Stigma and
The People Living with HIV Stigma Index

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Theme of presentation…

Suggesting ways how the PLHIV Index can enhance:

Programmes

Advocacy

Self Affirmation
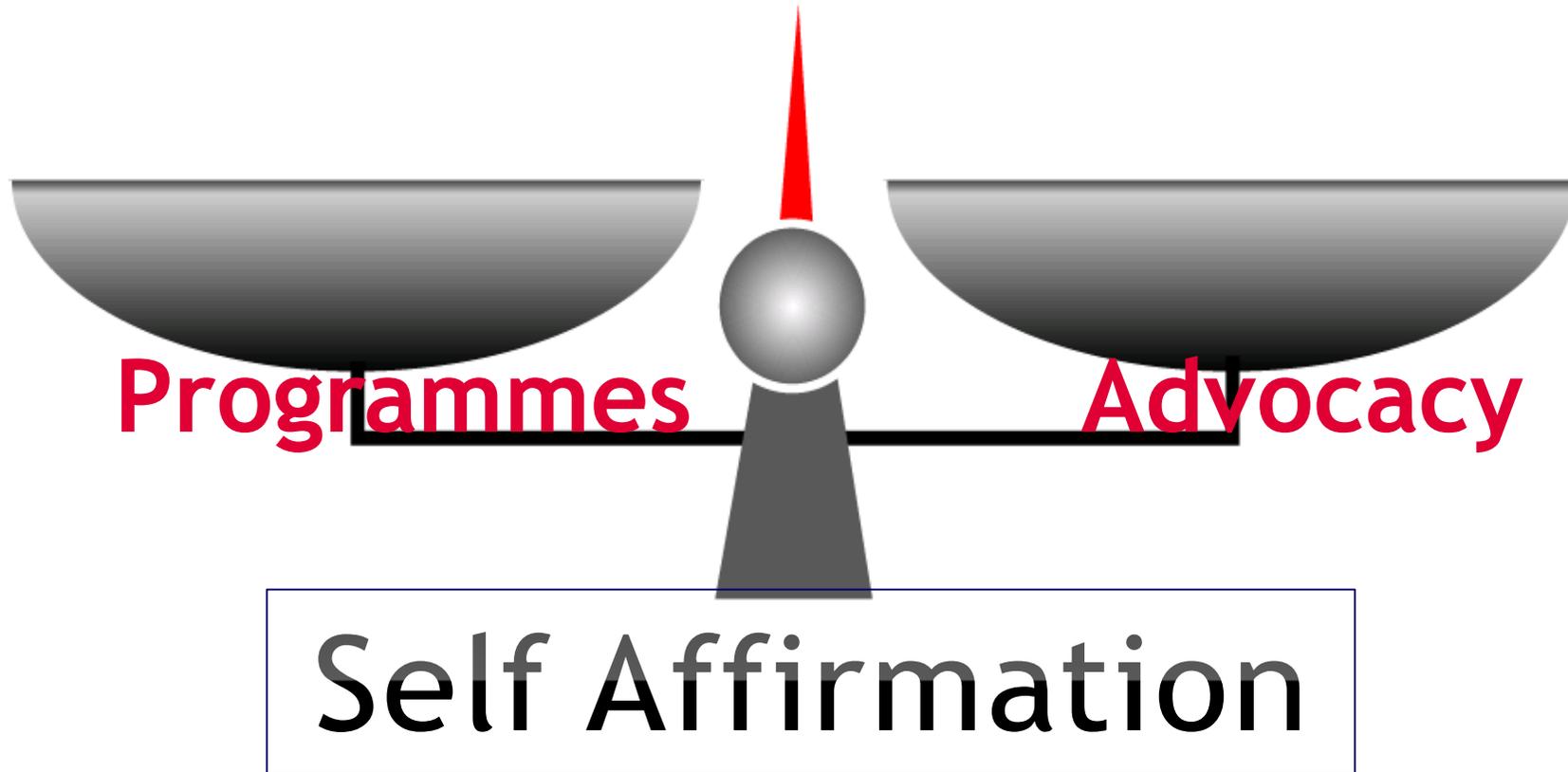
Why, What, Who

- > HIV related stigma and discrimination are known to be barriers to accessing HIV prevention, treatment and care services, but much of what we know about this stigma and the resulting discrimination, is anecdotal or fragmented

- > The Index is a tool to build evidence and measure the level of stigma experienced by PLHIV within their communities. It translates anecdotal evidence into systematically and measurable data to compare levels of stigma across borders, key populations and across time.

