Community Responses

Get email updates
for latest news and information

☐ Positive Living
☐ NAPWHA news
☐ Media digest

name:
email address:

Latest tweet

napwha NSW testing success: Details here: http://t.co/t0MW55lgp1 http://t.co/uz0pFEykfq.

Posted by @napwha 23 Sep 2015

napwha national association of people with HIV australia

POZ ACTION

Overview

- NAPWHA
- Social Determinants Of Health
- Community Responses Explored
- Community Responses In Australia
- What happens next

National Association of People with HIV Australia

is the Australian national HIV peer-based organisation

Our vision

A world where people with HIV live their lives to their full potential, in good health and free from discrimination.

Our mission

To provide national advocacy, leadership and representation across the diverse needs of all people living with HIV in Australia

Our principles

The embracement of the values of compassion, integrity and respect in all activities to build consensus, partnerships and coalitions.

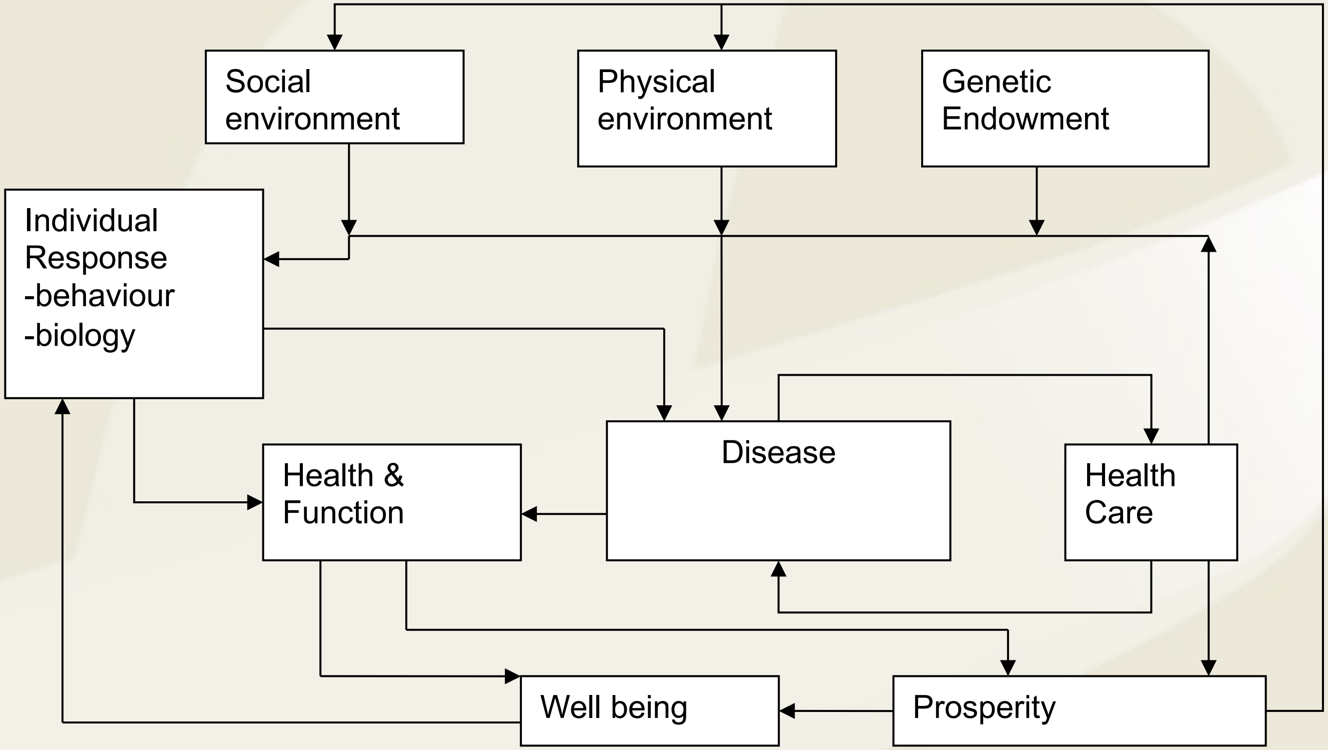
The promotion of the meaningful involvement, visibility and centrality of people living with HIV and utilising the diverse experiences of all people living with HIV to advocate for them in order to reduce the impact of the disease.

The strengthening of the national response to the HIV epidemic by ensuring the meaningful involvement of all people living with HIV and to play an active role in realising a partnership approach in all aspects of our response.

A commitment to the principles of the *Ottawa Charter*, the *Meaningful Involvement of PLHIV (MIPA)* and its own *Declaration of Rights for People Living with HIV/AIDS*.

napwha national association of people with HIV australia

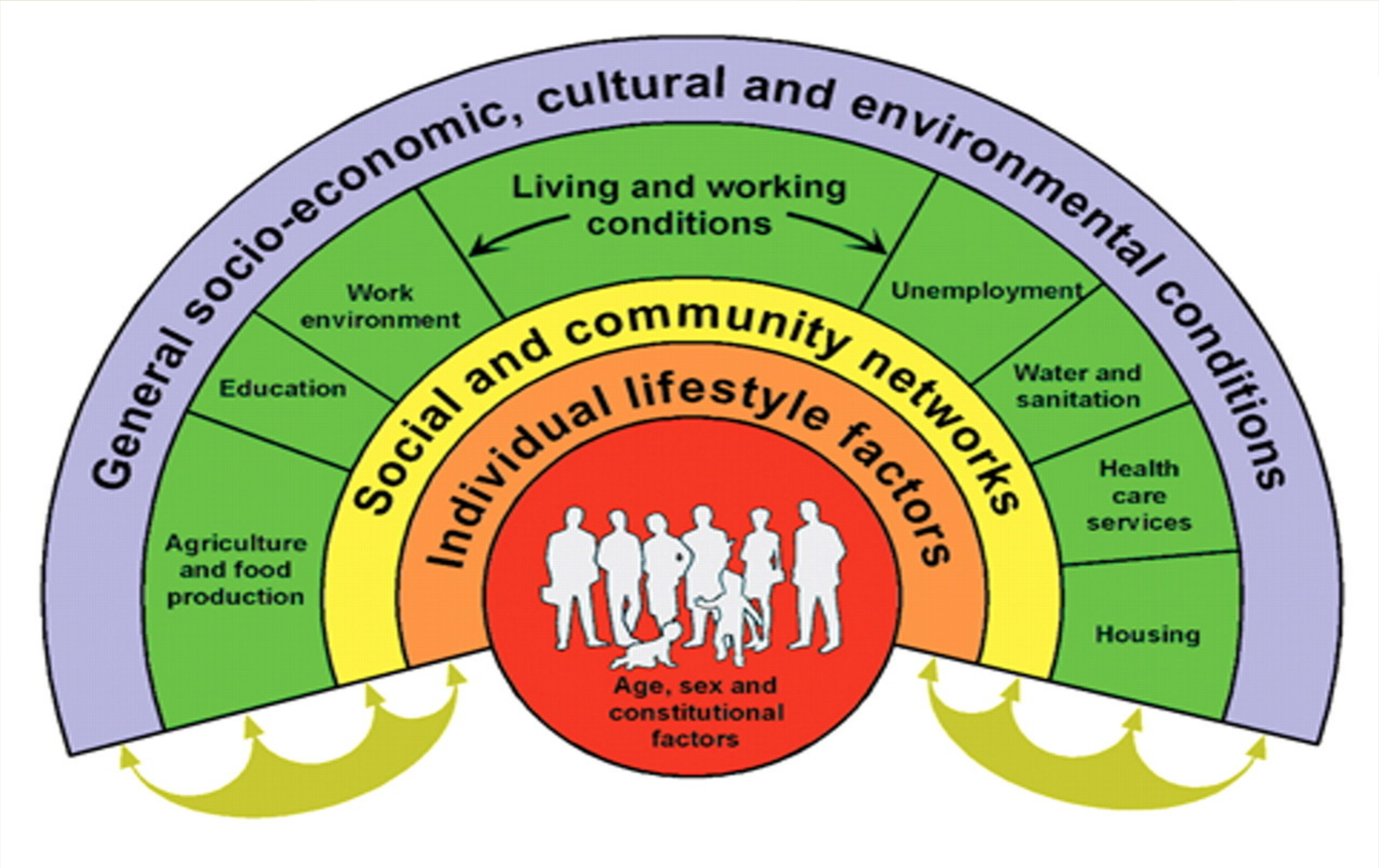
Determinants Of Health



Evans, RG & Stoddart, GL 1994, 'Producing Health, Consuming Health Care', in RG Evans, ML Barer & TR Marmor. de Gruyter (eds.), *Why are some people healthy and others not?*, New York, pp. 27-64.

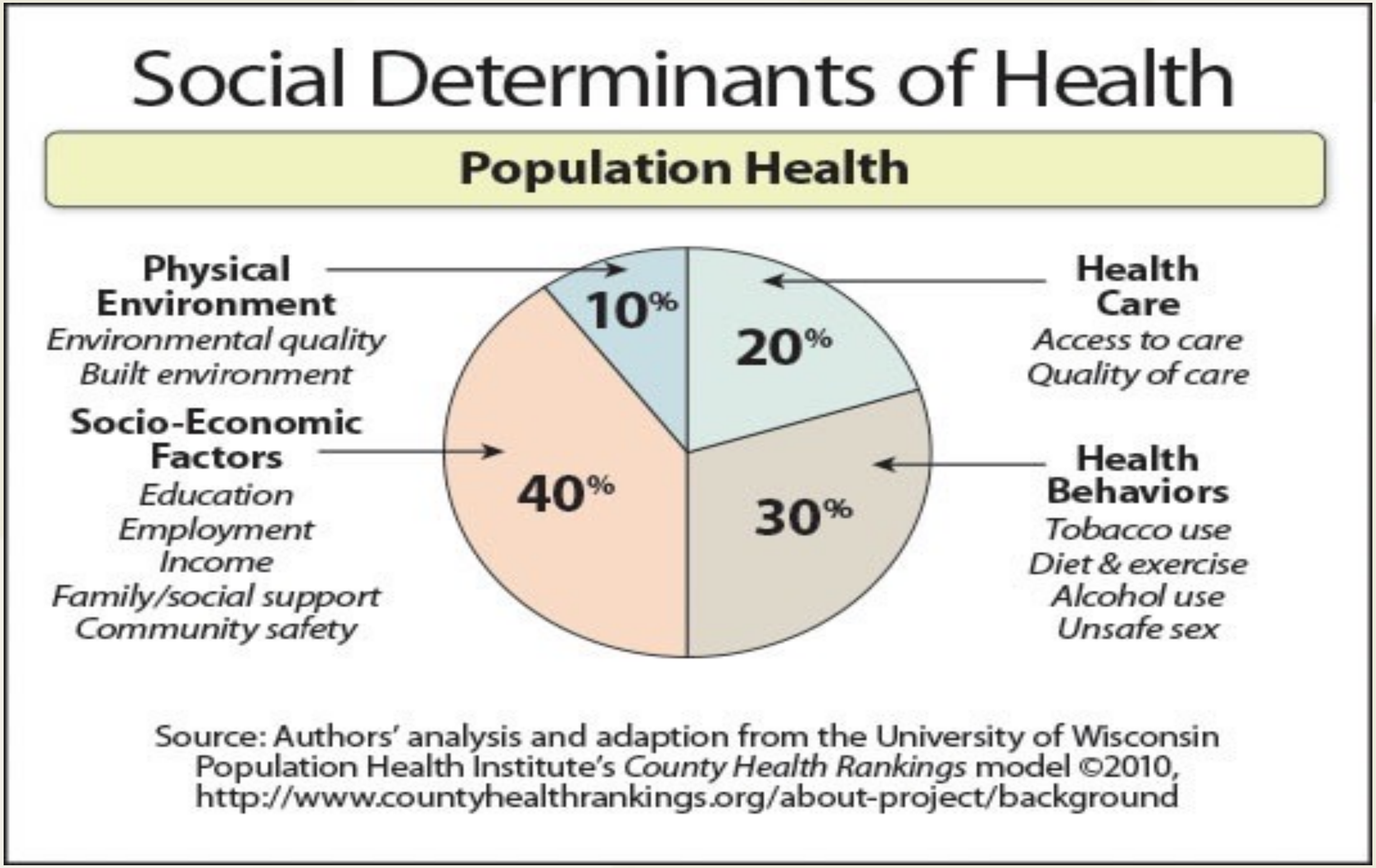
napwha national association of people with HIV australia

