



*Integrated Access to Care and Treatment*

**Empowering people living with HIV and others who are affected by HIV  
to learn, share, and live positively.**

# Programme Overview

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**A Programme of**

**South Africa Partners**

Fostering Partnerships Between the United States and South Africa



**USAID | SOUTH AFRICA**  
FROM THE AMERICAN PEOPLE



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## Introduction

**Founded in 2009, Integrated Access to Care and Treatment (I ACT) empowers people living with HIV (PLHIV) and others who are otherwise affected by HIV to confidently lead healthy lives.**

A national programme in South Africa, I ACT offers a highly participatory curriculum of facilitated, open and closed group meetings and public educational sessions. I ACT facilitators are highly trained to create a safe and trusting meeting culture that engages all participants. Meeting topics include:

- \* HIV/AIDS and opportunistic infections (OIs) including tuberculosis (TB)
- \* Treatment Literacy and Adherence
- \* Acceptance of Status
- \* Disclosure
- \* Nutrition and Healthy Living Principles
- \* Prevention with Positives

I ACT promotes the knowledge, network, and confidence for participants to advocate for their health care and make positive lifestyle changes, changes that can help to delay the need for treatment. I ACT groups are developed in coordination with local community organisations, faith-based groups, and health facilities. As a finite, curriculum-based intervention, I ACT provides participants with referrals for ongoing support services when needed and helps to promote a timely initiation of antiretroviral therapy (ART) when required.

I ACT is coordinated by the South African National Department of Health (NDoH) and South Africa Partners, an international charitable nonprofit organisation dedicated to building mutually beneficial partnerships between the US and South Africa in the areas of health and education. Provincial Departments of Health (PDoH), U.S. President's Emergency Plan for AIDS Relief (PEPFAR)-funded Lead Partner Organisations also guide I ACT's development and implementation in all provinces. This networked approach to programme management allows I ACT to create impact across geographic territories at the national, provincial, and local levels.

The ultimate goal is to help people to learn, share, and live positively.

This Programme Overview is designed to provide context, information, and resources regarding the I ACT model. This document complements I ACT's Implementation Guide, currently in development, which will provide detailed strategies to assist those interested in replicating the programme.

**For more information, please see [www.iactsupport.org](http://www.iactsupport.org)**



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## Programme Background

### The I ACT programme supports a vision of long and healthy lives for all South Africans.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that 5.7 million South Africans are HIV positive, more than in any other country in the world.<sup>1</sup> Through the coordinated efforts of the public sector, non-governmental organisations (NGOs), 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 May 2011, the South African Minister of Health announced that 1.4 million South Africans take antiretroviral (ARV) medication.<sup>2</sup>

HIV/AIDS support programmes, including I ACT, have become critical within South Africa's continuum of health care.

Voluntary Counselling and Testing (VCT) was first introduced in the early 1990s through city-based AIDS Training, Information, and Counselling Centres. The first VCT sites, operating before publicly-funded antiretroviral medications were available, offered few care options to follow a positive diagnosis. Over time, VCT expanded its services and referrals to become an important entry point for a range of care and support programmes.

PLHIV organisations also began to provide support to those who tested positive and formal and informal peer support groups developed around the country. As the continuum of care for PLHIV evolved, peer support groups became more numerous, effective, and integrated both into health facility and community-based services.

In developing a better understanding of how to support individuals after they receive an HIV positive test result, the focus is on strategies to lessen "loss to follow-up." An important study examined loss to follow-up in South Africa and identified three stages when vulnerable PLHIV were likely to leave the health care system:<sup>3</sup>

- (1) Patients with known HIV who need assessment and decisions for treatment
- (2) Patients in the first four months of ARV treatment
- (3) Patients on long-term ART

The study suggested that Stages 2 and 3 have received the most attention to date, despite the fact that 46% of deaths in the study occurred before treatment began – Stage 1.<sup>4</sup> I ACT was developed as one solution to reduce Stage 1 loss to follow-up.

