CD4 count is 350
   d. When the person has symptoms

3. Adherence to ARVs is important because:
   a. They sure STIs
   b. There are many medications available
   c. It can prevent resistance
   d. Do not know

4. Combination treatment refers to:
   a. Treating multiple illnesses at the same time
   b. Coming the treatment of TB and HIV
   c. Using more than one ARV
   d. Do not know

5. During the first 3 months of pregnancy, pregnant women should not take Efavirenz because:
   a. It can cause birth defects
   b. It can cause premature labor
   c. It causes nausea
   d. It is a new medication

Nutrition

1. What is nutrition important for?
    a. Decreasing risk of infections
    b. Helping to prevent heart diseases, fatigue, and diabetes
    c. Increasing your strength and energy
    d. All of the above

2. Potatoes, maize, rice, oil and sugar are some examples of energy-giving foods. Which one of the following nutrients best describes this group of food?
    a. Protein and Vitamins
    b. Carbohydrates and Proteins
    c. Fats and Minerals
    d. Carbohydrates and Fats

3. Which of the following describes why nutritional care and support should be part of any comprehensive care and treatment for people living with HIV/AIDS?
    a. Good nutrition cures TB
    b. Proper nutrition helps to maintain immune functions working properly
    c. A balanced diet provides nutrients to kill HIV
    d. Not sure

4. Making sure that uncooked food is kept separately from cooked food is an option to reduce one's risk for:
    a. PCP
    b. HIV transmission
    c. Food-borne illness
    d. TB transmission

5. It's important for persons infected with HIV to be careful about the food they eat. Germs in food can make you sick and cause mild to life-threatening illnesses. Which of the following foods is most likely to contain harmful germs?
    a. Pasteurized milk
    b. Boiled vegetables
    c. Raw or undercooked eggs
    d. Thoroughly cooked meat

Appendix Two

Basic Care Package
Content Training Trainer Evaluation

Please rate the usefulness of each section:

	Not Useful	Somewhat Useful	Useful	Very Useful
HIV Terminology	1	2	3	4
HIV Disease Progression	1	2	3	4
HIV and STI Transmission and Prevention	1	2	3	4
Mother-to-Child Transmission and Prevention	1	2	3	4
Voluntary Counselling and Testing	1	2	3	4
Acceptance of Status	1	2	3	4
Nutrition	1	2	3	4
Treatment Literacy	1	2	3	4
Presentation Skills	1	2	3	4

What was most helpful about this training?

Did you acquire the information and skills that you hoped to acquire from this training? If not, what was missing?

Please comment on the material covered and its relevance for your work.

Please comment on the activities and their level of connection to your background or culture.

Please comment on the training materials: (Slides, handouts, additional resources manual, etc)

Trainers:

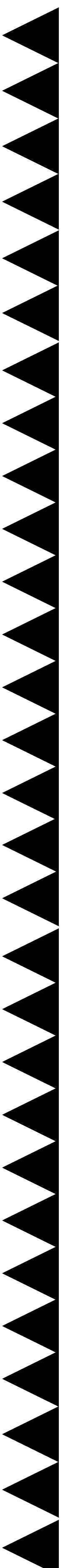
Please rate the trainers in the following areas:

	Unsatisfactory	Satisfactory	Good	Excellent
Knowledge of topic	1	2	3	4
Clarity of presentation	1	2	3	4
Thoroughness of presentation	1	2	3	4
Responsiveness to participants	1	2	3	4
Adequate time for questions/feedback	1	2	3	4
Engaging presentation style	1	2	3	4

General Comments about the trainers:

General Comments about the overall training experience:

Thank you for your time and participation!



Appendix Three

Basic Care Package
Facilitation Skills Training *Trainer Evaluation*

Please rate the usefulness of each section:

	Not Useful	Somewhat Useful	Useful	Very Useful
Introduction	1	2	3	4
Creating Effective Support Groups	1	2	3	4
Group Development	1	2	3	4
Facilitation Skills	1	2	3	4
Group Dynamics/Challenging Behaviours	1	2	3	4
Integrating the HLSG Toolkit	1	2	3	4
Self-care and Graduation	1	2	3	4

What was most helpful about this training?

Did you acquire the information and skills that you hoped to acquire from this training? If not, what was missing?

Please comment on the material covered and its relevance for your work.

Please comment on the activities and their level of connection to your background or culture.