Social Determinants Of Health



napwha national association of people with HIV australia

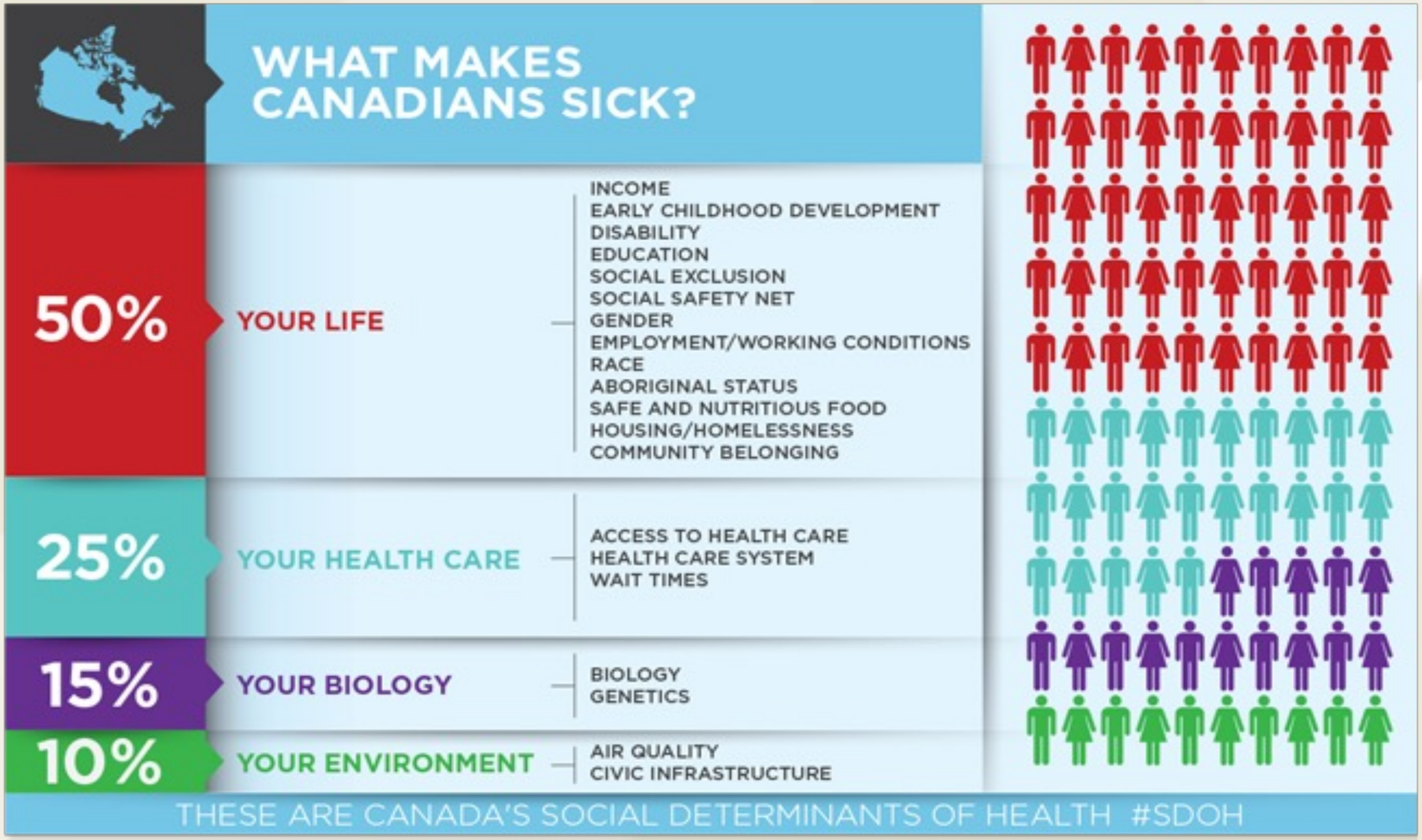
Are Determinants Of Health Equal



Social Determinants of Health

Source: Authors' analysis and adaption from the University of Wisconsin Population Health Institute's *County Health Rankings* model ©2010, http://www.countyhealthrankings.org/about-project/background

A Country Perspective



WHAT MAKES CANADIANS SICK?

50%	**YOUR LIFE**	INCOME EARLY CHILDHOOD DEVELOPMENT DISABILITY EDUCATION SOCIAL EXCLUSION SOCIAL SAFETY NET GENDER EMPLOYMENT/WORKING CONDITIONS RACE ABORIGINAL STATUS SAFE AND NUTRITIOUS FOOD HOUSING/HOMELESSNESS COMMUNITY BELONGING
25%	**YOUR HEALTH CARE**	ACCESS TO HEALTH CARE HEALTH CARE SYSTEM WAIT TIMES
15%	**YOUR BIOLOGY**	BIOLOGY GENETICS
10%	**YOUR ENVIRONMENT**	AIR QUALITY CIVIC INFRASTRUCTURE

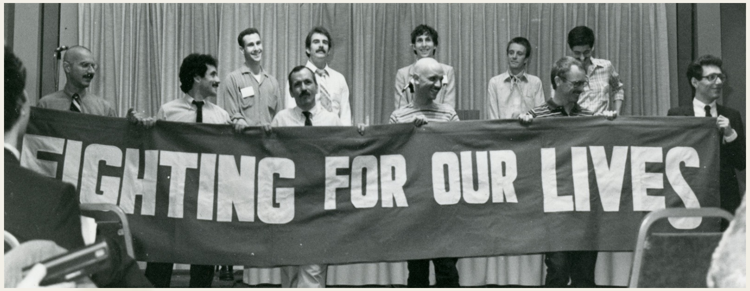
THESE ARE CANADA'S SOCIAL DETERMINANTS OF HEALTH #SDOH

Community Involvement- Denver Principles – 1983
When PLWHIV Demanded a place at the table

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others.
We are "People With AIDS."

RECOMMENDATIONS FOR PEOPLE WITH AIDS

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

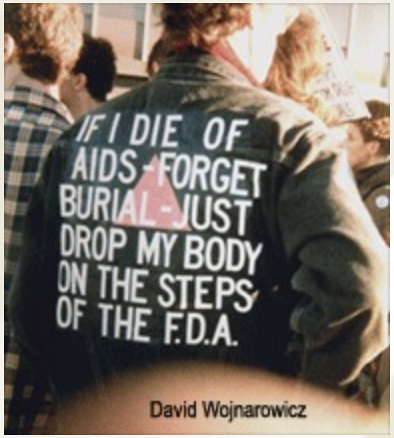


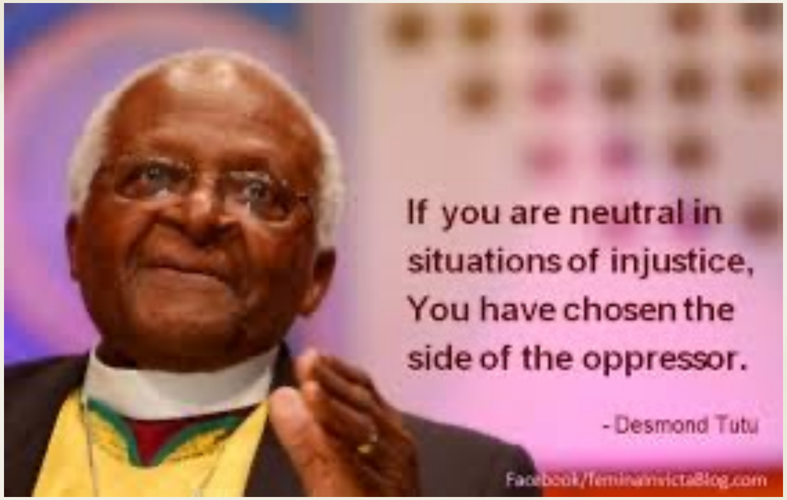
RIGHTS OF PEOPLE WITH AIDS

1. To as full and satisfying sexual and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
5. To die – and to LIVE – in dignity.

Denver 1983

AIDS Coalition To Unleash Power -1987





If you are neutral in situations of injustice, You have chosen the side of the oppressor.

- Desmond Tutu

Facebook/FeminaInvictaBlog.com

If you're not at the table, you're on the menu.

napwha national association of people with HIV australia

What Is GIPA? – Greater Involvement of People Living With HIV/AIDS

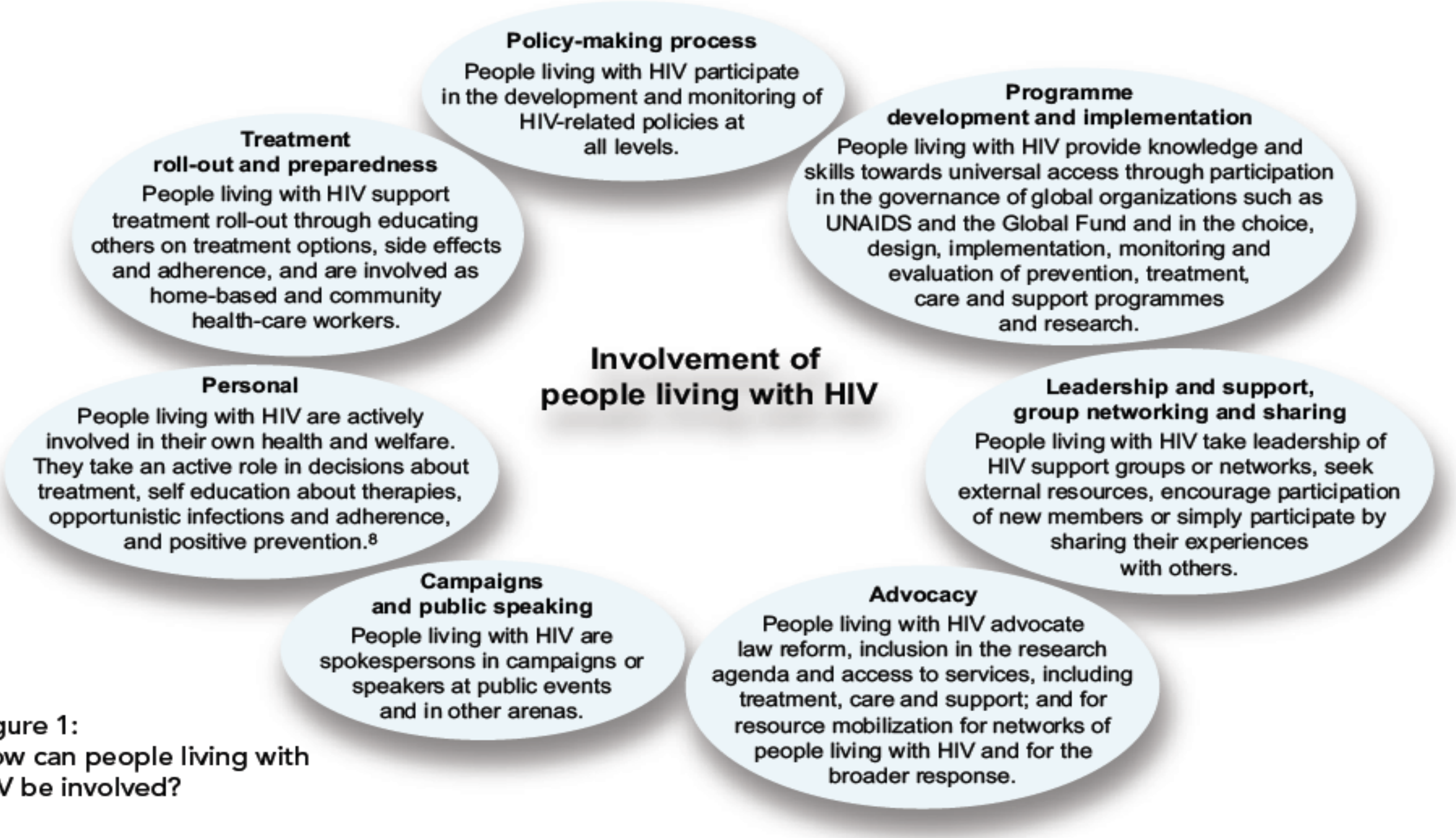
GIPA is not a project or programme. It is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives.