Healthy Living Support Groups, the pilot phase of I ACT, completed in August 2009 in the Eastern Cape, was developed by South

<sup>1</sup> UNAIDS Joint United Nations Programme on HIV/AIDS, "World AIDS Day Report 2011," page 7 [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2216\\_WorldAIDSday\\_report\\_2011\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2216_WorldAIDSday_report_2011_en.pdf)

<sup>2</sup> Health Budget Vote Policy Speech presented at the National Assembly on Marcy 31, 2011 by Minister of Health, Dr. A. Motsoaledi, text available at <http://www.doh.gov.za/show.php?id=1890>

<sup>3</sup> Lawn SD, Myer L, Harling G, Orrell C, Bekker LG, Wood R. Determinants of mortality and non-death losses from an antiretroviral treatment service in South Africa: implications for programme evaluation. *Clinical Infectious Diseases* 2006 Sep 15;43 (6):770-776.

<sup>4</sup> *ibid*

Africa Partners and the Eastern Cape Department of Health (ECDoH). South Africa Partners is an international NGO with offices in Boston (USA), East London, and Port Elizabeth. Other important project partners included JRI Health, the Eastern Cape Regional Training Centre (ECRTC), and

selected community-based NGOs operating in rural, peri-urban, and urban settings in five of the province's seven health districts. Funding for Healthy Living Support Groups was provided by Africare with PEPFAR funds from the CDC South Africa.

## Programme Goals, Objectives, and Principles

**The ultimate outcome of I ACT is for PLHIV and others who are affected by HIV to become advocates for their health care and treatment.**

The goal is to promote early recruitment and retention of newly diagnosed PLHIV into care and support programmes. I ACT also strives to reduce the high rate of loss to follow-up from the time of HIV diagnosis to successful commencement of ART.

I ACT's four objectives are:

**Objective 1.** Increase early identification and referral of newly diagnosed PLHIV into care and support services

**Objective 2.** Increase retention of newly diagnosed PLHIV into care and support services

**Objective 3.** Empower newly diagnosed PLHIV to advocate for and manage their health

**Objective 4.** Strengthen the active engagement of PLHIV, families, health care providers and communities in continuum of care and support

To achieve these objectives I ACT:

- \* Reduces AIDS morbidity and mortality
- \* Retains PLHIV in healthcare systems
- \* Reduces loss to follow-up
- \* Provides knowledge to PLHIV to inform decisions soon after diagnosis
- \* Mitigates stigma related to HIV, sexually transmitted infections (STIs), OIs, and TB
- \* Provides comprehensive information to ensure adherence and compliance for care and treatment regimens
- \* Reduces and prevent new infections of HIV, STIs, and TB
- \* Assists with referrals to strengthen healthcare systems

The basic principles of I ACT include the:

- \* Intentional involvement of PLHIV at all programme and service 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 I ACT programme was developed to support several objectives of South Africa's National Strategic Plan for HIV, STIs, and TB and several outputs of the Negotiated Service Delivery Agreement.

### Negotiated Service Delivery Agreement

I ACT supports the following outputs of the **Negotiated Service Delivery Agreement (NSDA)**:

#### *Output 1*

##### *Increase Life Expectancy*

I ACT provides knowledge about HIV, STIs, TB, and healthy living principles and with this knowledge comes the power to engage in strategies that increase life expectancy

#### *Output 2*

##### *Decrease Maternal and Child Mortality*

I ACT programmes provide detailed information about reproductive health and preventing mother-to-child transmission (PMTCT) of HIV

#### *Output 3*

##### *Combat HIV and AIDS and Decrease the Burden of Disease from TB*

I ACT programmes help participants to understand how HIV/AIDS is spread and how transmission can be prevented. The I ACT curriculum also provides information about OIs, including TB, and how they can be prevented.

#### *Output 4*

##### *Strengthening Health Systems effectiveness*

Linkages and referral systems are strengthened among the I ACT groups, NGOs, and health facilities. I ACT also trains and develops its group facilitators.