- > As well as being a partnership product of the four organisations GNP, ICW, IPPF and UNAIDS it has been supported and is a partnership at a national and regional level by PLHIV networks themselves, Civil Society organisations and alliances, foundations , universities and others . In Europe , Eastern Europe and Central Asia this includes, AIDSFonds , The MAC AIDS foundation, National Departments of health, UNDP, UNAIDS, UNFPA, The Levi Strauss Foundation and of course

HIV in Europe
Working Together for Optimal
Testing and Earlier Care
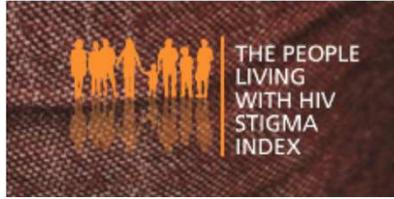
Some questions to start …

Stigma is widely recognised as a barrier to achieving universal access to prevention, treatment, care and support.

1. How does stigma have an impact on all the work we do?

2. How should we measure stigma?

3. How is the *People Living with HIV Stigma Index* different from other research initiatives to measure stigma?

And How can the evidence generate change in ….
1 The lives of people living with HIV?
2 Programme responses such as testing?
3 Policies such as criminalisation?

"Many a time I have heard people saying don't come next to me I am scared of you'"