In these efforts, GIPA also aims to enhance the quality and effectiveness of the AIDS response.

The idea that personal experiences should shape the AIDS response was first voiced by people living with HIV in Denver in 1983.5

The GIPA Principle was formalized at the 1994 Paris AIDS Summit when 42 countries agreed to "support a greater involvement of people living with HIV at all…levels…and to…stimulate the creation of supportive political, legal and social environments"6.

GIPA Is About "Meaningful Involvement" Not Tokenistic Participation



Involvement of people living with HIV

Policy-making process
People living with HIV participate in the development and monitoring of HIV-related policies at all levels.

Programme development and implementation
People living with HIV provide knowledge and skills towards universal access through participation in the governance of global organizations such as UNAIDS and the Global Fund and in the choice, design, implementation, monitoring and evaluation of prevention, treatment, care and support programmes and research.

Leadership and support, group networking and sharing
People living with HIV take leadership of HIV support groups or networks, seek external resources, encourage participation of new members or simply participate by sharing their experiences with others.

Advocacy
People living with HIV advocate law reform, inclusion in the research agenda and access to services, including treatment, care and support; and for resource mobilization for networks of people living with HIV and for the broader response.

Campaigns and public speaking
People living with HIV are spokespersons in campaigns or speakers at public events and in other arenas.

Personal
People living with HIV are actively involved in their own health and welfare. They take an active role in decisions about treatment, self education about therapies, opportunistic infections and adherence, and positive prevention.[8]

Treatment roll-out and preparedness
People living with HIV support treatment roll-out through educating others on treatment options, side effects and adherence, and are involved as home-based and community health-care workers.

Figure 1:
How can people living with HIV be involved?

UNAIDS

POLICY BRIEF

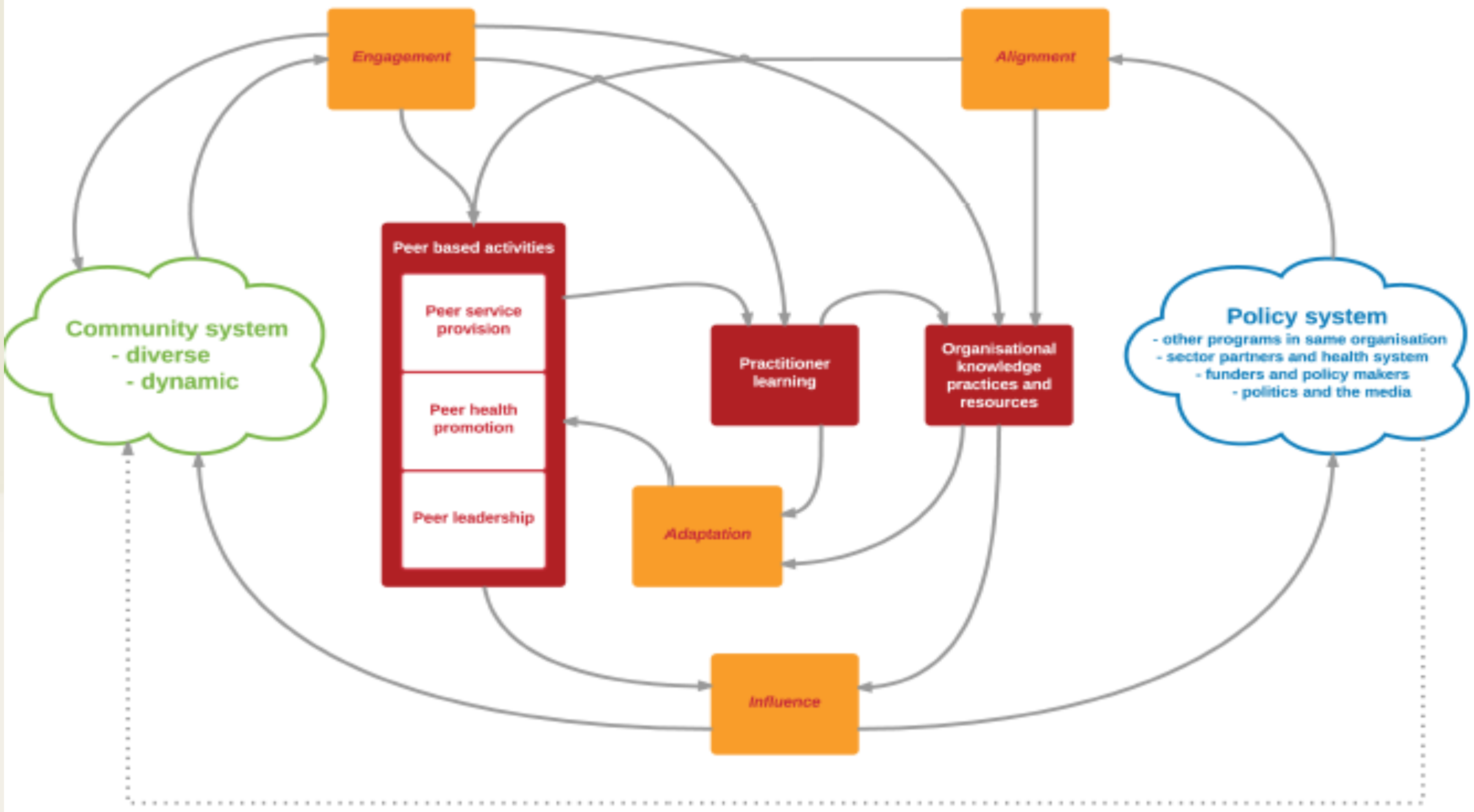
The Greater Involvement of People Living with HIV (GIPA)

napwha national association of people with HIV australia

The W3 Framework – What Works & Why

Four key functions for effective and sustainable peer based programs

Arrows represent regular flows of knowledge or influence that constitute the program as a system



Engagement

Alignment

Community system
- diverse
- dynamic

Peer based activities

Peer service provision

Peer health promotion

Peer leadership

Practitioner learning

Organisational knowledge practices and resources

Policy system
- other programs in same organisation
- sector partners and health system
- funders and policy makers
- politics and the media

Adaptation

Influence

Australian Research Centre in Sex, Health and Society

Positive leadership and policy advocacy

FINDINGS FROM THE WHAT WORKS AND WHY PROJECT

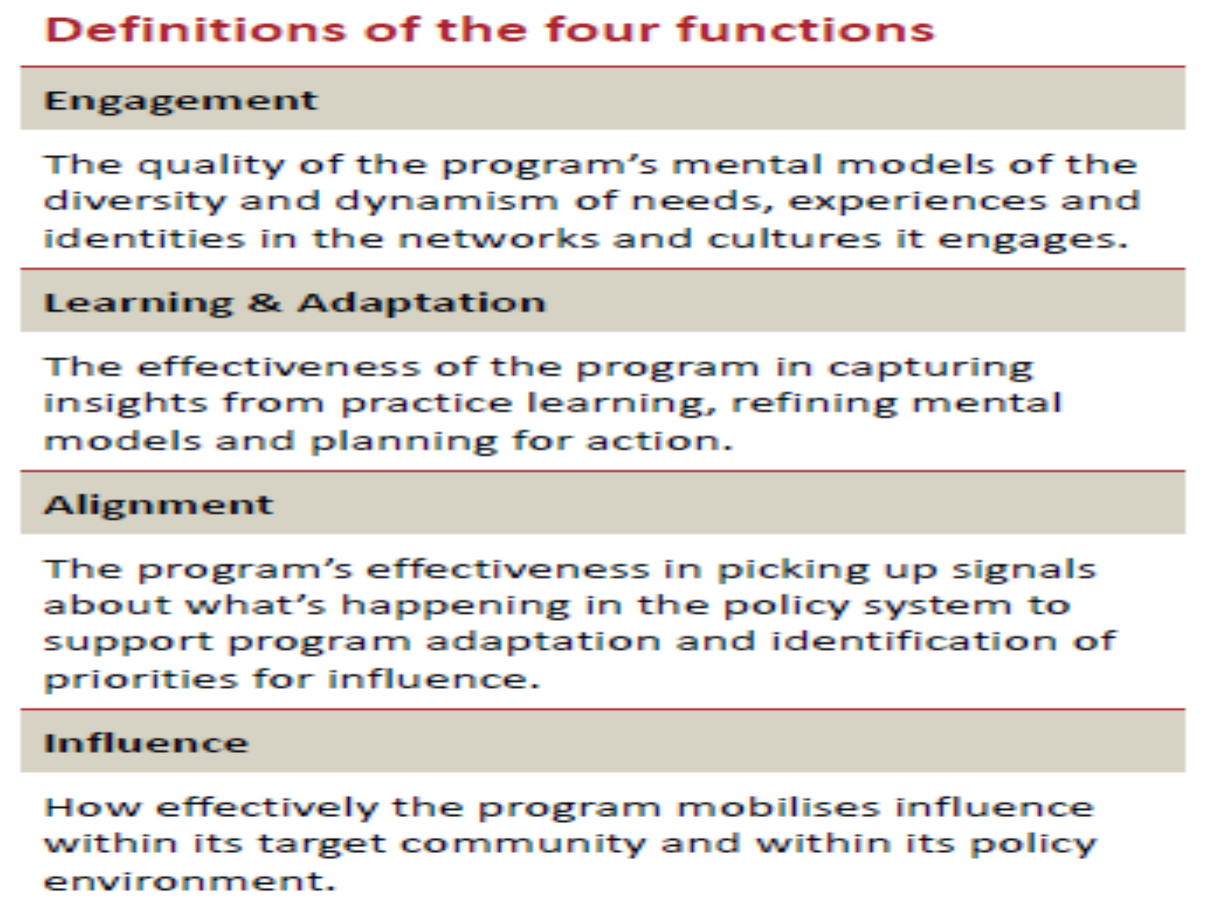
Authors

Graham Brown[1], Daniel Reeders[1] and Aaron Cogle[2]

[1] Australian Research Centre in Sex, Health and Society [2] National Association of People Living with HIV Australia

napwha national association of people with HIV australia

The W3 Framework – What Works & Why



Definitions of the four functions

Engagement

The quality of the program's mental models of the diversity and dynamism of needs, experiences and identities in the networks and cultures it engages.

Learning & Adaptation

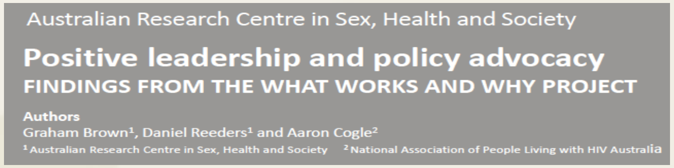
The effectiveness of the program in capturing insights from practice learning, refining mental models and planning for action.

Alignment

The program's effectiveness in picking up signals about what's happening in the policy system to support program adaptation and identification of priorities for influence.

Influence

How effectively the program mobilises influence within its target community and within its policy environment.



Australian Research Centre in Sex, Health and Society

Positive leadership and policy advocacy

FINDINGS FROM THE WHAT WORKS AND WHY PROJECT

Authors

Graham Brown[1], Daniel Reeders[1] and Aaron Cogle[2]

[1] Australian Research Centre in Sex, Health and Society [2] National Association of People Living with HIV Australia

napwha national association of people with HIV australia

Are We Working Together?