### National Strategic Plan

I ACT supports the following objectives of South Africa's **National Strategic Plan (NSP)** for HIV, STIs and TB (2012 - 2016)<sup>5</sup>

#### *Objective 1*

##### *Address Social and Structural Factors*

- \* I ACT curriculum, discussion, and activities enable learning, sharing and growth
- \* I ACT programmes work to reduce societal stigma
- \* After completion of the I ACT programme, participants are empowered to continue with activities that support this objective, including
  - ✓ Income generation activities such as food gardens and poultry rearing
  - ✓ Other local activities that promote skills development and community enhancement
  - ✓ Becoming self sufficient and self supporting
  - ✓ Referral into other activities of the government support mechanisms

#### *Objective 2*

##### *Prevent new HIV, STI, and TB Infections*

- \* I ACT programmes engage participants in behavioural and social interventions

#### *Objective 3*

##### *Sustain Health and Wellness*

- \* I ACT strengthens implementation of patient-centered pre-ART care and treatment
- \* I ACT programmes increase participants' knowledge of HIV/AIDS, STIs and TB and decreases loss to follow-up resulting in reduced disability and death

## What is the I ACT Programme?

**I ACT engages PLHIV and others impacted by HIV through structured, finite, curriculum-based group meetings offered in health facilities and community settings.**

I ACT facilitators conduct two-hour group meetings in either an open or closed format giving participants a choice for their level of involvement and commitment.

**Closed groups** are formed to serve PLHIV the majority of whom are not taking ARVs. “Closed” means that after the first session no new participants are allowed to join. Closed group participants commit to attend all six meeting topics to foster a supportive cohort.

Topics include:

1. HIV/AIDS and OIs including TB
2. Treatment Literacy and Adherence
3. Acceptance of Status
4. Disclosure
5. Nutrition and Healthy Living Principles
6. Prevention with Positives

See “The I ACT Curriculum” below for more detailed information about each topic.

**Open groups** cover the same six topic areas but serve PLHIV and others who are impacted by HIV. Open groups allow people drop in for the meeting topics they are most interested in; there is no obligation to attend subsequent sessions. This format helps participants address gaps in knowledge and learn about specific areas within the I ACT curriculum.

Up to fifteen participants attend open and closed group meetings. Closed groups have an average eight participants. This small group size supports the intention for all to participate, interact, and have their questions

answered. Small group size also creates opportunities for participants to develop a local network for peer support.

**Educational sessions** are offered to the public to provide information and build interest in the I ACT groups. Educational sessions are frequently held in locations where people might need help, including the waiting rooms of local health clinics, churches, taxi stands, and community centers. Educational sessions are usually less than thirty minutes and designed to convey I ACT’s key learning topics.

All I ACT offerings are designed to engage participants using adult learning techniques. All meetings are very interactive; participants do not sit and receive information but rather actively participate in the learning process.

Open and closed I ACT groups, and educational sessions, are implemented in health facility and community settings. Groups may convene in a school hall, community center, taxi (public transport), church, places where participants gather, occasionally even in a facilitator’s or a participant’s house. The underlying principle is to take the care and support to where people are. This increases participation, comfort, and trust.

Services for **Other Chronic Diseases**, e.g., diabetes, hypertension, may be developed by adapting the I ACT programme concept: “Understand your illness, know what treatment is available for you, accept that you have a chronic illness, discuss and disclose your chronic illness to others, learn healthy living principles for the chronic illness, plan for the future, and educate others.” A “plug in – plug out” module is currently being developed to facilitate this inclusion.



## The I ACT Curriculum

### **HIV/AIDS, STIs and OIs including TB**

- \* Basic understanding of HIV/AIDS
- \* HIV transmission and points of entry
- \* STIs
- \* OIs and TB
- \* Prophylactic treatment
- \* Self reliance and keeping appointments

### **Treatment Literacy and Adherence**

- \* Progression of HIV and AIDS
- \* Treatment options
- \* CD4 count and viral load
- \* Monitoring and reporting adverse treatment events
- \* Responsibility to adhere to treatment
- \* Positive aspects of ART

### **Acceptance of Status**

- \* Acceptance as the first step in taking charge of one's health
- \* Defining and coping with stigma
- \* Defining and overcoming denial
- \* Factors that inhibit acceptance of status
- \* Benefits of accepting status