1 How does stigma impact on our work: A Cycle of Impact

Self Worth

Prejudice

thought

Human Rights

Loss

Stigma

results

attitude

Legal Freedoms

Discrimination

act
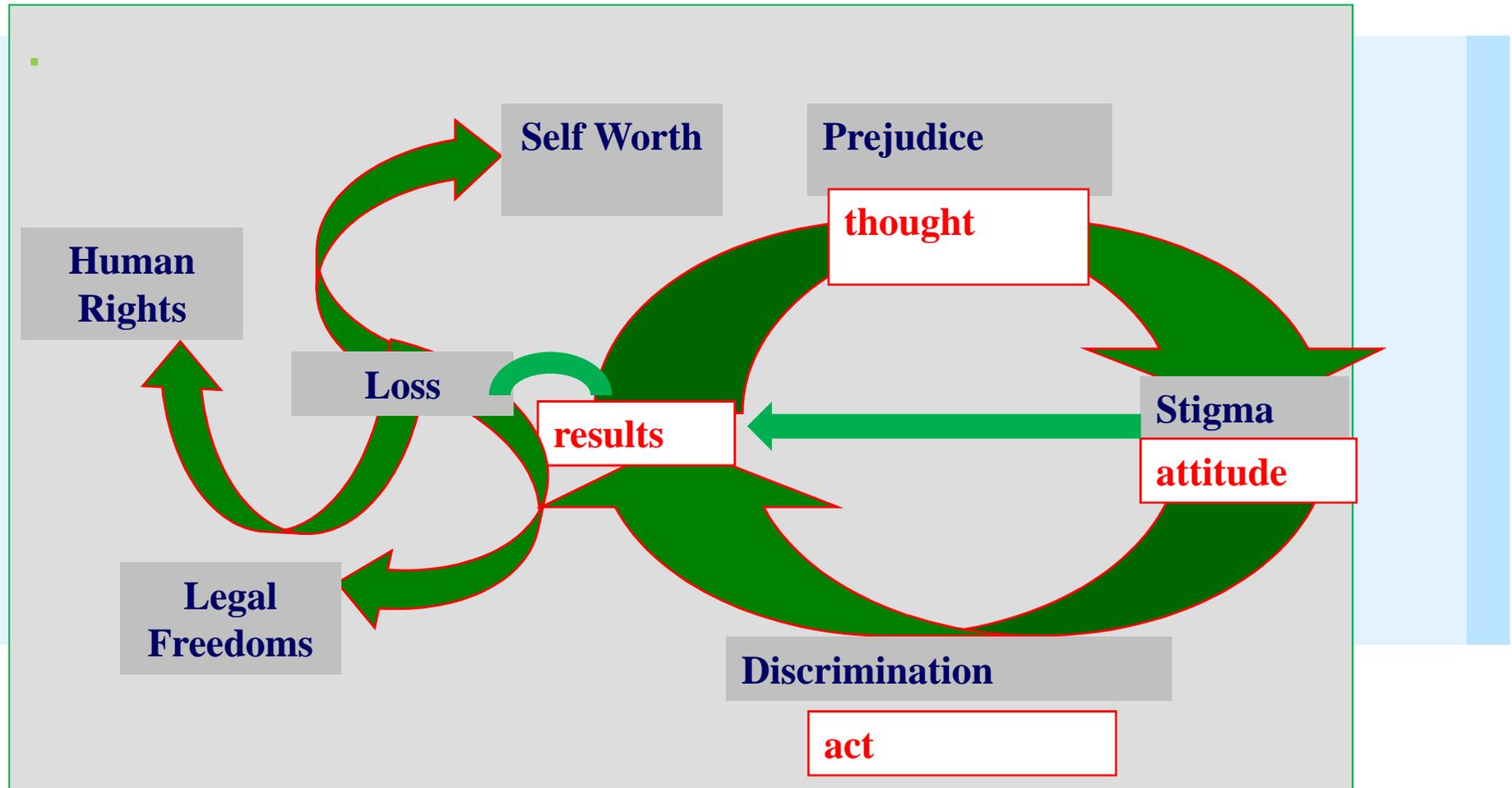
Understanding HIV related stigma…

- Pervasive power of stigma & discrimination

- Different forms (enacted, internal)

- Programmatic interventions create enabling environments not necessarily enabled people

- Subtly of stigma & discrimination has changed

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2. How should we measure stigma ?

Well, What have other indexes done
- Health Care Providers/Facilities Index

- Household and Community level attitudes

- Missing Gap:
  Asking PLHIV

Healthcare
providers/facilities

Household and
Communities

PLHIV
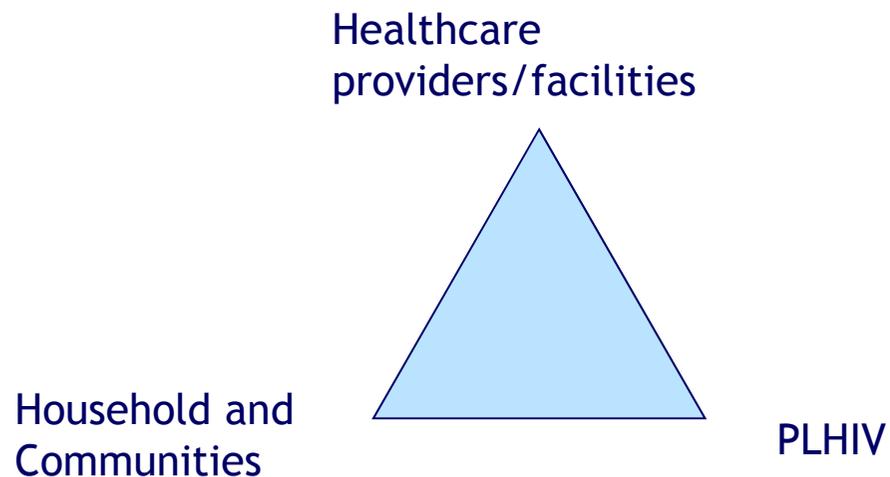
How is the *Index* different from other research initiatives to measure stigma?