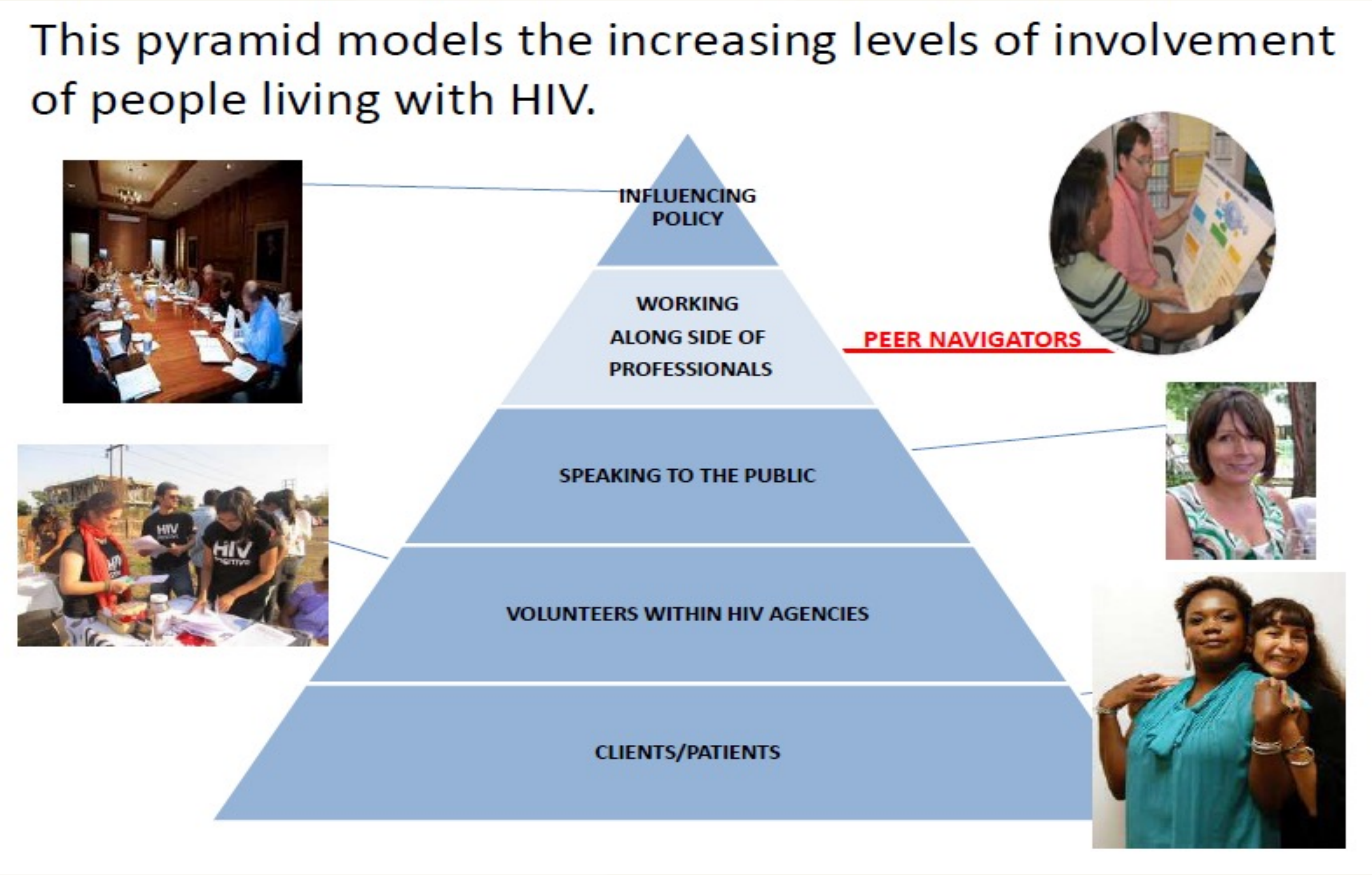
We will look after you

Nothing about us without us

I know what's best for me

napwha national association of people with HIV australia

Greater Involvement of People Living With HIV/AIDS



This pyramid models the increasing levels of involvement of people living with HIV.

INFLUENCING POLICY

WORKING ALONG SIDE OF PROFESSIONALS

PEER NAVIGATORS

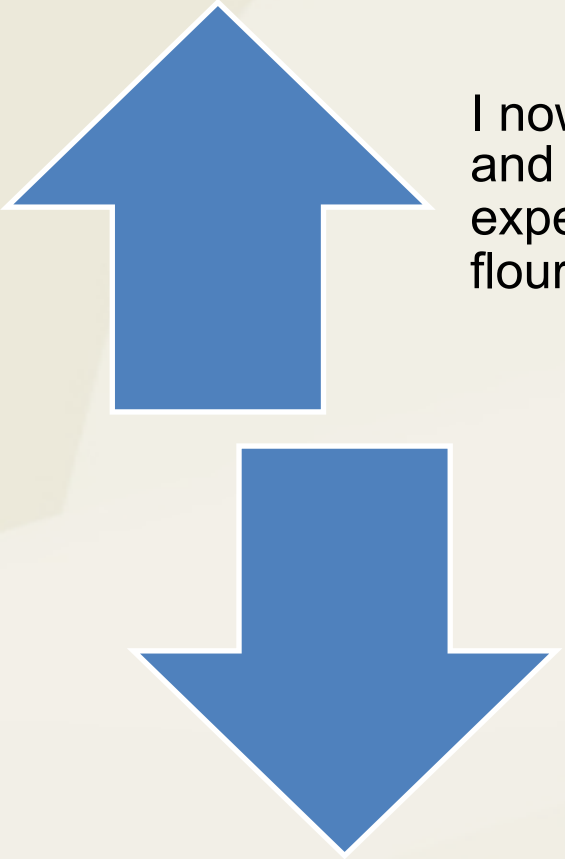
SPEAKING TO THE PUBLIC

VOLUNTEERS WITHIN HIV AGENCIES

CLIENTS/PATIENTS

napwha national association of people with HIV australia

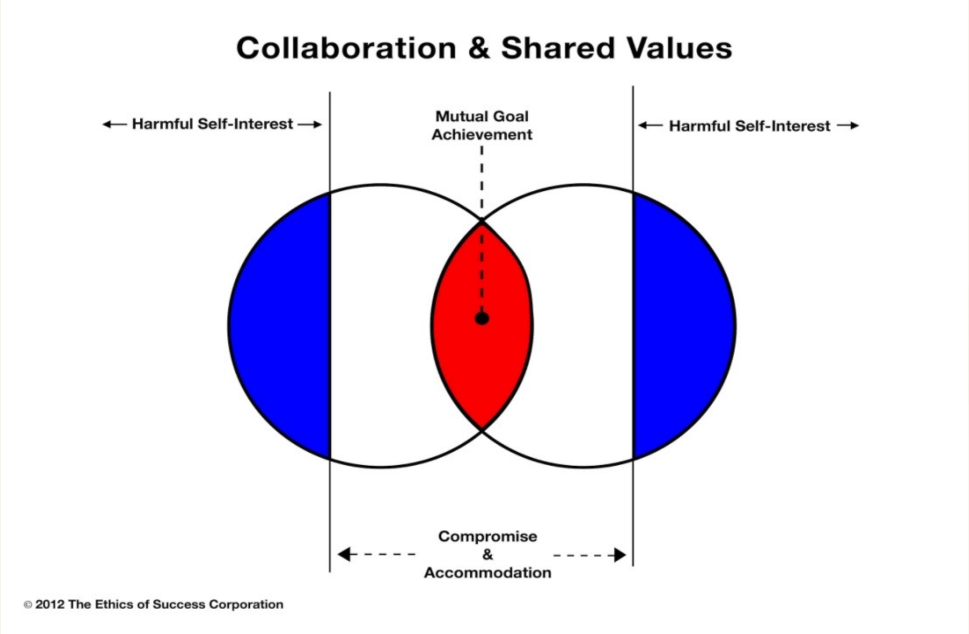
What Story Are We Telling Ourselves?



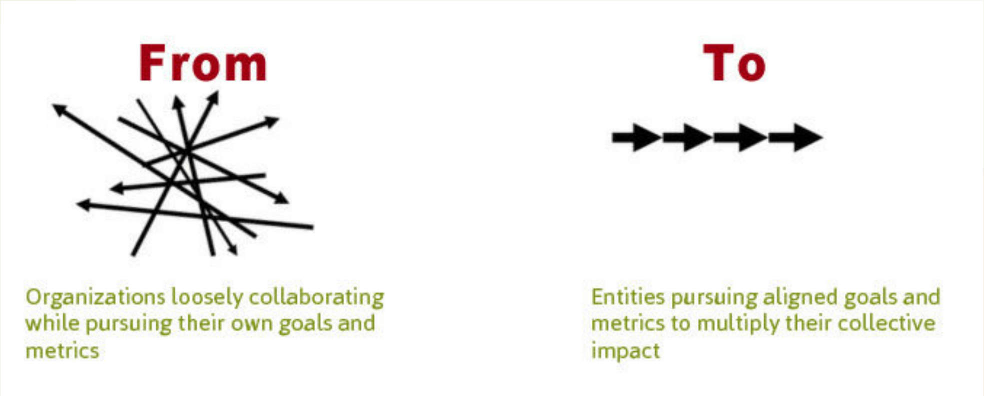
I now have HIV , I will survive and grow through this experience, I can still flourish.....

I am HIV Positive, what a stuff up, there’s no coming back from this, life will now be a constant struggle, I am alone with this, the future can only get worse......

How Do We Optimise Collaboration ?

