



Working towards a TB & HIV free community

# PWUD Community Advisory Groups: The South African Story

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**UNODC**  
United Nations Office on Drugs and Crime

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# South African Context

- UN says “second world/tier country”
- #1 tourist destination in Africa
- World’s most progressive constitution
- Legalized same sex marriage in 2005
- Largest free ART programme in the world
- Best health system in Africa
- Nelson Mandela



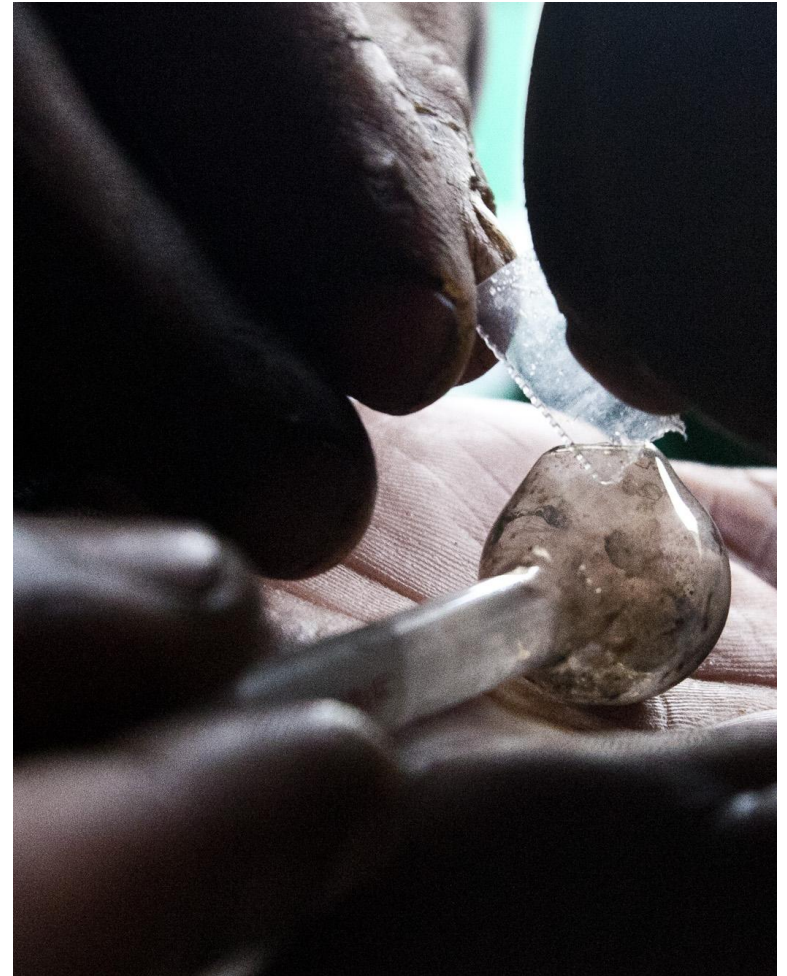
# South African Context

- Growing corruption
- Electrical load shedding
- Heading towards (-) economic growth rate
- Highest number of People living with HIV in the world
- One of highest rates of TB in the world (MDR/XDR)
- > 50% unemployment
- Rape capital of the world
- People are dying because can't access health services



# South African Context: Drug use

- Cape Town is believed to have one of the highest per capita users of Meth in the world.
- Heroin use and Injecting on the rise.
- Estimated 67,000 PWID in South Africa



***Yet, NO organisation or government facility provides the full package of evidence-based services to PWID***





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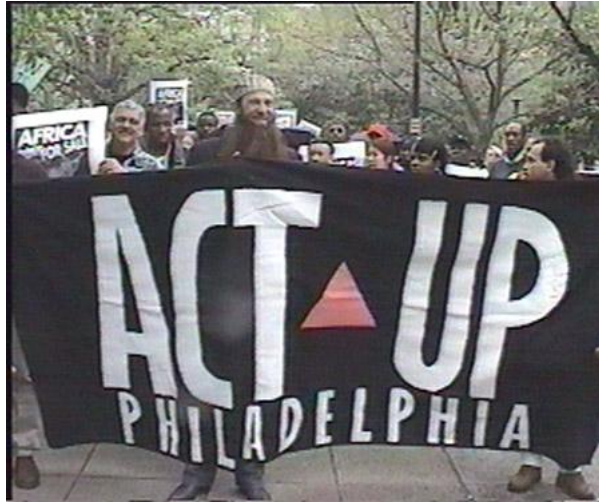
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# Community Involvement in Research/Service Delivery

- Early 1980's in the U.S. – MSM, HIV/AIDS
- Concerned about public health. Nothing being done.
- Large protests against the U.S. government and Pharmaceutical companies



# Community Involvement in Research/Service Delivery



SOLICITADA

## SILENCIO=MUERTE

La decisión de la Cámara de Apelaciones en lo Civil de negarle personería jurídica a la Comunidad Homosexual Argentina (CHA) es un intento de silenciar a las lesbianas y gays argentinos.