### **Disclosure**

- \* Building a support base for disclosure
- \* Strengthening relationships with health care providers and family
- \* Developing systems to adhere to treatment
- \* De-stigmatizing HIV
- \* Encouraging partners, family, and friends to get tested

### **Nutrition and Health Living Principles**

- \* The connection between healthy eating, health, and infection
- \* Nutritional support and nutritional needs
- \* Accessing nutritional food
- \* Preparing healthy meals
- \* Other health living principles

### **Prevention with Positives**

- \* Being a Positive role model
- \* Accessing PLHIV support organisations
- \* Family planning options
- \* Primary prevention strategies
- \* Symptoms of TB
- \* Prevention of STIs
- \* Positive Living with a Positive Diagnosis

## I ACT Participants

I ACT predominantly serves newly diagnosed PLHIV. The programme also focuses on PLHIV who were diagnosed earlier but have CD4 counts such that they are not taking ARVs. I ACT also engages PLHIV who qualify to take ARVs but lack the information or confidence to do so. I ACT also serves people who are already taking ARVs but have not engaged in support services.

A portion of I ACT's services, the facilitated open groups and educational sessions, are

also open to people who may not be HIV positive but are otherwise affected by HIV. The target audience then includes all PLHIV and others impacted by HIV with a focus on adult participants over fifteen years old.

I ACT is able to serve the diverse needs of these constituents because the curriculum is purposely complementary and easily adapted to be offered in coordination with other HIV and AIDS support services.

## I ACT Facilitators and Trainers

I ACT trains high quality facilitators to lead open and closed groups and educational sessions. See the Table below for a summary of I ACT's training opportunities. Facilitators, many of whom are HIV positive, learn the content both for themselves and to teach others. This aspect of the programme is very important: for participants are more likely to listen to a facilitator who is living with HIV than a professional nurse, particularly in open groups and educational sessions.

I ACT facilitators include health promoters, adherence counselors, health prevention strategists, and others. Facilitators' frequently work extended hours to reach their participant base.

Facilitators are required to learn and understand accurate and clear information on the six distinct and complex topics, as well as integrate and exhibit highly nuanced skills in facilitation and group dynamics.

Facilitators receive extensive training using an established training curriculum. Each curriculum section builds on and reinforces previous material. In this way, facilitators learn and integrate basic, underlying concepts to develop a nuanced understanding of I ACT topics. Facilitators build their confidence and experience while applying lessons learned.

The facilitator training is split into two distinct parts: a six-day Content training and a five-day Skills training.

**Content Training** provides facilitators with information, supporting articles, group activities, and other resources to empower them to speak accurately, confidently, and consistently on all I ACT topics.

Content training is technical and detailed and intended to equip I ACT facilitators with the

facts needed to challenge misinformation when it surfaces.

**Skills Training** allows facilitators to acquire the knowledge and skills to facilitate, organize, and maintain effective and sustainable I ACT groups. The skills training emphasizes the appropriate role for the facilitator and includes interactive sessions on setting boundaries, seeking self-care, managing challenging behaviours, and understanding key clinical issues facing PLHIV including disclosure, stigma, and acceptance of status.

Manuals from the Content and Skills training sessions include reference materials, in-class activities, and suggested homework. A curriculum "tool kit" has also recently been developed for use by facilitators in the field. This toolkit provides presentation materials, teaching guidance, handouts, and forms for the I ACT curriculum. Many activities for I ACT groups are modeled after facilitator training. Thus, facilitators are able to engage in these learning experiences first as participants and later as group leaders.

Throughout the Content and Skills training, facilitators learn to emphasize respect for the qualities that make participants diverse including race, ethnicity, gender, sexual orientation, age, physical ability, education, literacy level, spoken language, and economic status.

Both the Content and Skills Training is provided to facilitators by Trainers of Trainers (TOTs).

A five-day **TOT Training** provides TOTs with a deeper understanding of I ACT Topics and facilitation skills. TOTs are facilitators who are selected to take on more responsibility to train their peers. The TOT training is taught by I ACT Lead Trainers who are most



knowledgeable about the I ACT programme and its implementation.