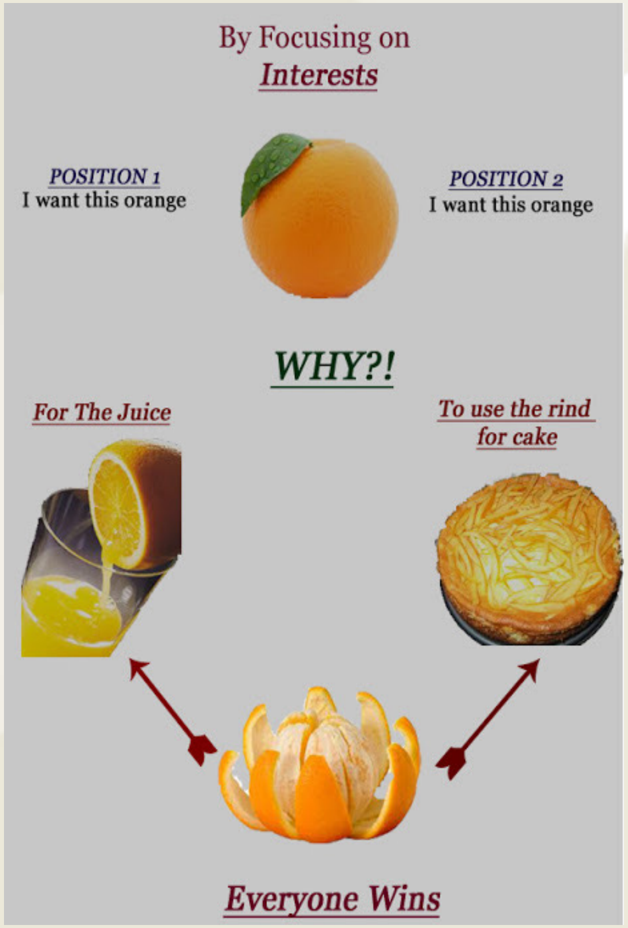


© 2012 The Ethics of Success Corporation



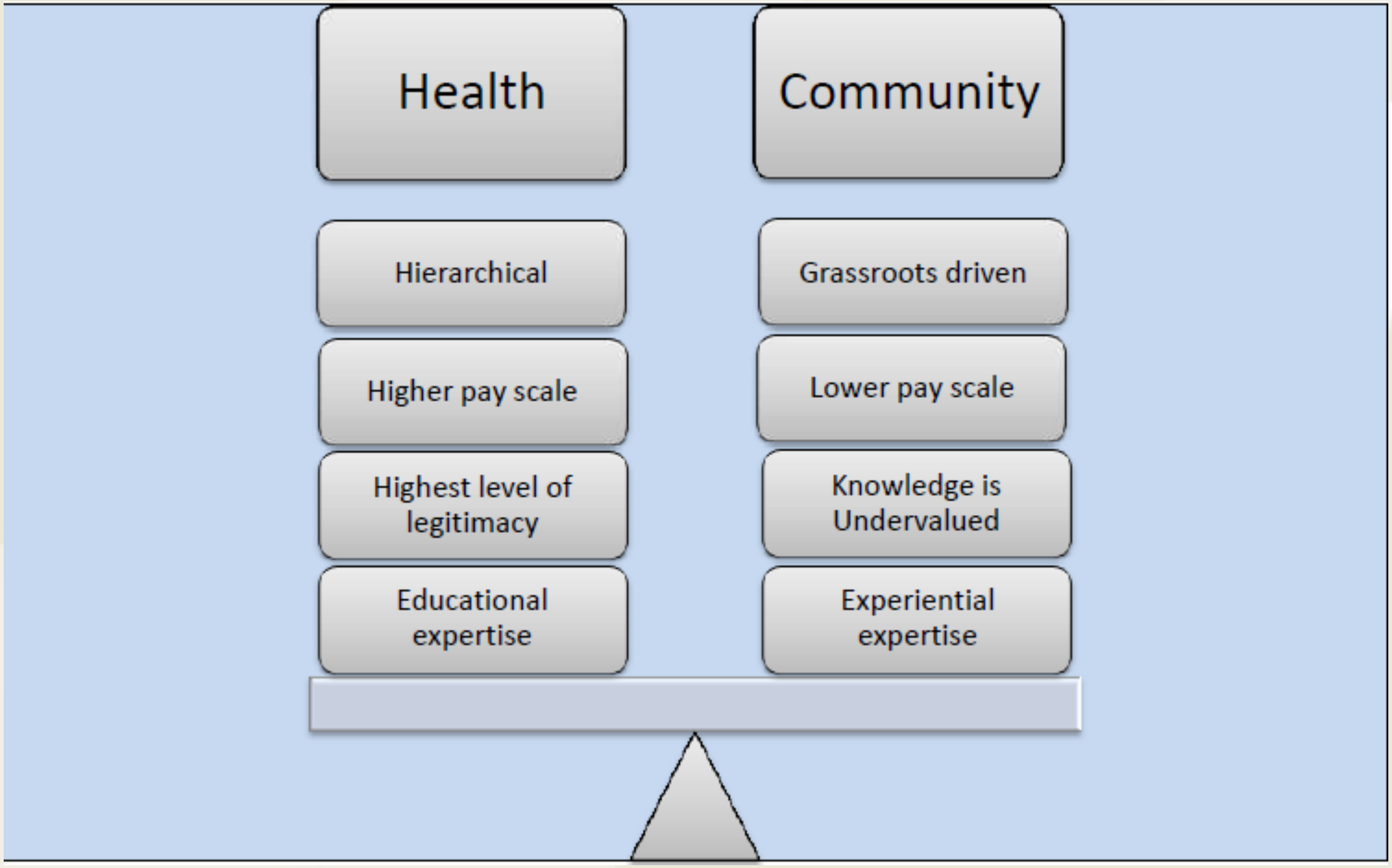
Organizations loosely collaborating while pursuing their own goals and metrics

Entities pursuing aligned goals and metrics to multiply their collective impact



napwha national association of people with HIV australia

Community Response & Structural Inequality



Health	Community
Hierarchical	Grassroots driven
Higher pay scale	Lower pay scale
Highest level of legitimacy	Knowledge is Undervalued
Educational expertise	Experiential expertise

Program Approaches With Community

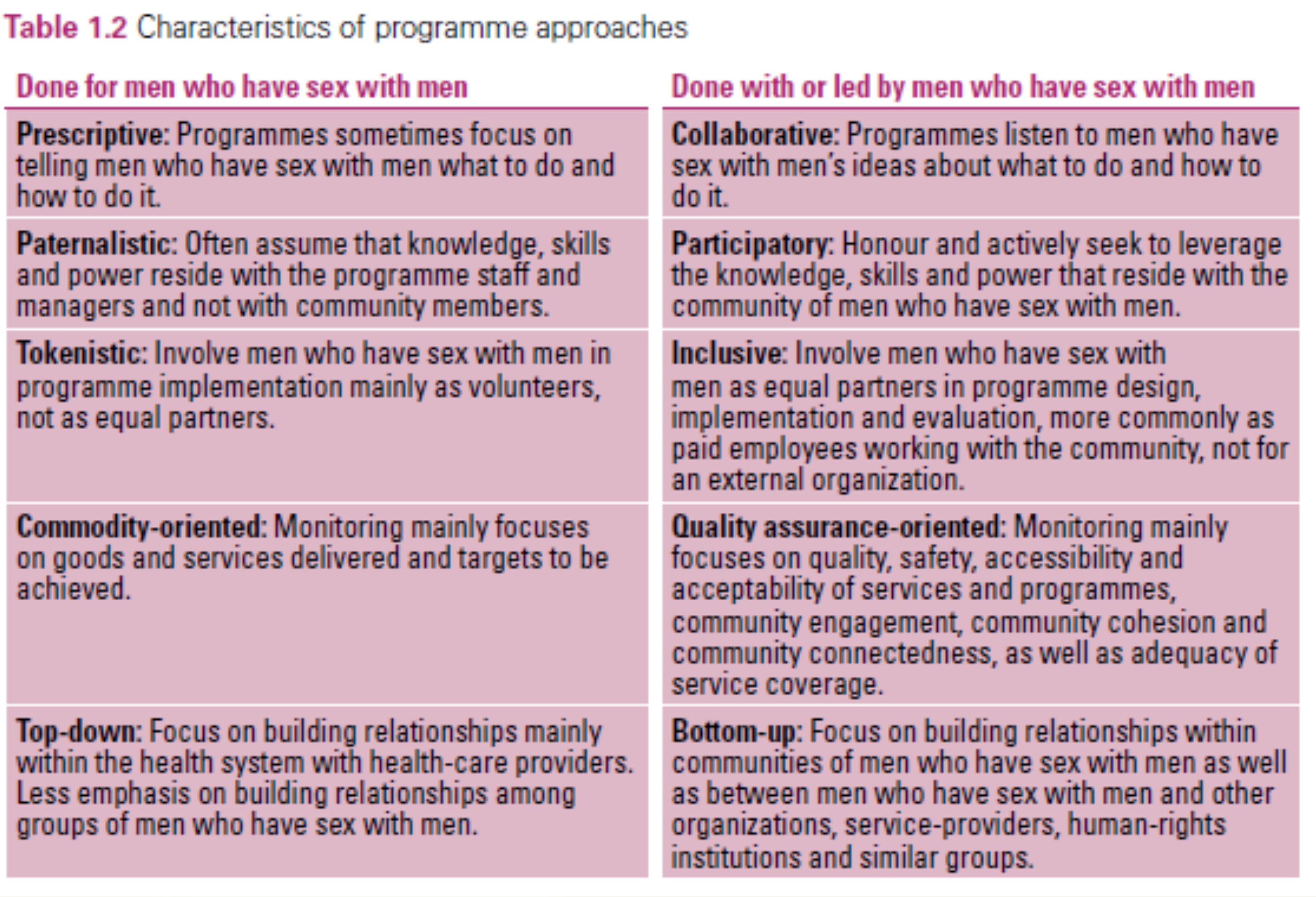
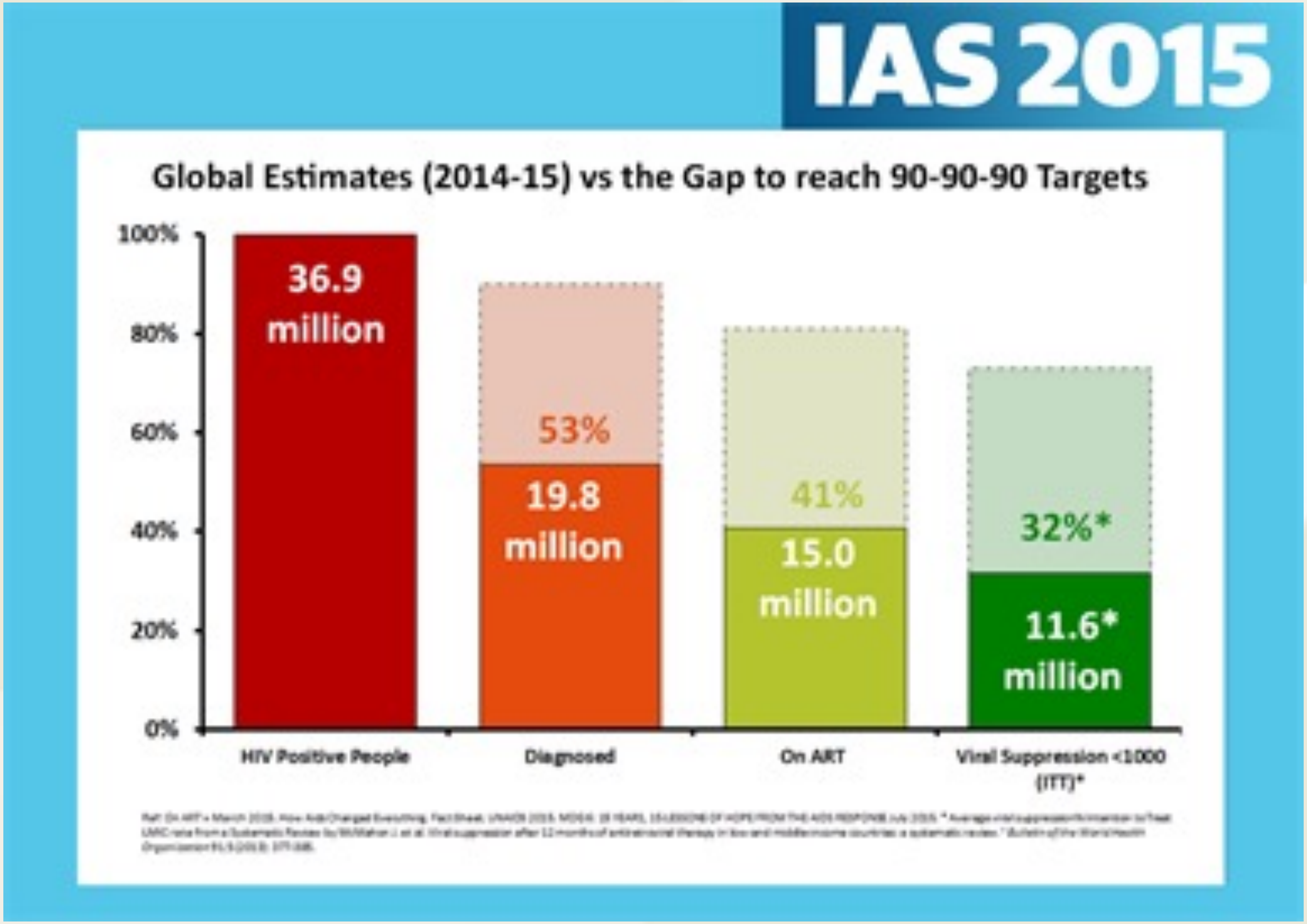


Table 1.2 Characteristics of programme approaches

Done for men who have sex with men	Done with or led by men who have sex with men
Prescriptive: Programmes sometimes focus on telling men who have sex with men what to do and how to do it.	**Collaborative:** Programmes listen to men who have sex with men's ideas about what to do and how to do it.
Paternalistic: Often assume that knowledge, skills and power reside with the programme staff and managers and not with community members.	**Participatory:** Honour and actively seek to leverage the knowledge, skills and power that reside with the community of men who have sex with men.
Tokenistic: Involve men who have sex with men in programme implementation mainly as volunteers, not as equal partners.	**Inclusive:** Involve men who have sex with men as equal partners in programme design, implementation and evaluation, more commonly as paid employees working with the community, not for an external organization.
Commodity-oriented: Monitoring mainly focuses on goods and services delivered and targets to be achieved.	**Quality assurance-oriented:** Monitoring mainly focuses on quality, safety, accessibility and acceptability of services and programmes, community engagement, community cohesion and community connectedness, as well as adequacy of service coverage.
Top-down: Focus on building relationships mainly within the health system with health-care providers. Less emphasis on building relationships among groups of men who have sex with men.	**Bottom-up:** Focus on building relationships within communities of men who have sex with men as well as between men who have sex with men and other organizations, service-providers, human-rights institutions and similar groups.

