

The People Living With HIV Stigma Index: South Africa 2014

A Cloete¹, Leickness Simbayi¹, K Zuma¹, S Jooste¹, S Blose¹,
S Zimela¹, N Mathabathe², D Pelisa³, & The South Africa PLHIV
HIV Stigma Index Survey Group¹

¹Human Sciences Research Council, South Africa, ²UNAIDS,
³Eastern Cape AIDS Council





THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX

“Being interviewed by another person living with HIV does make a difference – as you feel they really would understand more about how you feel about things related to being HIV positive.”

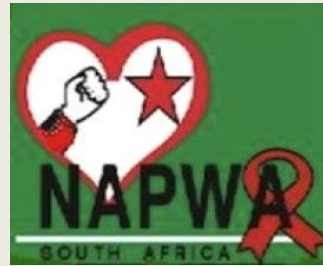
RESEARCHER, PILOT WORKSHOP, SOUTH AFRICA

THIS IS THE PEOPLE LIVING WITH HIV STIGMA INDEX.

IT IS AN INITIATIVE THAT HAS BEEN DEVELOPED AND IMPLEMENTED BY AND FOR PEOPLE LIVING WITH HIV.

IT AIMS TO COLLECT INFORMATION ABOUT THE EXPERIENCES OF PEOPLE LIVING WITH HIV RELATED TO STIGMA, DISCRIMINATION AND HUMAN RIGHTS.

Collaborators



Funders



Introduction

- **The People Living with HIV Stigma Index is a joint initiative of several organisations including:**
 - GNP+
 - International Community of Women Living with HIV
 - IPPF and
 - UNAIDS who have worked together since 2005 to develop this survey.
- **The Stigma Index collects information on HIV-related stigma and discrimination and the rights of PLHIV to help with advocacy efforts.**
- **To date over 50 countries from all parts of the world have undertaken national surveys using the PLHIV Stigma Index and our research team undertook the first national survey in South Africa during the last 4 months of 2014.**
- **We also examined TB-related stigma and discrimination.**



Methods: Design and Implementation

- A cross-sectional questionnaire-based survey in which PLHIV were interviewed by other PLHIV.
- A purposive sample of over 10 000 PLHIV:
 - Linked to an organisation for PLHIV (i.e. support group) or
 - Attending health facilities and NGOs for the purposes of accessing support or care related to HIV from 18 districts, one National Health Insurance (NHI) pilot district per each province and a second adjacent one in each province, were interviewed.

Methods : Design and Implementation

PROVINCE	DISTRICT	DISTRICT
Eastern Cape	OR Tambo	Buffalo City
Mpumalanga,	Gert Sibande	Ehlanzeni
Limpopo	Vhembe	Waterberg
Northern Cape	Pixley ka Seme	John Taolo Gaetsewe
Kwa-Zulu Natal	uMgungundlovu	Umkhanyakude
Western Cape	Eden	Cape Town
North West	Dr K Kaunda	Ngaka Modiri Molema
Free State	Thabo Mofutsanyane	Mangaung
Gauteng	Tshwane	Sedibeng

Methods: Data analysis

- All items in various modules were first scored individually
- Afterwards, composite scores were calculated using scales (all Cronbach alpha (α) coefficient of reliability or consistency ≥ 0.78) consisting of various items (number as shown in brackets) to obtain overall measures as follows:
 - Scale 1: Overall experience of external stigma (4 items, $\alpha = 0.786$)
 - Scale 2: Self-stigma (7 items, $\alpha = 0.871$)
 - Scale 3: Avoidance behaviour due to internalised stigma (9 items, $\alpha = 0.787$)
 - Scale 4: Fear of being stigmatised (5 items; $\alpha = 0.827$)