**¡BASTA DE SILENCIO!**

### EXIGIMOS:

- El reconocimiento de igualdad de derechos a la libre expresión y asociación a la comunidad lesbiana/homosexual.
- La derogación de edictos y leyes utilizados para perseguir a lesbianas/homosexuales.
- Que los derechos de los homosexuales no estén supeditados a los dogmas de ningún grupo religioso.
- El respeto y la protección de los derechos a las personas con SIDA o VIH seropositivos.
- Acceso a tratamientos y educación sobre el SIDA/VIH.

**ACCION=VIDA**

ENDORSADO POR: CACHA (Comité de Apoyo al CHA) - ACT UP/NEW YORK (SIDA: Coalición para Desencadenar el Poder) - ILGA (Asociación Internacional de Lesbianas y Gays) - Activistas Latinas/os Contra el SIDA - Queer Nation.

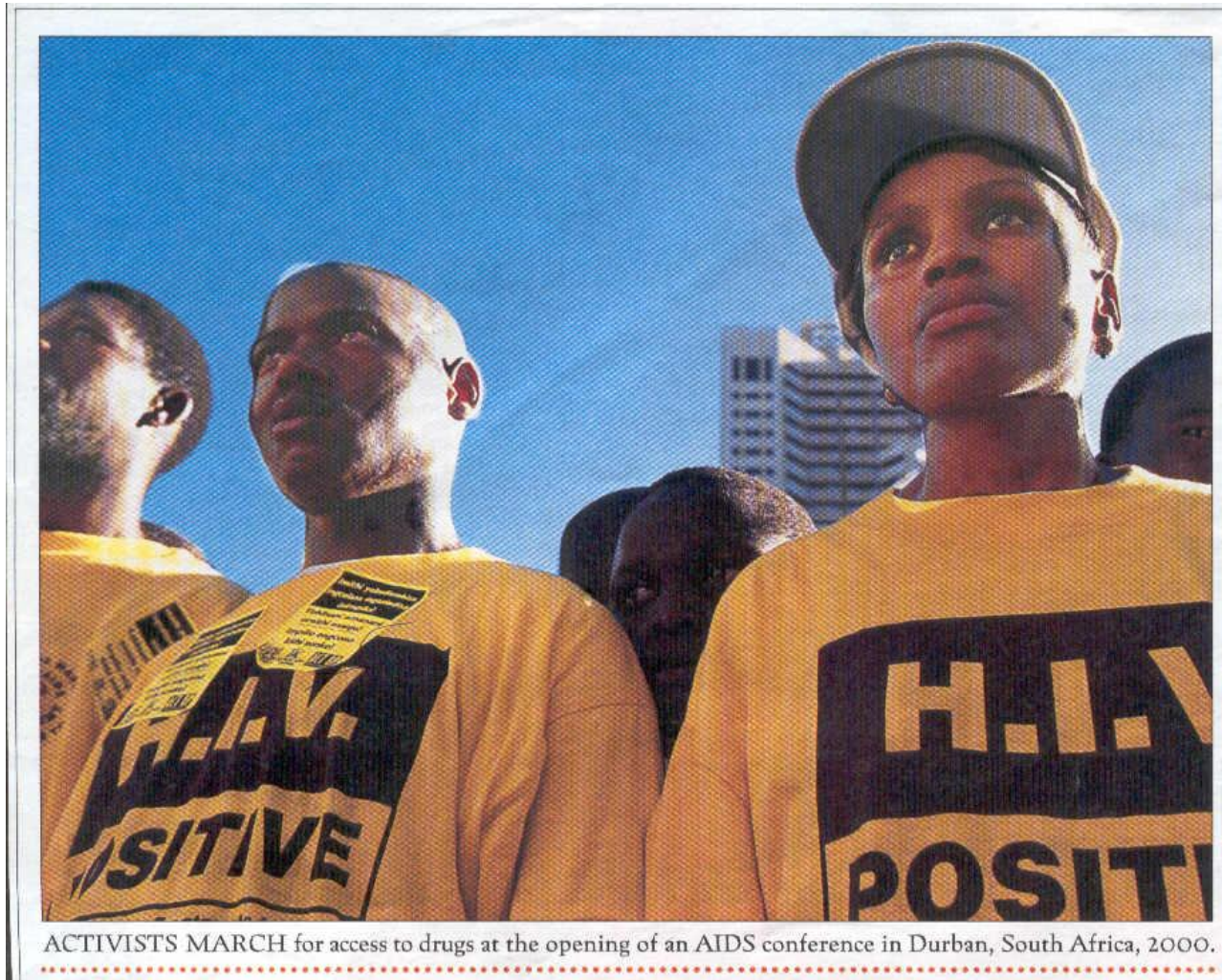
PARA MAS INFORMACION: CHA Catamarca 459 PB A-1213 Capital Federal Argentina.  
ACT UP 135 W 29th St 10th Floor, New York, NY 10001. Tel. 212-564-2437 Fax. 212-899-1797

**ACT UP AMERICAS**

Pagado por ACT UP/NY.