I ACT facilitators, TOTs, Lead Trainers are supported by a “Caring for the Carer’s” programme called “Mirror Sessions” developed by the University of Fort Hare Psychological Services Centre. Through these sessions, facilitators access debriefing

and resources to build their capacity to deal effectively with complex issues raised in I ACT groups. This support helps to prevent facilitators from burning out and/or becoming entwined in the lives of the group participants. This programme can be used for other staff who work in stressful environments.

**Three training paths for I ACT Participants, Facilitators, and Trainers:**

<b>I ACT Groups Implementation</b>	<b>I ACT Facilitators Career Pathing</b>	<b>I ACT Trainers (TOTs) Training and Mentoring</b>
Six sessions implemented by I ACT facilitators in either health facility or community settings	Six-day Content Training and five-day Skills Training for Facilitators who will implement open and closed I ACT Groups and educational sessions.	Five-day training for Trainers of I ACT Facilitators. Trainers are selected based on their previous training, experience, knowledge
Information is provided by I ACT facilitators to I ACT group participants	Training is given by an I ACT Trainer who successfully completed the TOT training session	The TOT training is given by formally trained I ACT Lead Trainers who are South Africa Partners’ employees
	This course is in the process of being accredited and placed within existing H&W Seta courses	

**Engagement of National and Provincial Stakeholders**

**Partnering with Provincial and National Departments of Health and other Provincial-based partners is essential for I ACT’s success and growth.**

A National Working Group (NWG), comprised of representatives from South Africa Partners, NDoH, PDoH, Provincial Regional Training Centres (RTCs), Lead Partner Organisations (see I ACT Structure below), together with representatives from the CDC, PEPFAR and UNAIDS, meets quarterly to oversee curriculum and programme quality,

recognize best practices, develop evaluation tools, and strategize the expansion plan for I ACT.

Although founded in the Province of the Eastern Cape, I ACT is now implemented in all of South Africa’s nine provinces in collaboration with the PDoH and PEPFAR-funded, Lead Partner Organisations (see I ACT National Footprint below).

All PDoH accept the I ACT Programme as part of their care and support programmes. All PDoH also promote the inclusion of I ACT

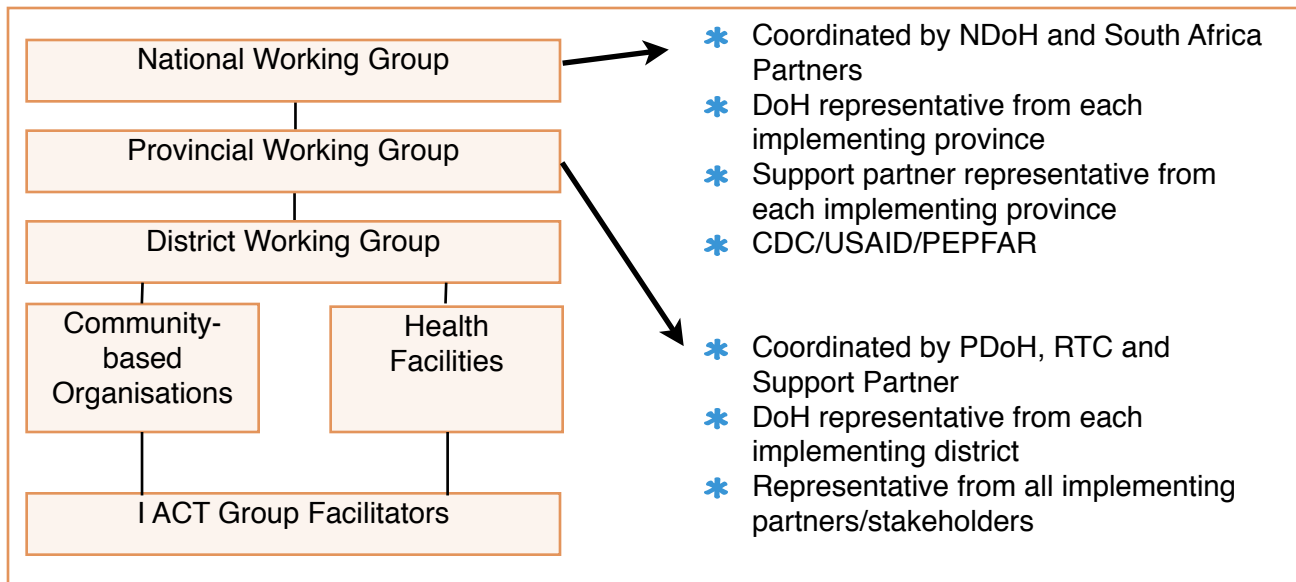
in PMTCT programmes. There is strong support to use I ACT to engage grandmothers, especially those that support orphans and vulnerable children (OVCs).