RESULTS



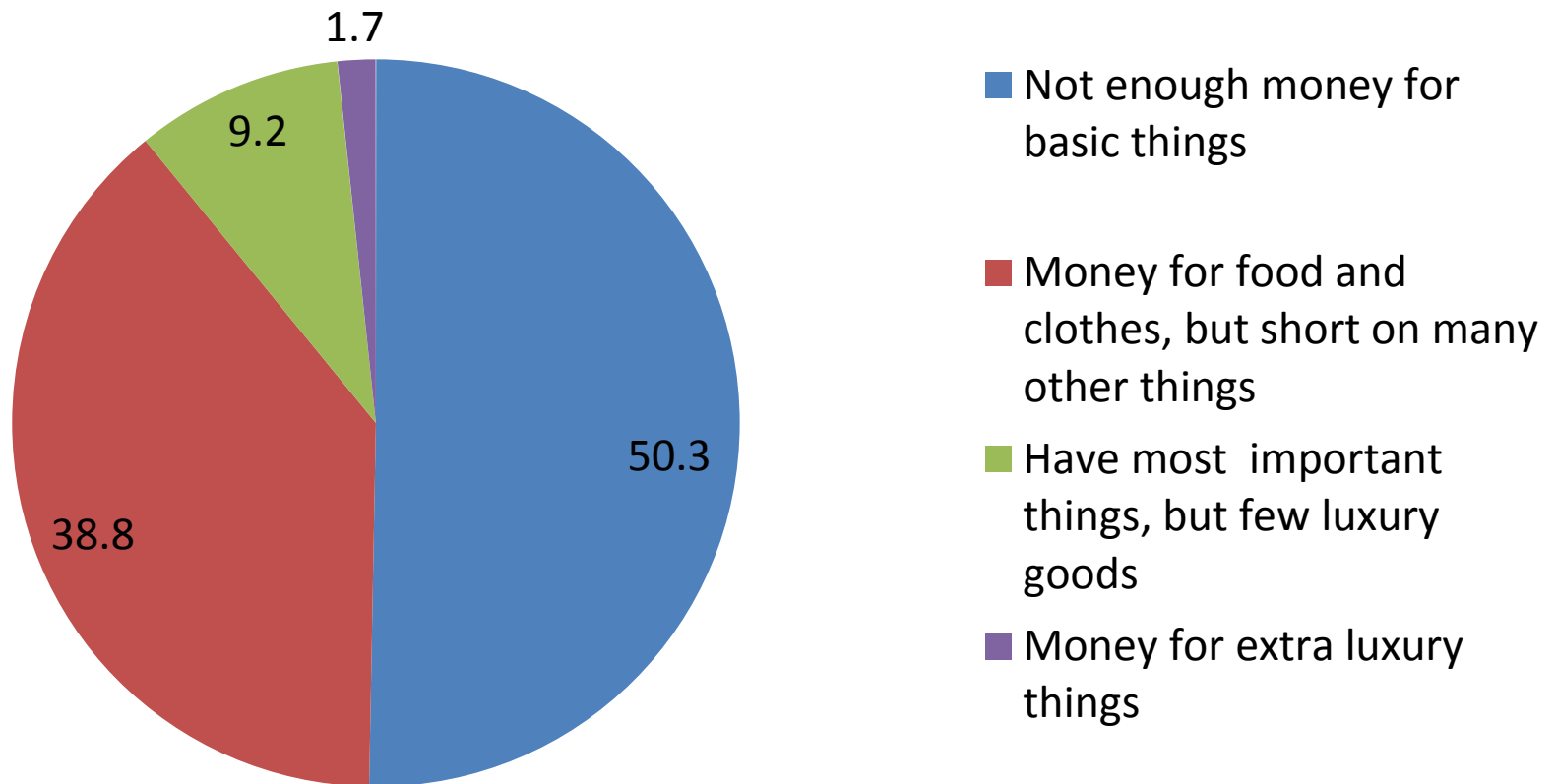
Demographic characteristics

- 10 473 PLHIV aged 15 years and older
- Mean age - 36 years
- The majority (65.4%) were female
- The majority (70%) were either married or in a relationship
- The large majority (88%) completed secondary or tertiary education
- 5.8% of respondents were disabled and 7.5% from Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) groups

Province and locality type

Province	A rural area		Small town or village		A large town or city		Total
	n	%	n	%	N	%	n
Western Cape	14	1.5	325	33.8	623	64.8	962
Eastern Cape	431	40.1	110	10.2	535	49.7	1 076
Northern Cape	194	20.7	737	78.7	6	0.6	937
Free State	179	13.8	947	73.2	168	13.0	1 294
KwaZulu-Natal	783	56.5	587	42.4	16	1.2	1 386
North West	284	39.4	120	16.6	317	44.0	721
Gauteng	93	7.2	854	65.8	351	27.0	1 298
Mpumalanga	730	56.1	506	38.9	65	5.0	1 301
Limpopo	491	38.6	776	61.0	6	0.5	1 273
Total	3199	31.2	4962	48.4	2087	20.4	10 248