napwha national association of people with HIV australia

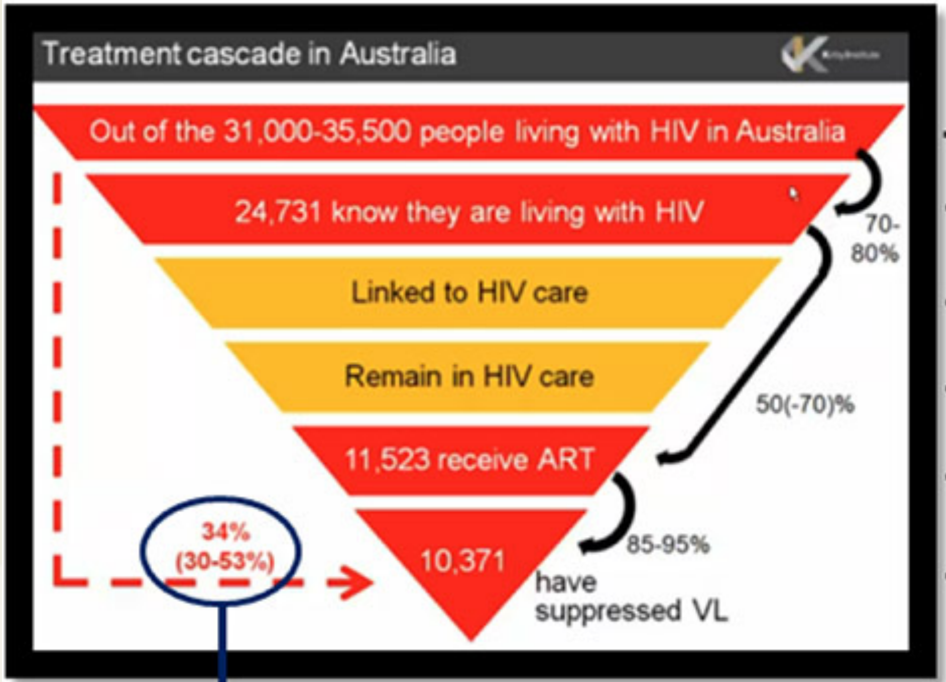


IAS 2015

Global Estimates (2014-15) vs the Gap to reach 90-90-90 Targets

napwha national association of people with HIV australia

A View Of The Problem



Treatment cascade in Australia

Out of the 31,000-35,500 people living with HIV in Australia

24,731 know they are living with HIV

Linked to HIV care

Remain in HIV care

11,523 receive ART

10,371 have suppressed VL

Source: Kirby Institute (Wilson, DP et al. *Early antiretroviral therapy: modelling the potential impact on the Australian epidemic*, Australasian HIV/AIDS Conference 2012, Melbourne, Australia, Paper Number 1162)

Undiagnosed HIV is estimated by using the CD4 count at time of Dx; average time between exposure & diagnosis is 4.6 years. ***Increased HIV testing required***.

Diagnosed HIV infection nationally

PLHIV are encouraged to remain engaged in care to optimise individual health benefits through appropriate treatment; secondary prevention benefit

Australia has committed to increasing the proportion of PLHIV on treatment with undetectable viral load

Studies indicate that Australia will require 90% of PLHIV to have an undetectable viral load in order to eliminate sexual transmission; this must be combined with significant efforts to increase the frequency of HIV testing to reduce the amount of undiagnosed HIV.

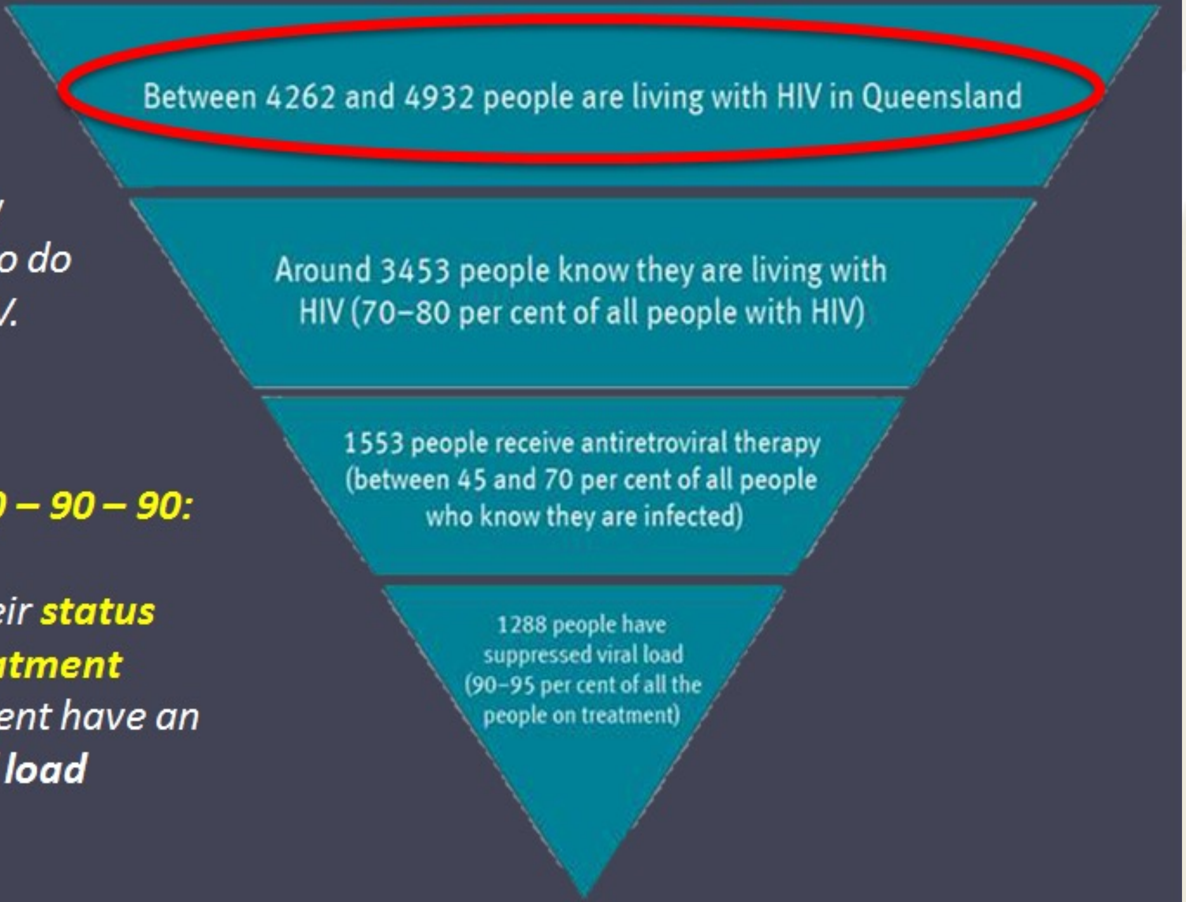
napwha national association of people with HIV australia

HIV Treatment Cascade

HIV is most commonly transmitted by people who do not know they have HIV.

The goals for QLD are 90 – 90 – 90:

90% *of PLHIV know their* ***status***
90% *of PLHIV on* ***treatment***
90% *of people on treatment have an* ***undetectable*** ***viral load***



Between 4262 and 4932 people are living with HIV in Queensland

Around 3453 people know they are living with HIV (70–80 per cent of all people with HIV)

1553 people receive antiretroviral therapy (between 45 and 70 per cent of all people who know they are infected)

1288 people have suppressed viral load (90–95 per cent of all the people on treatment)

Queensland Positive People - Rapid Testing

FREE RAPID HIV TESTING WITHOUT THE FULL Q&A.

RAPID.

RAPID is a new trial site using trained community members who understand the diverse communities of men who have sex with men. RAPID staff are not doctors or nurses, and do not keep clinical files that document sexual behaviour or injecting practices.

It offers rapid HIV and syphilis testing without the full Q&A.

You will still have an opportunity to ask questions and explore risk reduction strategies with a RAPID staff member who will respect your situation, and has a lot of knowledge about HIV and sexual health.

- No Appointments
- No Judgements
- No Notes

queensland positive people

napwha national association of people with HIV australia

Queensland Positive People - Rapid Testing

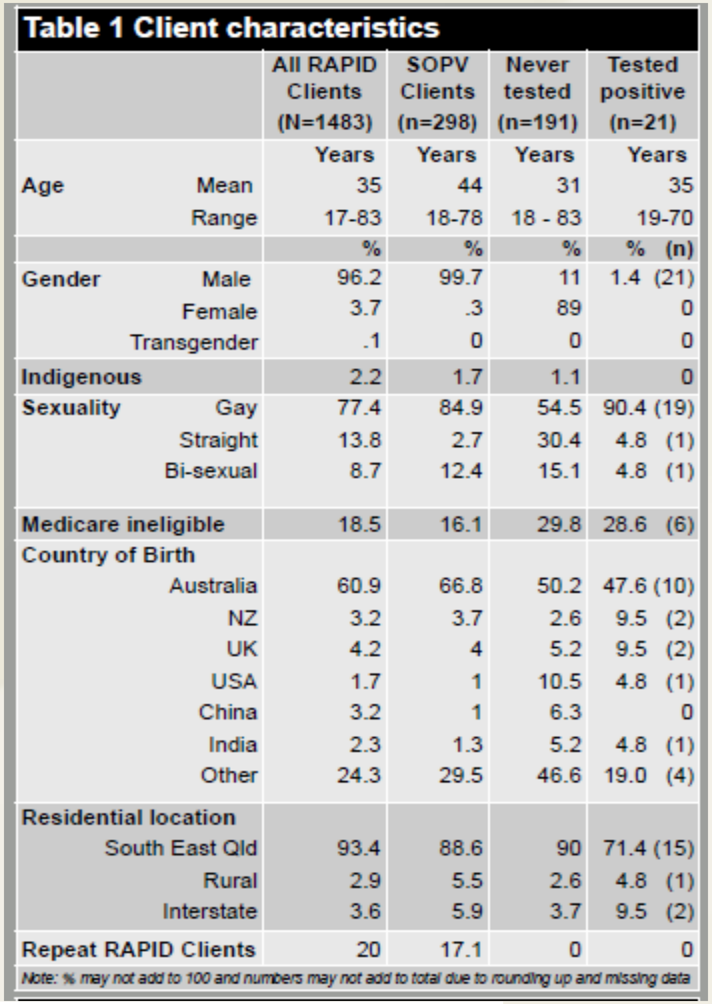


Table 1 Client characteristics

		All RAPID Clients (N=1483)	SOPV Clients (n=298)	Never tested (n=191)	Tested positive (n=21)
		Years	Years	Years	Years
Age	Mean	35	44	31	35
	Range	17-83	18-78	18 - 83	19-70
		%	%	%	% (n)
Gender	Male	96.2	99.7	11	1.4 (21)
	Female	3.7	.3	89	0
	Transgender	.1	0	0	0
Indigenous		2.2	1.7	1.1	0
Sexuality	Gay	77.4	84.9	54.5	90.4 (19)
	Straight	13.8	2.7	30.4	4.8 (1)
	Bi-sexual	8.7	12.4	15.1	4.8 (1)
Medicare ineligible		18.5	16.1	29.8	28.6 (6)
Country of Birth					
	Australia	60.9	66.8	50.2	47.6 (10)
	NZ	3.2	3.7	2.6	9.5 (2)
	UK	4.2	4	5.2	9.5 (2)
	USA	1.7	1	10.5	4.8 (1)
	China	3.2	1	6.3	0
	India	2.3	1.3	5.2	4.8 (1)
	Other	24.3	29.5	46.6	19.0 (4)
Residential location					
	South East Qld	93.4	88.6	90	71.4 (15)
	Rural	2.9	5.5	2.6	4.8 (1)
	Interstate	3.6	5.9	3.7	9.5 (2)
Repeat RAPID Clients		20	17.1	0	0