"THE STIGMA INDEX WILL HELP US DOCUMENT OUR OWN EXPERIENCES AND STRENGTHEN OUR ADVOCACY WORK. THIS IS A WAY THAT WE CAN START TO CHANGE THE CONVERSATION – WE WILL HAVE EVIDENCE TO BACK US UP."

THE PEOPLE LIVING WITH HIV STIGMA INDEX

What is the PLHIV Stigma Index ?

A way to understand experiences of stigma and discrimination, and how they change over time.

The process centres on PLHIV – making the Index a tool for, and by, PLHIV.

Key points:
- A Move away from 'boxed' responses
- Involves communities most vulnerable to infection (MSM, IDU, Sex workers, women and young girls) effecting change at the 'personal' level
- Tool for GIPA enactment – informs ADVOVACY, ACTIVISM and CREATES PARTNERSHIPS FOR CHANGE

What does the index look like?

Factors of stigma and discrimination the questionnaire addresses:

1 Experience of Stigma & discrimination from others

2 Access to work and services

3 Internal stigma and fears

4 Rights, laws and policies

5 Effecting change

6 Testing & diagnosis

7 Disclosure & confidentiality

8 Treatment

9 Having children

10 Self-assessment of stigma & discrimination

Preliminary results

Feelings experienced because of HIV status

	Percent
I feel ashamed	14%
I feel guilty	19%
I blame myself	22%
I blame others	10%
I have low self esteem	17%
I feel I should be punished	1%
I feel suicidal	6%
I don't have any such feelings	11%

The Questionnaire

PLHIV INDEX QUESTIONNAIRE
CONFIDENTIAL AND ANONYMOUS

'Side by side' approach: The questionnaire is done with, not to, PLHIV. This is key to ensuring the Index is an empowering process.

GIPA: Key to the Index is recognising PLHIV are agents for change. This section seeks to understand the roles people are playing.

The Userguide:

- **The Userguide supports the implementation of the questionnaire.**

- **It gives guidance on ethical considerations, confidentiality and practical issues such as population sampling.**

- **This is key to the Index being a free-standing tool adaptable to local circumstance and needs but still robust.**

People Living with HIV/AIDS (PLHIV) Index Survey
An Index to measure the stigma and discrimination experienced by
People Living With HIV (PLHIV)

THE USER GUIDE

CONTENTS
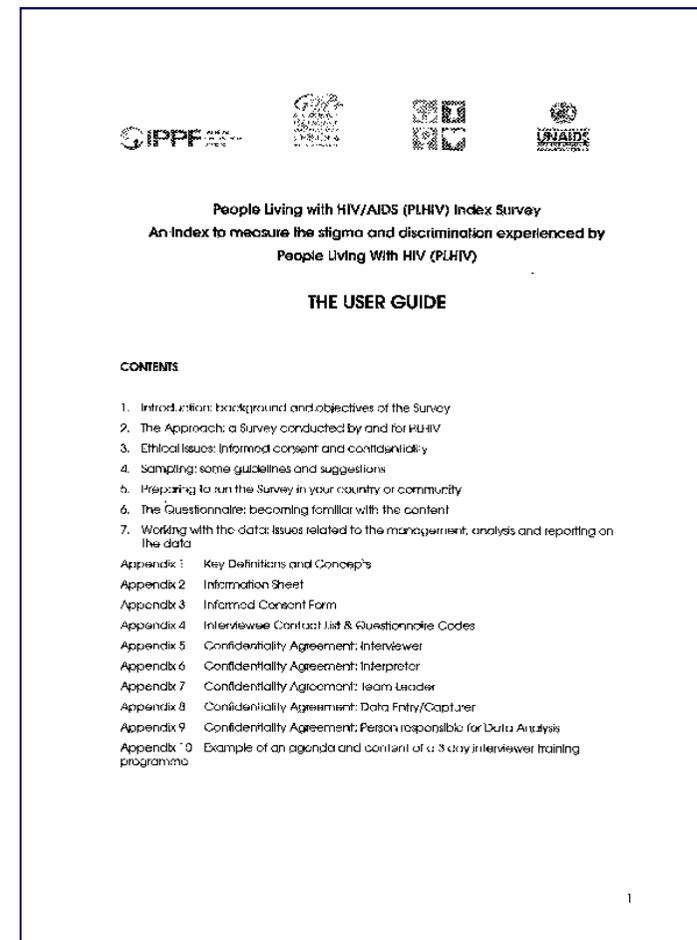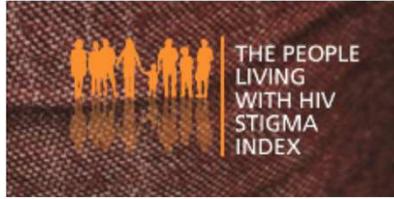
Where we are now—regional rollout and capacity building as of November 2009