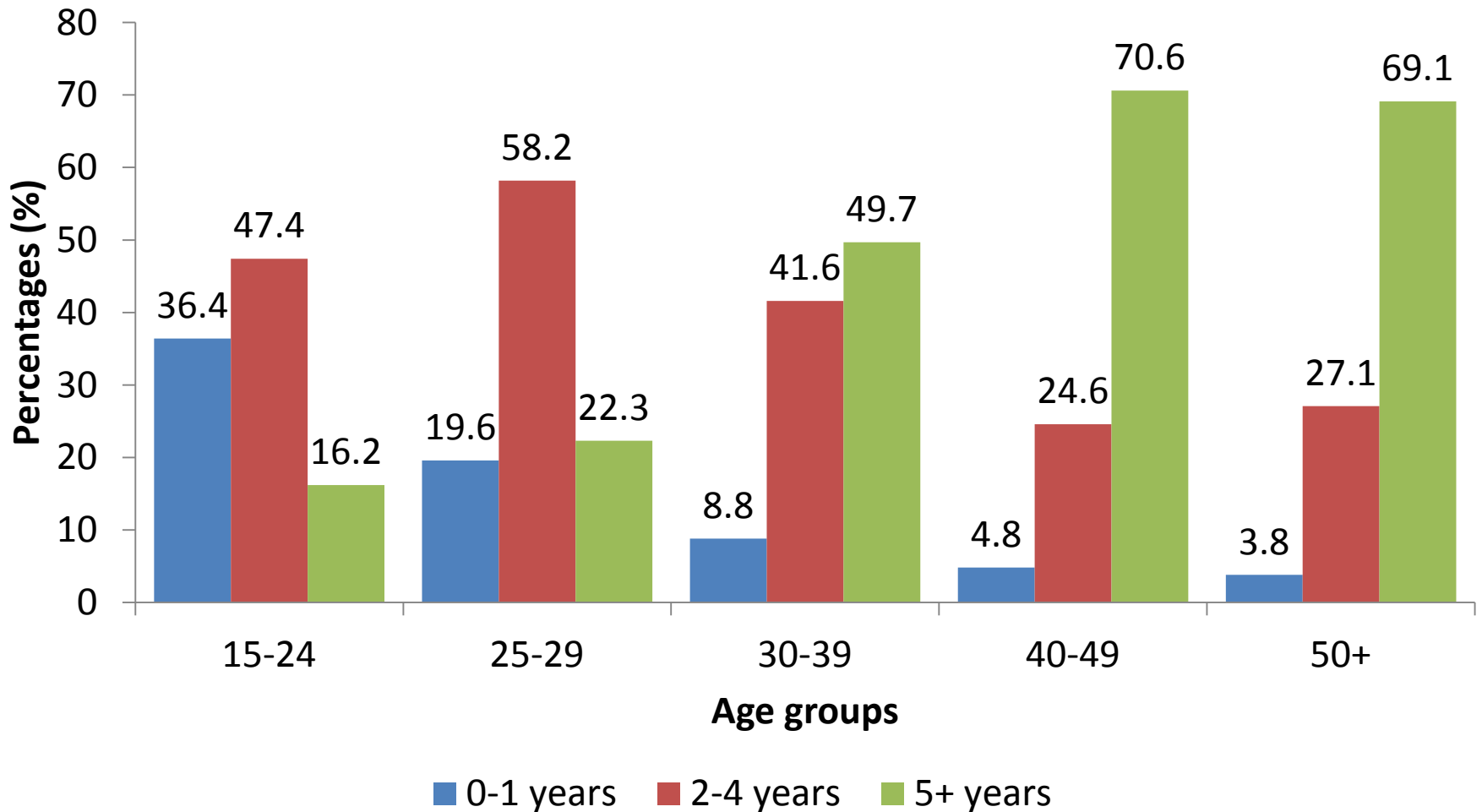
Economic situation in households of respondents in the survey




Employment

- 61% reported having no form of employment and that they were not looking for work
- 8% reported that they were currently a student
- 32% reported that they were either full-time or part-time employed

Years living with a HIV diagnosis by age





**EXPERIENCES OF STIGMA
AND DISCRIMINATION FROM
OTHER PEOPLE
(External Stigma)**



EXPERIENCES OF STIGMA AND DISCRIMINATION FROM OTHER PEOPLE

Type of social activity excluded from

- Social gatherings
- Family activities
- Workplace activities
- Religious activities
- School/university activities

Perceived reason for exclusion

- Because of your HIV status
- Other reason(s)
- Both because of your HIV status and other reason(s)
- Not sure why