Please comment on the training materials: (Slides, handouts, additional resources manual, etc)

Trainers:

Please rate the trainers in the following areas:

	Unsatisfactory	Satisfactory	Good	Excellent
Knowledge of topic	1	2	3	4
Clarity of presentation	1	2	3	4
Thoroughness of presentation	1	2	3	4
Responsiveness to participants	1	2	3	4
Adequate time for questions/feedback	1	2	3	4
Engaging presentation style	1	2	3	4

General Comments about the trainers:

General Comments about the overall training experience:

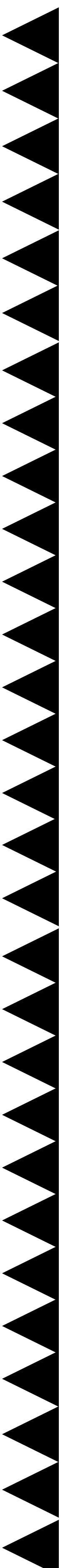
Rate Yourself:

Please rate your comfort level in the following areas:

Not Comfortable	Somewhat	Comfortable	Very Comfortable
1	2	3	4
1	2	3	4

Understanding of content
Comfort in facilitating

Please describe any areas that you would still like to learn more about or want more support with:



Thank you for your time and participation!

Appendix Four

BCP Support Group Facilitator JOB DESCRIPTION

The Basic Care Package program is a U.S. President's Emergency Fund for AIDS Relief (PEP-FAR) funded venture.

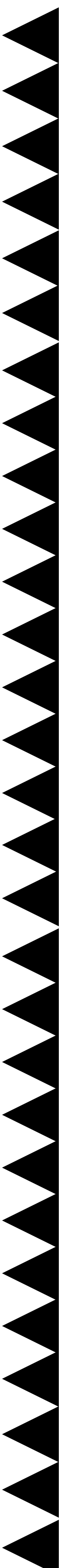
The aim of this program is to promote early recruitment and retention of newly diagnosed PLHIV into care and support programs. In particular, it seeks to reduce the high rate of loss to follow-up from the time of HIV diagnosis to commencement of antiretroviral treatment (ART). The project will finalize a Basic Care Package (BCP) national curriculum and establish BCP support groups in the Eastern Cape that provide information and support to newly diagnosed individuals at health facilities and within communities.

Responsibilities

- Attend 6.5 day BCP Curriculum Training
- Attend 3 day BCP Facilitation Training
- Attend additional trainings and/or planning meetings related to the BCP support groups as needed
- Complete all requirements needed to obtain SAQA accreditation
- Present 6 or more topics on BCP to an already existing support group under evaluation
- Establish and run BCP Support Groups for newly diagnosed PLHIV
- Participation in all scheduled mentoring and supervision sessions
- Compile monthly progress reports to SA Partners BCP Support Group Coordinator
- Submit weekly documentation forms to SA Partners BCP Support Group Coordinator
- Establish and maintain good working relations with referral sites, facilities and service providers
- Perform referrals for BCP support group attendees as needed
- Mobilise and market the BCP Project to the community and to health facilities
- Conduct community mapping for resources available in your locality that can be include in the resource sheet to be used for referrals
- Maintain regular communication with the BCP Support Group Coordinator regarding challenges or strengths
- Maintain regular communication with your associated NGO regarding your BCP work

COMPENSATION: As compensation, SGF will receive a stipend of R250 per session; up to six (6) sessions per month. From time to time, SA Partners will organize trainings and/or planning meetings related to the BCP support groups. You will receive a R100/day stipend for each day you attend trainings and/or planning meetings.

Appendix Five



Interviewer Questionnaire for the NGO Situational Analysis in Nelson Mandela Bay for SA Partners, Inc.

NAME OF ORGANISATION ....

NAME OF PERSON/S BEING INTERVIEWED

....

CONTACT DETAILS ....

FIELDWORKER ....

Introduction

Thank you for agreeing to an interview with us. I am representing South Africa Partners which is a non-profit organization focusing on partnership development in the Eastern Cape. The partnerships usually address issues related to health and HIV/AIDS, including optimizing access to treatment and services for PLHIV. More recently we have been working with the Department of Health nationally and within the Province to develop a Basic Care Package for PLHIV. This is a programme which provides PLHIV with all the necessary information, knowledge and understanding of HIV to enable people to live healthy lives, while living with HIV. The package includes issues like disclosure, opportunistic infections, adherence counseling, treatment literacy, nutrition and acceptance of status. It is a structured programme which we are in the process of developing into a standardized accredited curriculum, to be held within a Support Group setting. We intend to train facilitators who will run support groups. There are multiple aims in this process but primarily we are promoting the early recruitment and retention of newly diagnosed PLHIV into care and support programmes so as to reduce the high rate of loss to follow up from the time of diagnosis to commencement of ART.