Regional workshops

➢ 7 regional workshops so far involving; 66plus PLHIV organisations from at least 55 countries

Seed grants ($2000)

➢ 40 plus proposals from country teams to catalyse resource mobilisation and partnership development for in country national rollouts a further 20 plus in development

National implementation

➢ As of November 2009: Bangladesh, China, Dominican Republic, Pakistan, Thailand, UK, Kenya, Nigeria, Zambia, Philippines, Fiji all in process of national roll-out

Europe, Eastern Europe and Central Asia

UK about to deliver results, 9 countries in EECA involved at the seed grant stage, 5 other countries wanting to get involved in the INDEX, and more always welcome …

■ Belarus, Estonia, Georgia, Moldova, Poland, Russia, Turkey, Ukraine, Uzbekistan already involved

■ Albania, Belgium, Greece and Portugal have all expressed a desire to be involved in the project – and there are possibly others interested.

THE PEOPLE LIVING WITH HIV STIGMA INDEX
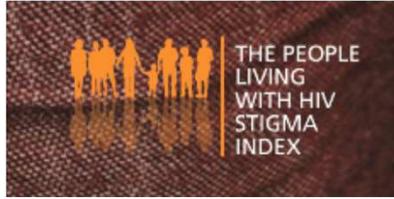
Where we are now—54 other countries involved at some level