Excluded from social gatherings (Individual items)

Social situation excluded from	n	%
Social gatherings (n = 1 011)		
Because of your HIV status	440	43.5
Other reason(s)	237	23.4
Both because of your HIV status and other reason(s)	265	26.2
Not sure why	69	6.8

Excluded from family activities (Individual items)

Family activities (n = 801)	n	%
Because of your HIV status	353	44.1
Other reason(s)	190	23.7
Both because of your HIV status and other reason(s)	217	27.1
Not sure why	41	5.1

Experiences of being gossiped about, verbal assaults and physical harassments (individual items)

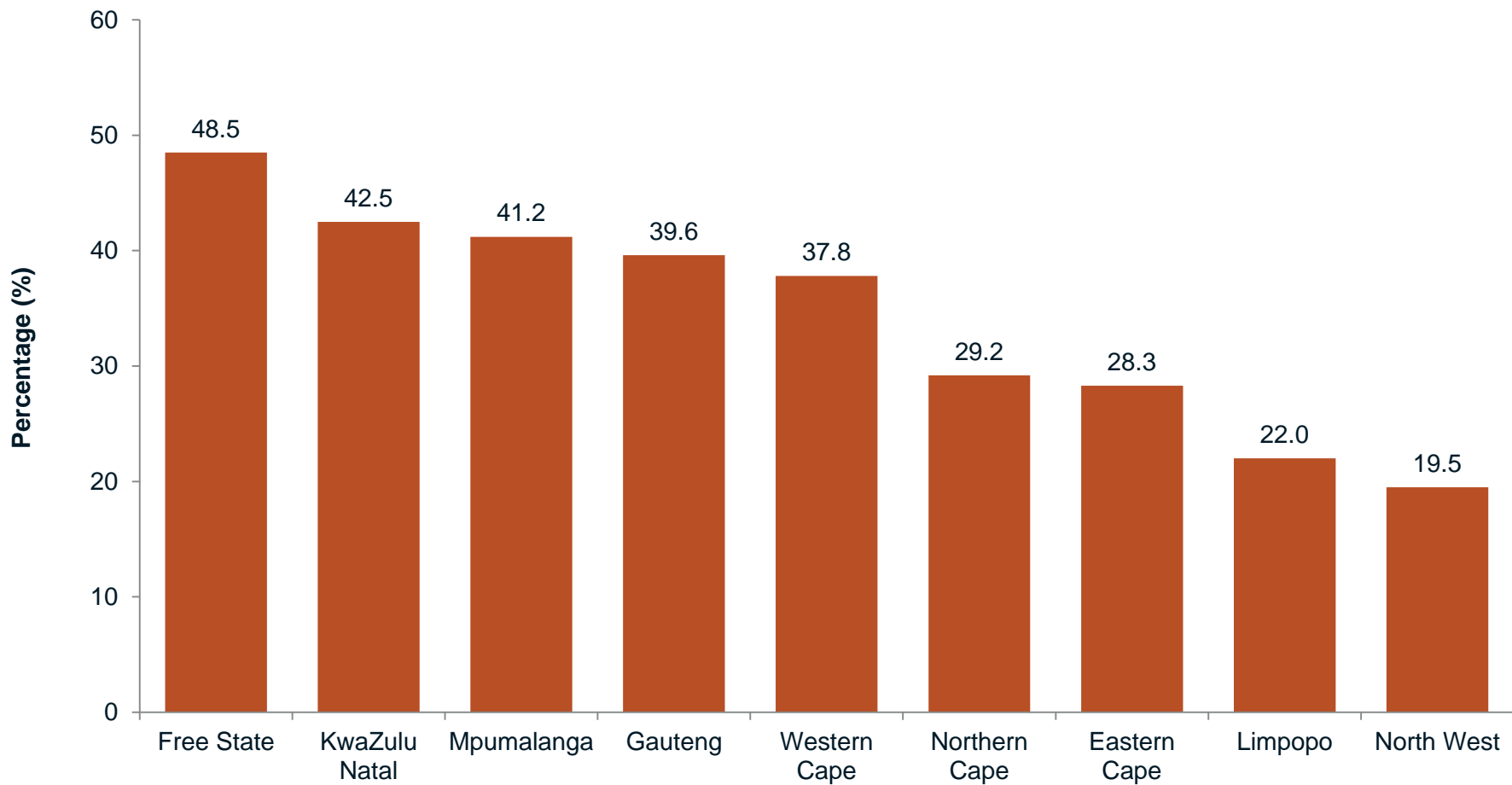
Experienced the following (once/few times/often) in the last 12 months	%
Being gossiped about	21
Experienced discrimination	21
Being verbally insulted and harassed	15
Excluded from social gatherings	10
Excluded from family activities	9
Being physically harassed and/or threatened	8