Each Province has a Provincial Working Group (PWG) that is chaired by the PDoH representative and includes participants from the district health teams of the Province,

NGOs implementing the programme, Funders, Lead Partners, and other relevant role-players.

In some districts, District Working Groups have been established along similar guidelines.

### I ACT Structure



## Programme Implementation

The I ACT implementation strategy supports the the following principles:

- \* I ACT is implemented as a joint effort of DoH, RTC, PEPFAR partners, and NGOs
- \* Core activities of the I ACT programme include:
  - ✓ **Education Sessions**, twenty to thirty-minute didactic teaching of I ACT’s core topic areas, in locations where people gather and may seek assistance (e.g. churches, taxi ranks,

community centres, healthcare facilities)

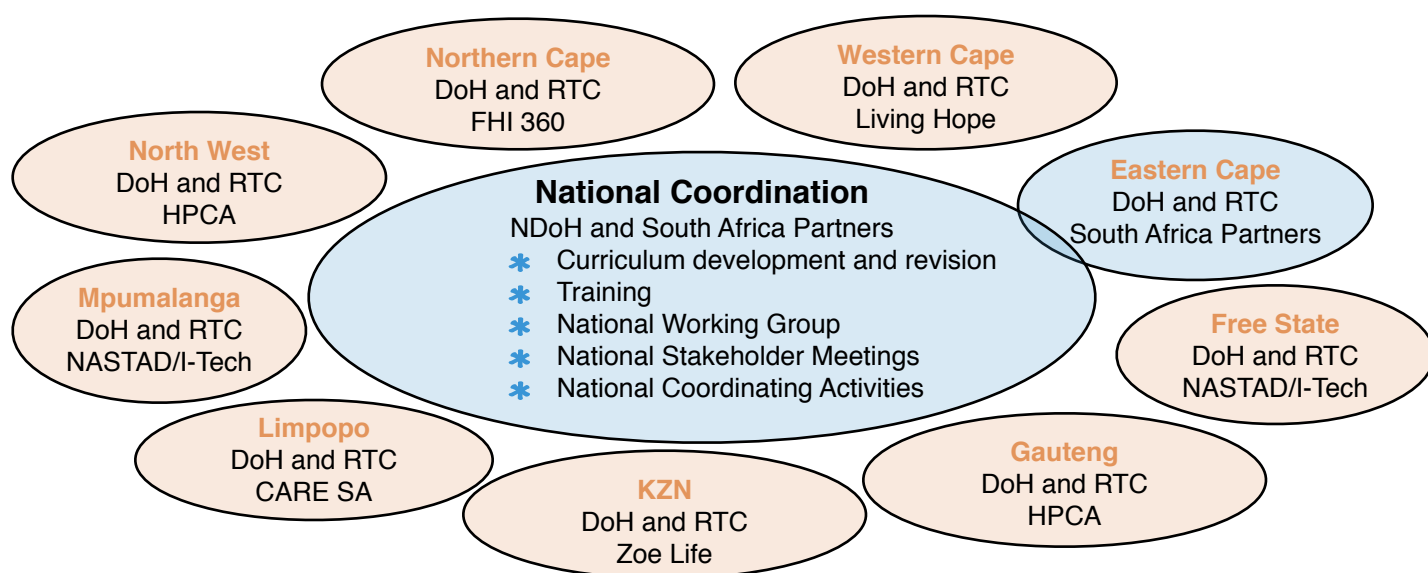
- ✓ **I ACT Group Meetings** (closed and open-format follow similar implementation) with groups of up to 15 people that cover six topics, a maximum of 2 hours per topic
- \* Training and support for I ACT facilitators and TOTs is an ongoing process, training must include topical content and facilitation skills