Africa

Burkina Faso Burundi Cameroon Congo Kenya Malawi

Mozambique Namibia Nigeria Republique Central Africaine

Rwanda Senegal South Africa Swaziland Tanzania Zambia

Asia Pacific

Bangladesh Cambodia China Fiji India Indonesia Malaysia

Myanmar Nepal Niger Pakistan Papa New Guinea Philippines

 Sri Lanka Thailand

Caribbean

Dominican Republic Haiti Jamaica Trinidad

Latin America

Argentina Brazil Colombia Ecuador El Salvador Guyana Honduras Mexico

Panama Paraguay

Middle East and North Africa

 Egypt Iran Jordan Lebanon Somaliland Sudan Tunisia

"WHEN IT COMES TO CRYING, SHOUTING, SPEAKING OUT AGAINST STIGMA – I HAVE DONE IT. BUT I HAVE BEEN STRUGGLING WITH THE EVIDENCE TO QUANTIFY IT. AS A RESEARCHER AND AS AN ADVOCATE I NOW HAVE THE MISSING LINK."
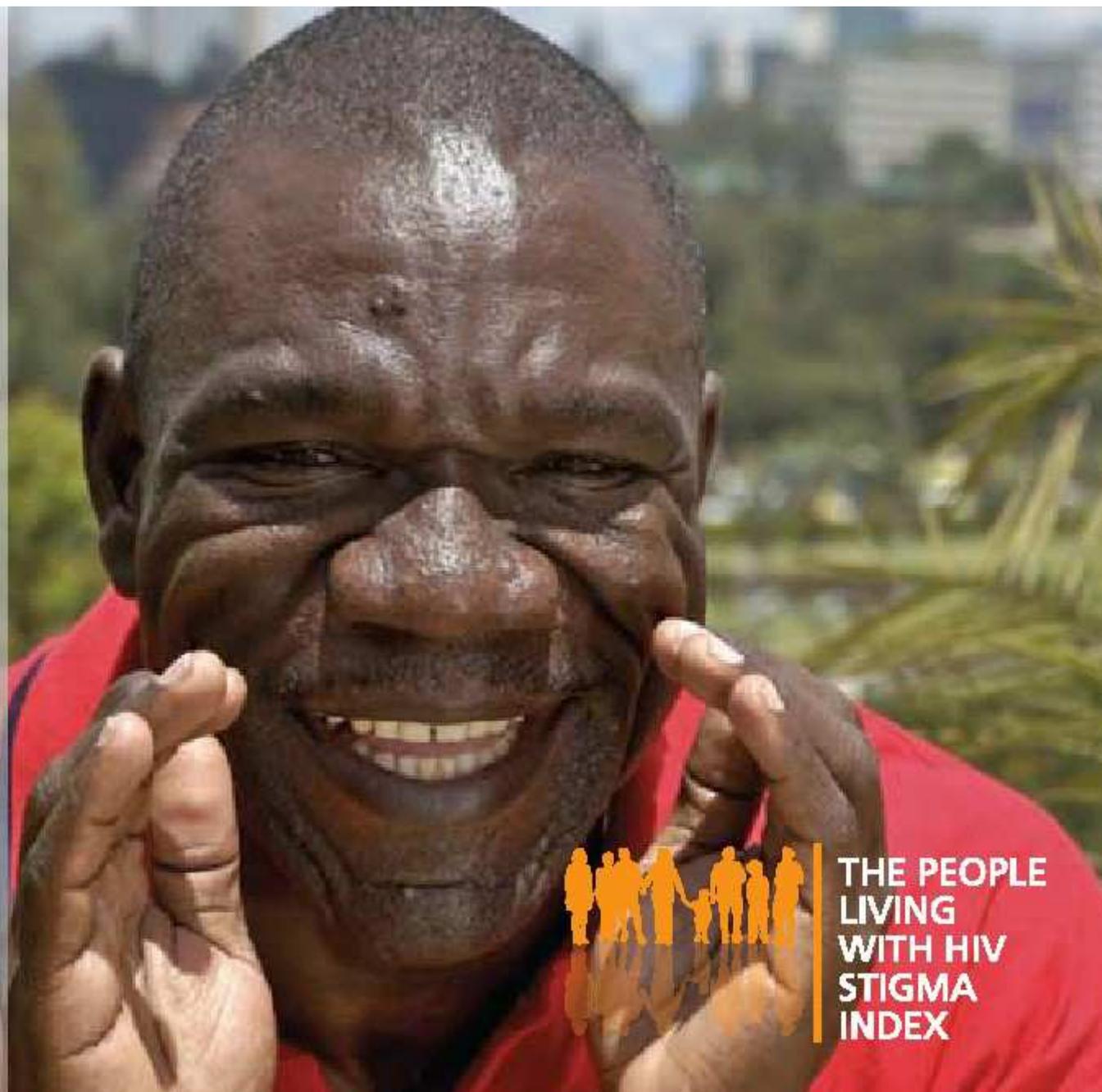
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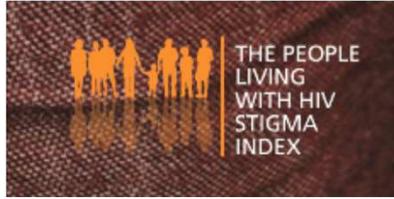
Finally : the Impact of the INDEX

1. **Evidence to improve policies** and ensure that policies are grounded in the realities of living with HIV. The findings from the Index will be used to promote the human rights of people living with HIV and advocate for policy change on key issues including the criminalization of HIV transmission

2. **Improved programmes influenced by the perspectives of people living with HIV** to better meet the needs of people living with HIV and increased access to, and uptake of, services

3. **Models best practice for the greater involvement of people living with HIV (GIPA)** by putting people living with HIV at the centre of the process and ensuring that it remains by and for people living with HIV throughout all stages of implementation

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thanks – and I hope your baptism into the tool has been a pleasant one

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