Overall prevalence of external stigma

- Overall, it was found that over one-third of the respondents (35.5%) experienced some external stigma

Overall prevalence of external stigma





Access to work and health and educational services

Access to work and health and educational services

Experienced the following (once/few times/often) in the last 12 months	%
Lost a job	11
Refused employment	8
Denied sexual and reproductive health services	5
Denied health care services	3
Dismissed, suspended or prevented from attending educational institution	1



INTERNALISED STIGMA

Internalised stigma

Ever experienced the following feelings in the last 12 months	%
Blamed myself	30
Felt ashamed	28
Felt guilty	22
Low self-esteem	22
Blamed others	19
Felt I should be punished	11
Felt suicidal	11

Overall prevalence of internalised stigma

- 43% of the respondents reported that they had had some experiences of feeling internalised stigma

Overall feelings of internalised stigma

Socio-demographic characteristic	No feelings of internalised stigma	Some feelings of internalised stigma	p
	%	%	
Total	57.0	43.0	
Sex of respondent			0.110
Male	58.0	42.0	
Female	56.4	43.6	
Age groups (years)			0.000
15-24	46.5	53.5	
25-49	57.9	42.1	
50+	60.0	40.0	
Length of time living with HIV			0.000
0-1 year	45.2	54.8	
2-4 years	56.1	43.9	
5+ years	60.5	39.5	
Relationship status			0.000
Married or cohabiting with partner in household	62.0	38.0	
Married or cohabiting but partner temporarily not in household	48.4	51.6	
In a relationship but not living together	57.0	43.0	
Single	55.8	44.2	
Divorced or separated	49.0	51.0	
Widow or widower	53.9	46.1	
Educational level			0.000
No formal education	50.4	49.6	
Primary school	58.0	42.0	
Secondary school	57.9	42.1	
Technical college/university	52.1	47.9	

Overall feelings of internalised stigma

	No feelings of internalised stigma	Some feelings of internalised stigma	
Socio-demographic characteristic	%	%	p
Total	57.0	43.0	
Locality type			0.000
A rural area	54.6	45.4	
A small town or village	56.7	43.3	
A large town or city	61.9	38.1	
Times gone without food			0.000
Often	46.5	53.5	
Sometimes	57.5	42.5	
Rarely	56.9	43.1	
Never	59.4	40.6	
Employment status			0.615
Employed	57.4	42.6	
Currently not working	56.9	43.1	



DISCLOSURE AND CONFIDENTIALITY

Disclosure and confidentiality

Group of people concerned	% Told them
Husband/wife/partner	89
Other adult family members	85
Children in family	68
Friends/neighbours	66
Co-workers	54
Employer(s)/boss(es)	49
Health care workers	49
Religious leaders	44
Teachers	30
Community leaders	25