Before we embark on this however, we want to develop an understanding of the terrain in which we are working, and assess the need for such a programme. We are not in any way wanting to take on the work that organizations are currently doing but rather to determine whether there is scope or need for further working together. Together with the Eastern Cape Department of Health, we have identified NMBM in which to conduct the pilot process. As a start we are talking to various NGOs to determine the scope of their work, especially with regard to Support Groups and to canvas opinion about the needs of people living with HIV whose CD4 count is above 200.

I hope that provides some clarity. Do you have any questions you may want to ask?

Could I now ask you some questions about your organization?

1. I'd like to find out more about your organization and the work you do.

a. Can you tell me a little about the history of your organization, when it was started and what motivated its inception.
(Questions b and c may not be necessary if the interviewee answers very fully)
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b. What is the focus of the work of your organisation and what are the services your organisation offers?
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c. Who is your organisation's target group?
……………………………………………………………………………………………………
……………………………………………………………………………………………………

d. How many people are involved in your organization?

i. As employees? ………………………………………………………………………………
ii. Volunteers? ………………………………………………………………………………
iii. Beneficiaries or participants? ……………………………………………………………
iv. Others ………………………………………………………………………………………

e. What is the geographic or physical area that the organisation covers? …………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………

f. Who supports your organization with funding? ………………………………………………
……………………………………………………………………………………………………

g. Do you have support from government via the Department of Health or Department of Social Development? ……………………………………………………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………

2. We are interested in support groups for PLHIV. Is your organization involved with Support Groups?

IF THE ANSWER IS YES, continue with the questionnaire and IGNORE Question 2.2.

IF THE ANSWER IS NO, continue to Page 7, Question 2.2

2.1 If the organization is involved with Support Groups, the following questions need to be answered.

a. How many Support Groups does your organisation support? ……………………………………
……………………………………………………………………………………………………

b. What does your organization provide to the support groups? (We need to understand the depth of the organisation's involvement and participation in support groups.) ………………
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c. What needs does your organization meet through your support groups?
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……………………………………………………………………………………………………

d. **Target group**: How many people attend the support groups?
……………………………………………………………………………………………………

e. How are support group participants recruited or drawn into your groups? …………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………
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……………………………………………………………………………………………………

f. Are there PLHIV that are missed, forgotten, ignored or marginalized in the support group process? ……………………………………………………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………
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……………………………………………………………………………………………………

g. **Venue**: What venues do your use for support groups? ………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………

h. **Frequency**: How regularly do they meet? ………………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………

i. **Procedures**: Who convenes these support groups? …………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………

j. Who are the facilitators of your organisation's Support Groups? ……………………………
……………………………………………………………………………………………………
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……………

k. How are your facilitators selected? ………………………………………………………
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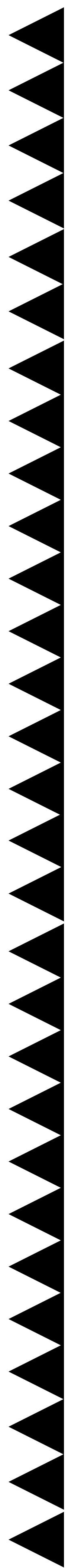


l. Are your facilitators recruited on the basis of living openly with a positive HIV status?

m. Do the facilitators have any training in facilitation?

i. Are there any suggestions that your organisation might have for the development of skilled facilitators?

ii. What are the things that make for a good facilitator?

iii. How do you develop these skills?

n. Do the facilitators receive a stipend, or are they provided with any other incentives? Discuss how facilitators are compensated.

o. How do you manage the emotional load and provision of support to the facilitators? Does your organization have procedures for debriefing?

p. Are there internal governance structures and portfolios within the support groups? Chairperson, secretary, organizer, treasurer?

q. **Sustainability**: Sustainability of support groups is often a challenge. How have you managed to keep support groups going? ....
....
....

r. Do you have criteria for new people to join the support groups? ....
....
....
....
....

s. How do you integrate new people into the Support Group? ....
....
....
....
....

t. Is there incentive other than support and information that the support group participants receive? Eg lunch, taxi fare ....
....
....
....
....

u. What's the content of the support groups? What topics do you cover? ....
....
....
....
....
....
....
....