Note: % may not add to 100 and numbers may not add to total due to rounding up and missing data

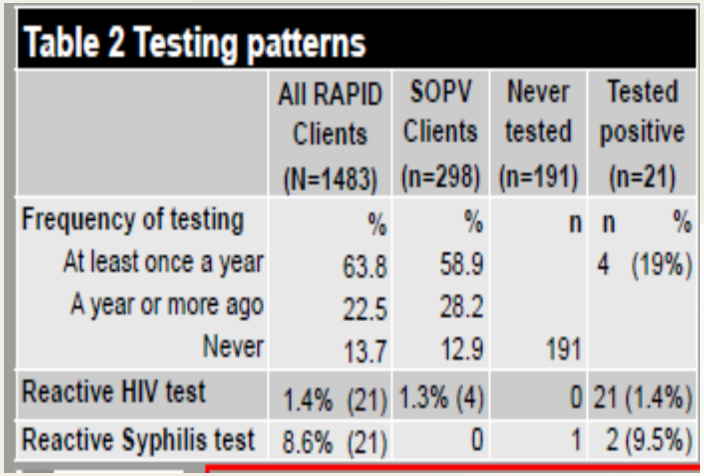
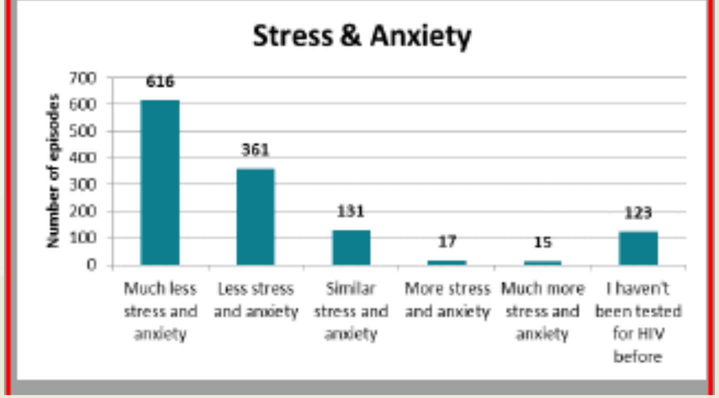


Table 2 Testing patterns

	All RAPID Clients (N=1483)	SOPV Clients (n=298)	Never tested (n=191)	Tested positive (n=21)
Frequency of testing	%	%	n	n %
At least once a year	63.8	58.9		4 (19%)
A year or more ago	22.5	28.2		
Never	13.7	12.9	191	
Reactive HIV test	1.4% (21)	1.3% (4)	0	21 (1.4%)
Reactive Syphilis test	8.6% (21)	0	1	2 (9.5%)

Diagram 3 Stress level with RHT test



queensland positive people

The University Of Queensland Australia

napwha national association of people with HIV australia

Queensland Positive People - Peer Navigators

•Awareness has been raised that certain CALD communities in Australia experience limited access to health care and services, resulting in poor health outcomes.

•To address this issue, the Community Navigator Model was developed and implemented in four CALD communities in Logan, Queensland, through a partnership between government and non-government organisations.

•The model draws on local natural leaders selected by community members who then act as a conduit between the community and health service providers. The navigators were trained and employed at one of two local non-government organisations

•The navigators' role included assessing client needs, facilitating health promotion, supporting community members to access health services, supporting general practitioners (GPs) to use interpreters and making referrals to health services.

'Community navigators': making a difference by promoting health in culturally and linguistically diverse (CALD) communities in Logan, Queensland
Saras Henderson [A C] and Elizabeth Kendall
Australian Journal of Primary Health 17(4) 347-354
http://dx.doi.org/10.1071/PY11053
Submitted: 3 May 2011 Accepted: 11 August 2011 Published: 15 November 2011

napwha national association of people with HIV australia

Common Themes - Peer Navigators

(1) commitment to an altruistic attitude of servility allowing limitless community access to their services;

(2) becoming knowledge brokers, with a focus on the social determinants of health; and

(3) ‘walking the walk’ to build capacity and achieving health outcomes for the community.

community navigators have the potential to make a difference to health equity in our communities, thus contributing to ending the HIV epidemic.

napwha national association of people with HIV australia

PositiveLifeNSW
the voice of people with HIV since 1988

Community Dispensing HIV Medication

Resources Information

- Brochure, tear-off pad, eBanner adverts, shout-outs, news items
- Pharmacists resource Booklet – ASHM / PSA

Collecting HIV treatments from chemists
The choice is yours

From 1 July 2015, people living with HIV (PLHIV) will be able to access HIV medications from chemists

The Australian Government is expanding options for dispensing HIV medications.

What do I need to do?

If you want to collect your HIV medications from a hospital pharmacy, you can continue with that arrangement.

Will it cost more?

We understand the cost will remain the same whether from a chemist or hospital pharmacy.

Collecting HIV treatments from chemists
The choice s yours.

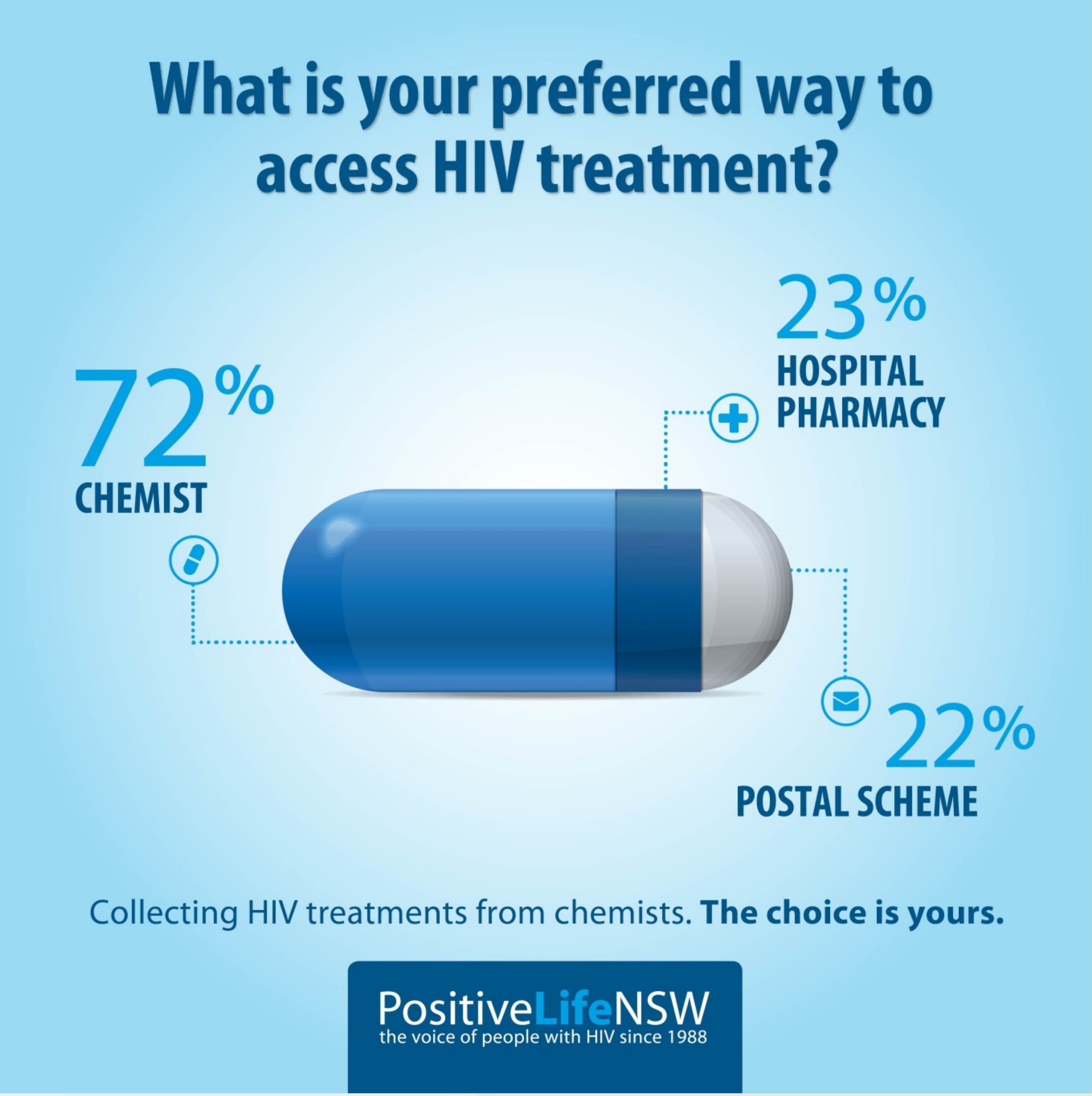
Australian Government is
nding options for dispensing
nedications.

1 July 2015, people living with HIV
able to access HIV medications
hemists as well as pharmacies.

re information visit:
ositivelife.org.au

veLifeNSW
ople with HIV since 1988

napwha national association of people with HIV australia



What is your preferred way to access HIV treatment?

72% CHEMIST

23% HOSPITAL PHARMACY

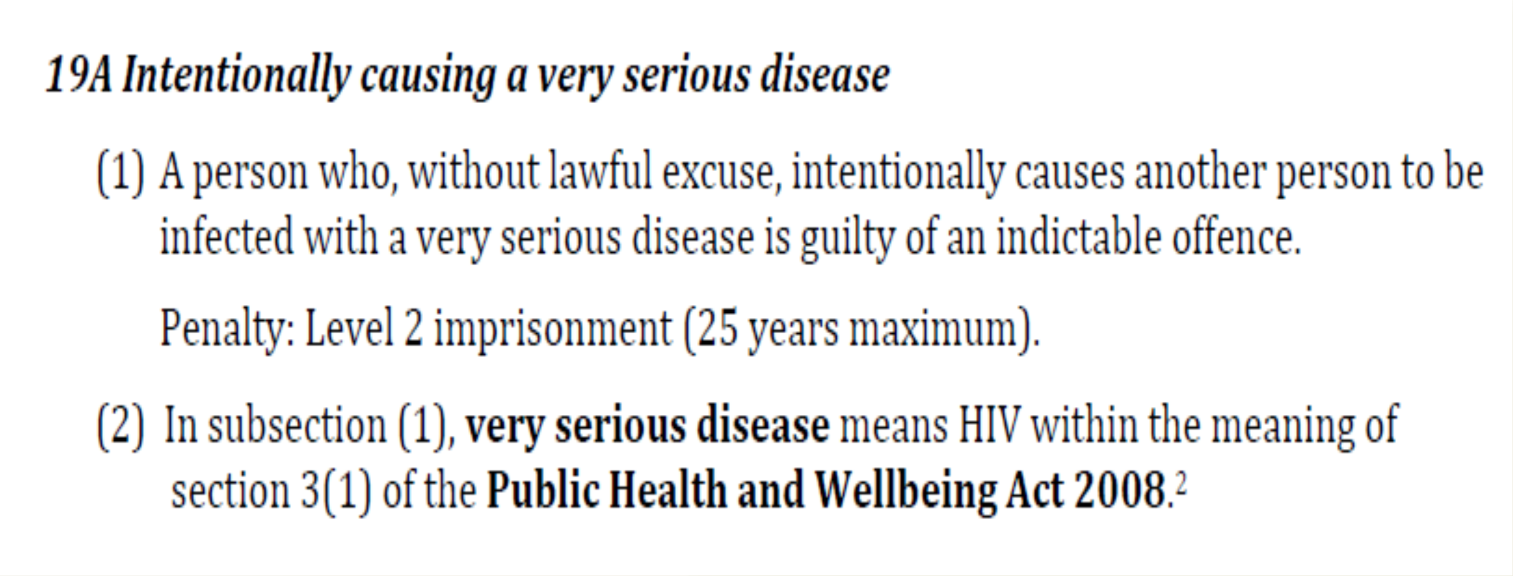
22% POSTAL SCHEME

Collecting HIV treatments from chemists. **The choice is yours.**

PositiveLifeNSW
the voice of people with HIV since 1988

The Problem With 19A

Section 19A of the *Crimes Act1958* (Vic)establishes the criminal offence of ‘intentionally causing a very serious disease’–with ‘very serious disease’ defined exclusively to mean HIV infection.
This is the only HIV---specific criminal offence in force in any Australian jurisdiction.