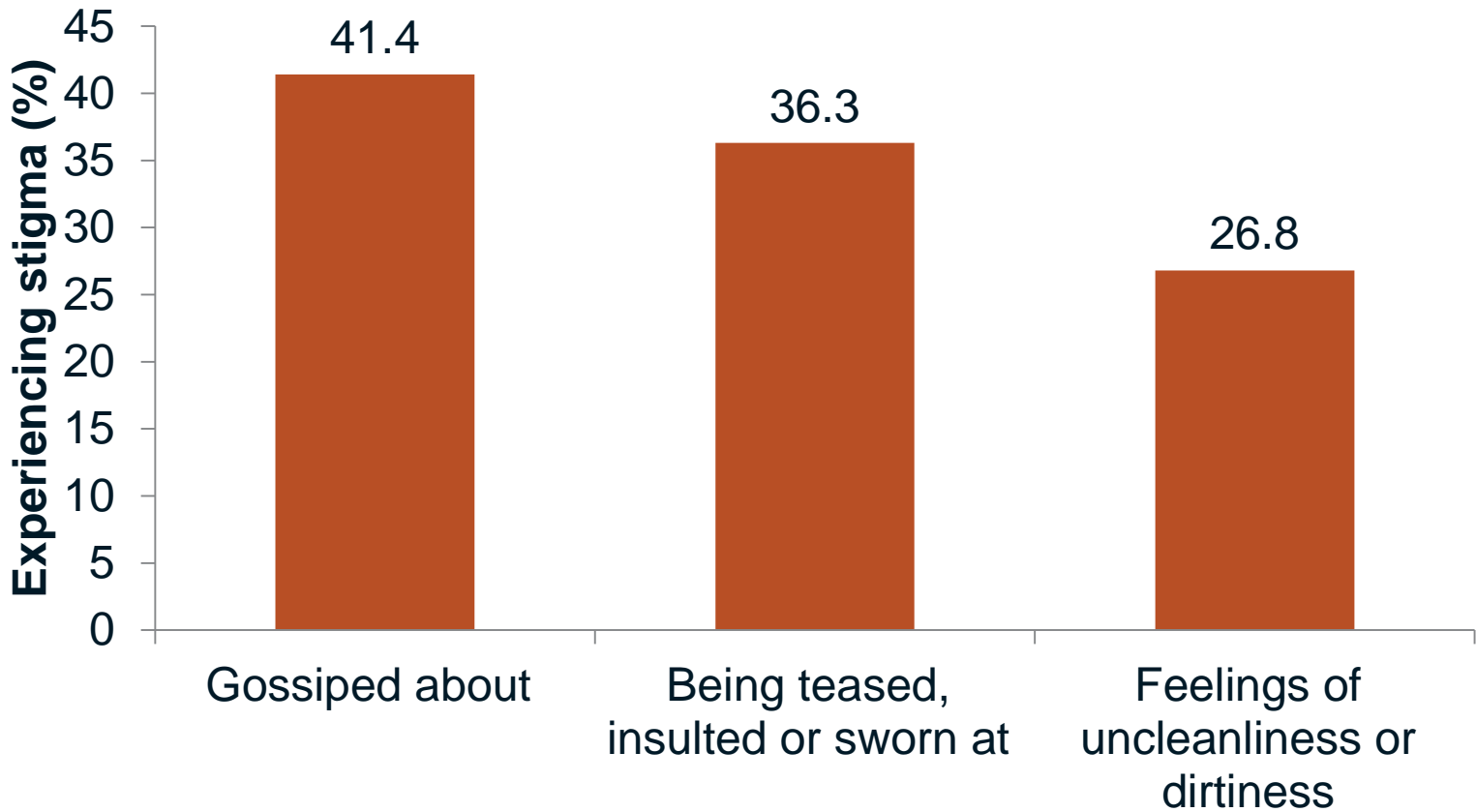
Disclosure of HIV status to other people without their consent by a health care professional

- 73% of the respondents indicated that their status was **not** disclosed without their consent
- 65% expressed confidence that their medical records **will be kept** completely confidential
- 5% indicated that it was clear to them that their medical records were not being kept confidential



TB-RELATED STIGMA

TB-related stigma





Recommendations

- The following recommendations were made to SANAC
 - There is an urgent need to develop and implement a national stigma mitigation campaign led by SANAC to address internal and external stigma.
 - Particular emphasis should be placed on addressing internalised stigma on an individual level among PLHIV, where existing support group structures should be utilised and invigorated to implement psychosocial support for PLHIV.
 - There is a need for on-going monitoring and evaluation (M&E) of HIV stigma and discrimination issues at all levels by SANAC.



CONCLUSIONS

Conclusions (1)

- This study found evidence of great strides made with regards to combating stigma and discrimination as experienced by PLHIV especially in the health care sector as only a very small proportion in the present study reported having experienced discrimination because of their HIV-positive status.
- Nevertheless, there is still some evidence of stigma and discrimination against PLHIV having been experienced in the health care sector.

Conclusions (2)

- South Africa has made good progress in dealing with HIV related stigma and the levels of stigma are relatively low when analysing instances of stigma independently of each other.
- When composite scores of external and internal scores are analysed the data shows that there is still a moderate level of stigma affecting about one-third of PLHIV who took part in the study.
- Of concern is the level of internalised stigma found in this study, which is probably a consequence of the lack of adequate psychosocial support that is currently available for PLHIV to address the psychological consequence of receiving an HIV-positive diagnosis including associated mental health issues.

Conclusions (3)

- Stigma is a complex social process dependent on specific cultural contexts (Maughan-Brown; 2006; Parker & Aggleton, 2003).

Thank you for your attention