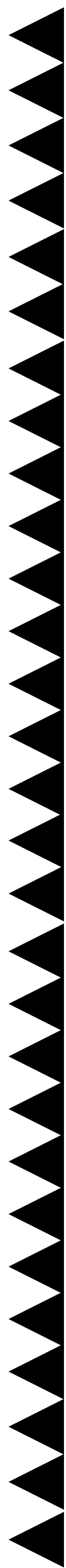
v. **Monitoring**: Is there supervision or monitoring of support groups and their facilitators? ...
....
....

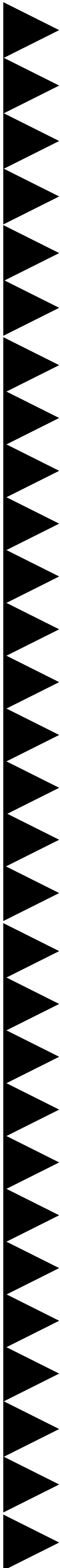
If you have supervision, how is this conducted? ....
....
....
....
....

w. Does your organisation provide opportunities for support to family and friends of PLHIV? ...
....
....
....
....

x. **Marketing**: How are support groups marketed? How do PLHIV get to know about your Support Groups? ....
....
....
....
....
....
....

y. Are the groups known within the community? ....





……………………………………………………………………………………………………
……………………………………………………………………………………
z. **Stigma**: How have you dealt with the issue of stigma in the support groups? ………………
……………………………………………………………………………………………………
……………………………………………………………aa. **Networking**: Do you work with other NGOs or with the clinics in the support group process at all? ……………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………
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bb. Do you work with the local clinic in any way? Which clinic is this? …………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………

2.2 If the NGO is not involved in support groups, we need to find out whether they would or have considered the establishment of support groups.

a. Have you considered Support Groups? ………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
b. Why did your organisation decide against the establishment of Support Groups? ……
……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
c. Do you refer PLHIV to other NGOs or health facilities which offer Support Groups services? Which NGOs, groups or clinics do you use? ……………………………………
……………………………………………………………………………………
……………………………………………………………………………………
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3. Have there been any lessons that your organisation has learned through your experience of Support Groups, or from other NGOs who run support groups that you would like to share with South Africa Partners. Have there been any particular challenges or successes that are noteworthy? ………………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………
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....
....
From your organisatioin's experience, what do you think makes a support group succesful? ...
....
....
....Are there things to be avoided when running support groups, things that present challenges and make the support group vulnerable? ...
....
....
....
....
....
....

4. A key issue that we want to address through the Basic Care Package is the provision of information to PLHIV whilst their CD4 counts are still above 200. We would preferably like to be able to provide this information as close as possible to the time of the diagnosis, whilst the person is still healthy. We want to prevent loss to follow up and to maintain good health, prolonging the onset of the need for ARVs.

We would like to hear from you what information you think would be relevant to include in such a programme. ....
....
....
....
....
....
....
....
....
....
....
....
....

We have reached the end of our questionnaire.

Thank you very much for your support and for the time you have given me. Once we have collated the information we will provide a report to you on our findings.

Contact Details for South Africa Partners via the Ibhayi Living Centre :
Pakama @ 041 – 373 0157

Appendix Six

BASIC CARE PACKAGE SUPPORT GROUPS
NGO APPLICATION FORM

Organisation:

Contact Person:

Telephone: Fax: Email:

Mailing Address:

Physical Address (if different)

Brief Organisational Overview:

Listing of Current Services:

Years in Operation:

Annual Budget:

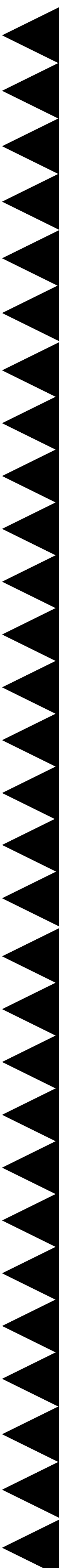
Why does your organization want to be part of the BCP Project?

How would you integrate the BCP Project into your current activities?