- \* Facilitators can assist participants in accessing referrals and other resources for support and care
- \* A caring-for-the-carer programme, Mirror Sessions, is critical for helping facilitators to not burn out or become entwined in the lives of the participants in the groups
- \* All activities can be based in local community buildings and health facilities
- \* All activities can be “piggy-backed” on to existing services at minimal cost

- \* I ACT groups create a network for participants to mutually support each other after the I ACT meetings are completed

An I ACT Implementation Guide is being developed to provide more detailed information for those who are implementing the I ACT programme.

### I ACT National Footprint



### Systems Strengthening

As I ACT continues to develop services and expand into more locations, the programme will strengthen key components of South Africa’s health care systems.

#### I ACT supports primary healthcare (PHC) re-engineering:

- \* I ACT provides a finite, curriculum-based intervention that can re-energize existing, on-going support group structures
- \* The I ACT facilitator training will be held as an in-service programme for relevant clinic staff, including counselors,

community health workers, and professional staff, in collaboration with needs identified by the NDoH

- \* I ACT complements existing chronic care services to support PLHIV and others living with chronic illnesses in coordination with District Health Management and PHC outreach teams
- \* The ultimate goal for I ACT is to empower participants to manage their care and take ownership of their health, reinforcing the connection between client and healthcare facility

**I ACT supports the management of HIV/AIDS, STIs, OIs, TB and other diseases**

- \* I ACT’s curriculum includes content to help participants identify chronic illnesses associated with HIV/AIDS OIs, TB, hypertension and diabetes

**I ACT engages target populations in expanded geographic regions**

- \* I ACT is being implemented in all nine Provinces of South Africa
- \* Target populations include recently diagnosed adult PLHIV and others affected by HIV

**I ACT is planning for the programme to be integrated into the NDoH over time, ensuring sustainability.**

- \* I ACT will strive to be included in the DoH strategic plan as a standard for post-HIV test and pre-treatment and a tool for other chronic illness

- \* I ACT can be used as an indicator for DoH, e.g., the number of newly diagnosed PLHIV enrolled in pre-ART who participate in I ACT services

**I ACT will continue measurement and evaluation (M&E) plans.**

- \* Monitoring and evaluation is undertaken by the Health Information Systems Programme and future data capture will be completed using the DHIS14 data management system
- \* Training for data collection and processing is now offered by HISP in all provinces on request
- \* Efforts are underway to integrate I ACT’s current data system into the DHIS
- \* If a different data collection system is used in a province, the monitoring and evaluation system is adapted to suit the needs of the province and avoid creating a parallel record keeping system

## Conclusion

**I ACT is a focused intervention and for many, the entry point into care and support.**

### The I ACT Programme

- ✓ **Increases** knowledge and skills about HIV/AIDS, STIs, and OIs including TB
- ✓ **Inspires** PLHIV to accept their status and live positively
- ✓ **Empowers** PLHIV to become advocates for their health
- ✓ **Ensures** care and support for PLHIV
- ✓ **Strengthens** referral systems and connections in local communities
- ✓ **Encourages** greater local access to and responsibility for improved HIV care and support

### I ACT Groups:

- \* Nurture participants’ sense of belonging
- \* Enable expression and sharing of feelings
- \* Provide accurate information
- \* Encourage hope
- \* Facilitate new ways of doing things
- \* Create space for personal growth
- \* Promote positive living with a positive diagnosis
- \* Are a safe haven

The I ACT programme is the “**golden key**” to better health improvement and self-advocacy for PLHIV and those living with other chronic illnesses.

**For more information, please see [www.iactsupport.org](http://www.iactsupport.org)**