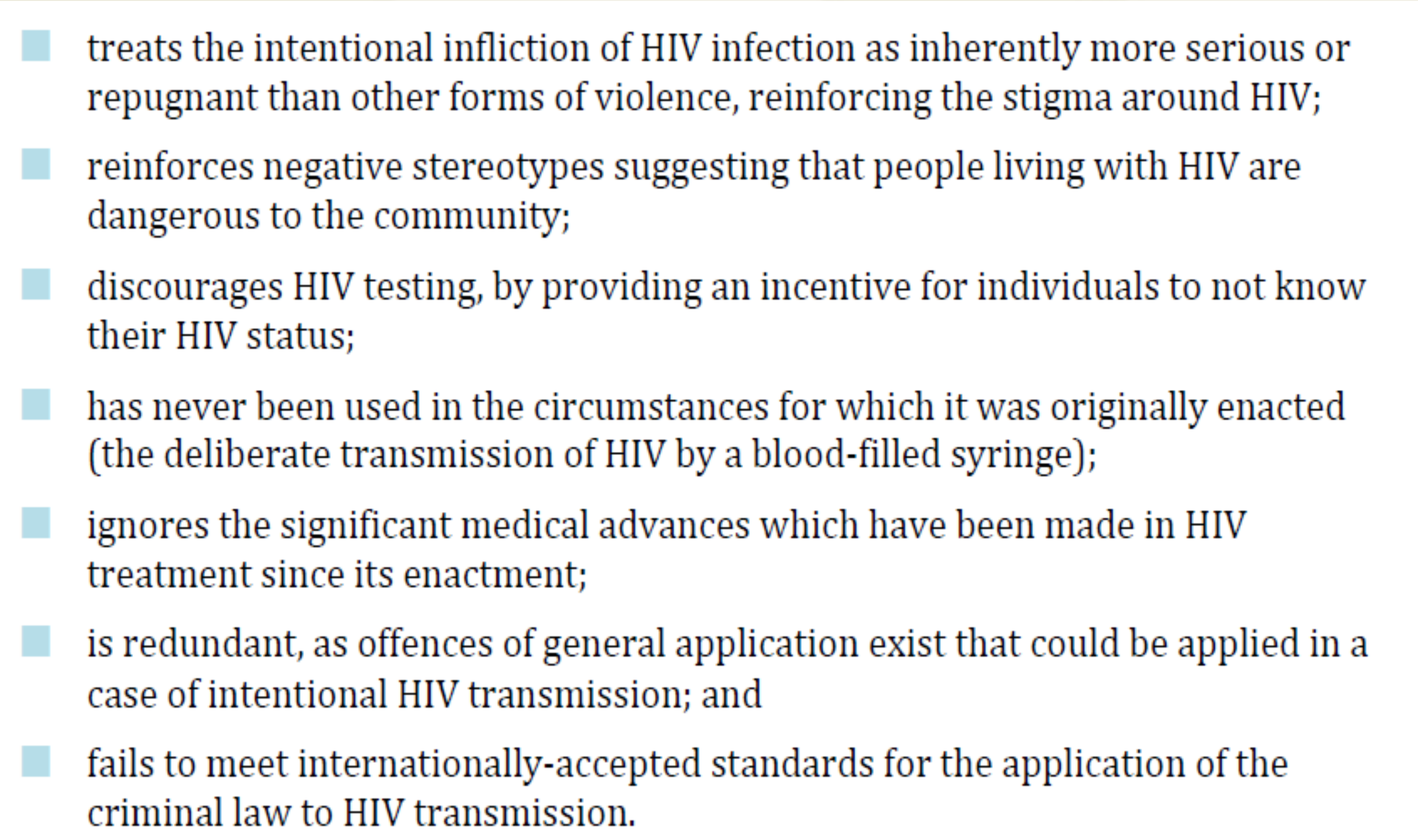
19A Intentionally causing a very serious disease

(1) A person who, without lawful excuse, intentionally causes another person to be infected with a very serious disease is guilty of an indictable offence.

Penalty: Level 2 imprisonment (25 years maximum).

(2) In subsection (1), **very serious disease** means HIV within the meaning of section 3(1) of the **Public Health and Wellbeing Act 2008**.[2]

What's The Problem ?



- treats the intentional infliction of HIV infection as inherently more serious or repugnant than other forms of violence, reinforcing the stigma around HIV;
- reinforces negative stereotypes suggesting that people living with HIV are dangerous to the community;
- discourages HIV testing, by providing an incentive for individuals to not know their HIV status;
- has never been used in the circumstances for which it was originally enacted (the deliberate transmission of HIV by a blood-filled syringe);
- ignores the significant medical advances which have been made in HIV treatment since its enactment;
- is redundant, as offences of general application exist that could be applied in a case of intentional HIV transmission; and
- fails to meet internationally-accepted standards for the application of the criminal law to HIV transmission.

napwha national association of people with HIV australia

Living Positive Victoria - Repeal 19A

napwha national association of people with HIV australia

Result

19A finally repealed in Victoria

MAY 28

19A FINALLY REPEALED IN VICTORIA

napwha national association of people with HIV australia

PLDI™ Positive Leadership Development Institute™

PLDI is a unique community service partnership that aims to build the resilience and leadership capacities of people living with HIV (PLHIV) in Australia and New Zealand and was borne as a community response to HIV stigma identified in the NAPWHA Stigma Audit (2012).

The HIV Stigma Audit
Community Report

napwa NCHSR

We understand the profoundly negative effect that HIV stigma has upon the response to HIV
we need to support strong and confident leaders to challenge stigma and exemplify resilience.

Supporting an emerging generation of PLHIV leaders is vital to continuing the partnership approach to HIV in Australia and beyond

The 3-day residential workshop aims to enhance emotional intelligence, psychological resilience, and leadership skills. All planning, delivery and evaluation of the courses are led by PLHIV.

living positive victoria
PEOPLE LIVING WITH HIV/AIDS VICTORIA

napwha national association of people with HIV australia

PLDI™

Positive Leadership Development Institute™
Australia

At the World AIDS Conference in 2014, PLDI graduates took part in the planning and organisation of the conference.

The synergy created in this workshop enables emerging and long term leaders to work collaboratively. The power and passion then enhances the performance of the HIV sector, addressing a concern of the decline of meaningful involvement in and commitment to, the sector of PLHIV.

With over 70 graduates from across Australasia and a leadership team of 8 facilitators.

From this alumni, PLDI is now offered across the country with a waiting list of over 100 PLHIV.

Over 25 businesses and organisations in every state/territory in Australia have committed over $100,000 per annum in sponsorship to this remarkable effort.

Leadership workshops such as PLDI are crucial in reinvigorating involvement in the sector and community more broadly

napwha national association of people with HIV australia

How Will NZ End HIV First ?

90% diagnosed

90% on treatment

90% virally suppressed

[TEST MORE] + [TREAT EARLY] + [STAY SAFE] = ENDING HIV

Everything has changed. We can end HIV.

national association of people with HIV australia

Thank You Collaborators

BODY POSITIVE
NEW ZEALAND
Tinana Ora Aotearoa

queensland
positive
people

living positive victoria
PEOPLE LIVING WITH HIV/AIDS VICTORIA

PositiveLifeNSW
the voice of people with HIV since 1988

POZ ACTION

napwha national association of people with HIV australia

Community Conversations ?

12:28 am Poz guy here looking for raw sex

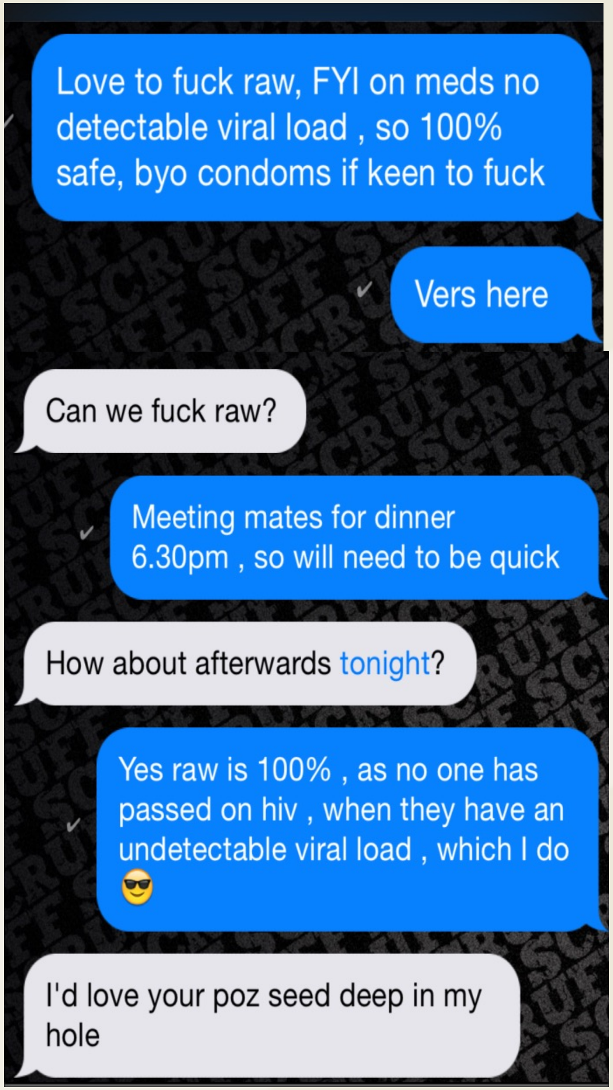
Sorry, safe only 12:35 am

12:36 am Oh I am , on meds, undetectable viral load, 100% safe 😀

Ah k 12:44 am

I don't know much about it 12:44 am

What you into? any more pics? 12:44 am



Love to fuck raw, FYI on meds no detectable viral load , so 100% safe, byo condoms if keen to fuck

Vers here

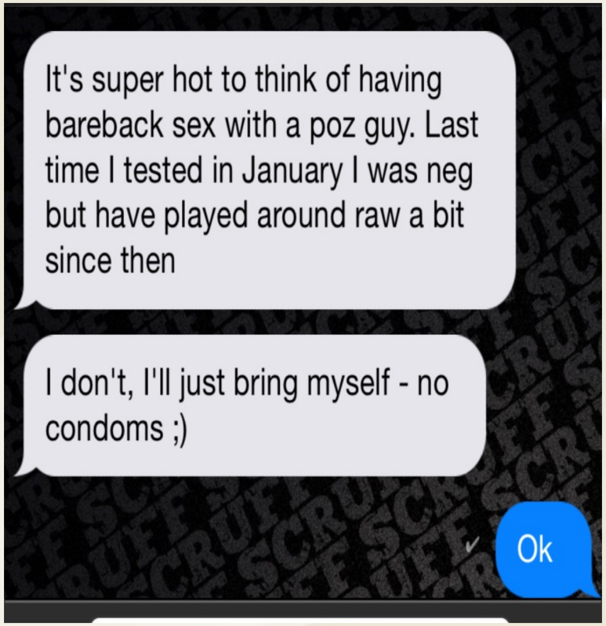
Can we fuck raw?

Meeting mates for dinner 6.30pm , so will need to be quick

How about afterwards tonight?

Yes raw is 100% , as no one has passed on hiv , when they have an undetectable viral load , which I do 😎

I'd love your poz seed deep in my hole



It's super hot to think of having bareback sex with a poz guy. Last time I tested in January I was neg but have played around raw a bit since then

I don't, I'll just bring myself - no condoms ;)

Ok

napwha national association of people with HIV australia

napwha national association of people with HIV australia