Do you currently have staff or volunteers that could be deployed for the piloting of BCP Support Groups? If so, who are they and do they meet the stated criteria for facilitators? *(See description at the end of this form)*

Criteria for Support Group Facilitators

1. Ability to read and write; do simple calculations
2. Maturity – Experience
3. Fluency in local language and understand English
4. Prior involvement with community care program
5. Good interpersonal skills
6. Respect for others and commitment to maintain confidentiality
7. Enthusiasm for the work involved
8. Physically fit to carry out the work
9. Potential to advance career
10. Must be from the same community he or she is serving
11. PLHIV preferred



Appendix Seven

Memorandum of Understanding

Between

XXXXX

and South Africa Partners

Basic Care Package Support Group Project

Purpose of the Memorandum of Understanding:
The purpose of this Memorandum of Understanding [MOU] is to outline the relationship between ____ [NGO] and South Africa Partners (the "Parties") as it relates to the implementation of the Basic Care Package [BCP] Support Groups. It also strives to clarify the objectives, mutual rights, principles, and individual roles and responsibilities pertaining to work to be carried out in partnership. By outlining these aspects, the MOU aims to foster a mutual understanding of the parameters of the partnership, thereby providing the partners with general guidance for pursuing shared interests within the context of the partnership.

The Project Overview
The BCP Support Group Project is led by South Africa Partners (SA Partners), in collaboration with JRI Health and Africare. Its purpose is to develop a BCP national curriculum and establish BCP support groups in the Eastern Cape that provide information and support to newly diagnosed individuals at health facilities and within communities. BCP support groups are designed to provide newly diagnosed PLHIV with important information that promotes 'healthy living' and delays the need for ART. These support groups are also intended to offer a system for retaining a dynamic connection to HIV positive individuals in the public health system that are not yet ready to begin ART.

This MOU outlines the specific areas of collaboration between the BCP Support Group Project and the NGO.

Article 1:
Roles and Responsibilities: NGO

The NGO will assume the following roles and responsibilities:

1.1 Identify XX individuals to be trained as BCP support group facilitators[1].

1.2 Support the establishment of a BCP support group led by the trained facilitator, including:
    1.2.1 Providing a secure space for the BCP support group to meet;
    1.2.2 Ensuring that the group meets regularly and attendance is documented;

[1] See attached BCP support group facilitator job description.

1.2.3 Facilitating mentoring of the BCP support group facilitators by the SA Partners BCP Coordinator; and

1.2.4 Establishing, or strengthening, the NGO's ability to refer BCP support group members to local health facilities or other NGOs, when additional services are necessary

1.3 Ensuring that the BCP support group maintains a minimum membership of 10 people.

1.4 Maintain ongoing and timely communication with the SA Partners BCP Coordinator.

Article 2:
Roles and Responsibilities: South Africa Partners

South Africa Partners will assume the following roles and responsibilities:

2.1 Provide training for the BCP support group facilitators.

2.2 Manage a stipend of R250 per support group session that will be paid to the BCP support group facilitator during the length of the project.

2.3 Provide supervision and mentoring for the BCP support group facilitators to ensure success of the support groups and the accreditation of the facilitator.

2.4 Assist with facilitation of a referral system between the NGO and local health facilitates.

Article 3:
Settlement of Disputes

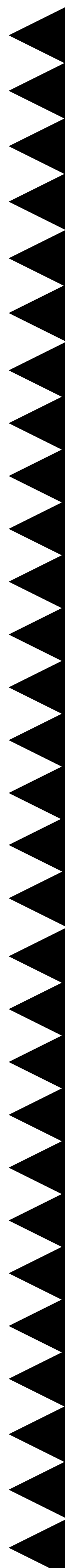
The Parties will work for the implementation of the provisions of this MOU. Any question or dispute related to the interpretation or execution of this MOU will be resolved through the consultation of the Parties.

Article 4:
Length of the Agreement

This MOU will be in effect from the time of signing through 31 August, 2009.

Article 5:
Termination

This Agreement may be terminated for cause by any of the Parties upon 30 days written notice to each of the Parties to this MOU. However, prior to such written notice of intent to terminate, all parties must be given written notice of any cause, including but not limited to insufficient performance or violation of the terms, and be provided with at least 15 business days to redress any defect or to improve performance, except that any allegation of illegal activity by any party or its representative may lead to tem-



porary suspension of the contract pending investigation.

Article 6:
Language

Communication between the Parties shall be conducted in English.

Article 7:
Effective Date

This Memorandum of Understanding shall enter into force on the date of signing by the Parties. Performance of all obligations hereunder shall commence immediately upon signing this agreement.

For and on behalf of:

XXX [NGO]

______________________	______________________
Signature	Date
______________________	______________________
Name	Title

South Africa Partners

______________________	______________________
Signature	Date
______________________	______________________
Mary Tiseo	Executive Director

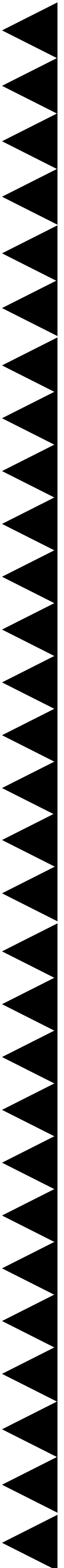
Appendix Eight

BCP Self-Assessment Feedback Form

Presenter Name: ______________________ Date: ______________________

Observer Name: ______________________ Number of Participants: ______________________

Presentation or Support Group Topic:
What I did well:
What could I have done better:
Areas that I would like help with:
Rate Session out of 10 (Score of 1 is not great, 5 is average and 10 is excellent) 1 2 3 4 5 6 7 8 9 10



Appendix Nine

BCP CLOSED SUPPORT GROUP PARTICIPANT IN-TAKE FORM

Thank you for agreeing to complete this form. The information will kept confidential, and is being gathered to help us assess the effectiveness of the support group you are joining. This support group is part of a larger effort to provide support to individuals who have been recently diagnosed as HIV positive. Your participation will assist us as we refine and scale-up this effort. If you have any questions, please speak with your support group facilitator.

Sincerely,
South Africa Partners

PERSONAL DETAILS

FIRST NAME [ ] SURNAME [ ]

AGE [ ] DATE OF BIRTH [ ]

GENDER ○ Female ○ Male

LANGUAGE OF CHOICE

○ XHOSA ○ ENGLISH ○ AFRIKAANS ○ SESOTHO ○ ZULU

○ OTHER (PLEASE SPECIFY) ____________________

CONTACT DETAILS

Suburb/ Location /Township

____
____

POSTAL CODE ____________

HOME **CODE** (   ) WORK **CODE** (   )

CELL [ ] EMAIL [ ]

PERSONAL INFORMATION

PLEASE TICK A RELEVANT ANSWER BELOW

MARITAL STATUS

○ SINGLE ○ MARRIED ○ SEPARATED ○ DIVORCED ○ WIDOWED

EMPLOYMENT STATUS

○ EMPLOYED ○ SELF EMPLOYED ○ UNEMPLOYED ○ RETIRED ○ STUDENT

QUALIFICATIONS

○ MATRIC ○ DIPLOMA ○ DEGREE ○ POST GRADUATE ○ OTHER (SPECIFY)

____

WHEN WERE YOU DIAGNOSED? (DD/MM/YY) ______________________

WHERE WERE YOU DIAGNOSED? ______________________

DO YOU KNOW YOUR CD4 COUNT? ☐ YES ☐ NO

IF YES, PLEASE TELL US WHAT IT IS ______________

HOW DID YOU HEAR ABOUT THIS SUPPORT GROUP?

☐ COMMUNITY MEMBER ☐ CLINIC (CLINIC SISTER / LAY COUNSELLOR)

☐ CHURCH ☐ CBO/NGO (please specify name) ______________

☐ OTHER (Please specify) ______________

HOW MUCH DO YOU KNOW ABOUT HIV/AIDS?

☐ NOTHING ☐ VERY LITTLE ☐ I HAVE AVERAGE KNOWLEDGE ☐ I KNOW A LOT

WHAT ARE YOU EXPECTING FROM THE SUPPORT GROUP?

____

____

____

____

____

I______________________, declare that the above information is true. I was informed about the Support Group and the Closed Group Sessions by the support group facilitator. I therefore commit to attend all sessions offered within this group for the duration of 6 weeks.

______________________ ______________________

Participant's Signature *Date*

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89 South Street Suite 701
Boston, MA 02111
Tel: 617.443.1072
Fax: 617.443.1076
Email: info@sapartners.org
www.sapartners.org

South Africa Office
16 Wynne Street
Southernwood, 5201
East London
Tel: 043.722.4254
Email: tdiesel@sapartners.org.za