# South Africa's Treatment Action Campaign (TAC) : AIDS Advocacy Movement



ACTIVISTS MARCH for access to drugs at the opening of an AIDS conference in Durban, South Africa, 2000.

# Community Advisory Boards (CAB) 1990's - Present:



HIV PREVENTION TRIALS NETWORK



# Good Participatory Practice (GPP) Guidelines

- <http://www.avac.org/good-participatory-practice>
- “Nothing about us without us”





- First PWID harm reduction health and human rights programme in South Africa
- Received funding January 2014 PEPFAR/CDC; January 2015 Mainline
- 3 Cities: Cape Town, Pretoria and Durban

# Phase 1

## Initial engagement

National reference group & provincial task team establishment, stakeholder engagement

## Planning & set-up

Plans, staff, training, systems

Community Consultation Workshops

Establish CAG, identify peers

# Phase 2

## Formative assessment

Protocol development & approval

Mapping

Size estimation

Triangulation & report to inform project

# Phase 3

## Implementation

Outreach services

Wellness Centre

IEC activities

Referrals

Needle syringe programme

Monitoring

Capacity building, training

Community engagement

# Phase 4

## Evaluation

Evaluation

Data analysis

Ongoing engagement

Ongoing advocacy

# Initial PWID Community Consultation Workshop (CCW)

## What was covered

- The project was introduced
- Challenges and needs faced by the community
- Challenges with State
- Way forward
- **CAG established**

## Who involved

- ± 25 PWID per city
- PWID programme staff
- Community Allies
  - Dept of Health (Durban)
  - Law Enforcement (Cape Town)

# CCWs: Example Site Key Issues Identified

MEDICAL	LAW ENFORCEMENT	PSYCHOSOCIAL
Abscesses	Bribery	Depression
Depression	Harassment	Homelessness
Kidney/bladder infections	Unlawful incarceration	Detachment from family
TB/HIV	Lack of respect of human rights	Stigmatisation
Constipation	Guilty by association “being tagged”	Discrimination
Lack of facilities to manage overdose and rehabilitation	Withdrawal symptoms whilst incarcerated	Confiscation/loss of IDs
Mental health issues		

# Monthly Community Advisory Groups (CAGs)

- Safe Spaces
- Education and awareness
- Health and Wellness  
Service delivery and support
- Human rights abuse discussions
- Psychosocial and human rights discussions



# Typical CAG Agenda: develop with members

## Community Advisory Group Meeting - 9 January 2015

Time	Activity	Person Responsible
9:00	Welcome and Introduction	Kalvanya
9:15	Introduction of Project + Feedback from Pervious meeting	Zara
9:30	Feedback from PWID Community	Kalvanya
10:00	Discussion around Cape Town and learning outcomes	Zara/Peers
10:45	Update around Ethical approval and Formative Assessment	Kalvanya
11:00	Team Building	Zara
11:30	Planning: Next Steps and Next CAG Meeting	Kalvanya
Closing		

# CAG Minutes

- Document discussions, ideas, suggestions
- Follow up and incorporate into programming

## Meeting Minutes

<b>Team met with:</b>	Community Advisory Group		
<b>Date:</b>	12 August 2015	<b>Time:</b>	09:00
<b>Location:</b>	Sediba Hope Medical Centre		
<b>Meeting Purpose:</b>	CAG		
<b>Attendees:</b>	Henri Bam		
	Angela Mc Bride		
	Derick Louw		
	33 CAG members.		

## Agenda

Time	Activity	Person Responsible
09:00	Gathering Time, Welcome	Henri & Angela
09:05	Community Challenges	Henri & Angela
09:20	SAPS Feedback & Situation with SAPS Stations	Henri
09:45	Presentation of Updated Outreach Schedule	Angela
09:55	Reminder of Next of Kin Lists	Angela
10:00	Closing and Next Steps	Henri

## Key Points Discussed

No.	Topic	Highlights
1	Welcome	<ul style="list-style-type: none"> <li>• Henri and Angela welcomed the members to this meeting.</li> <li>• A CAG member stated that they had come across a c</li> </ul>

# ± 100 PWID CAG Members

- 30 – 40 members per site
- Monthly CAG meetings
- 16 months of meetings (June 2014 – present)
- 1,600 person meetings



# CAG Outcomes

**step**  
**UP**  **PROJECT** |

# CAG Outcomes

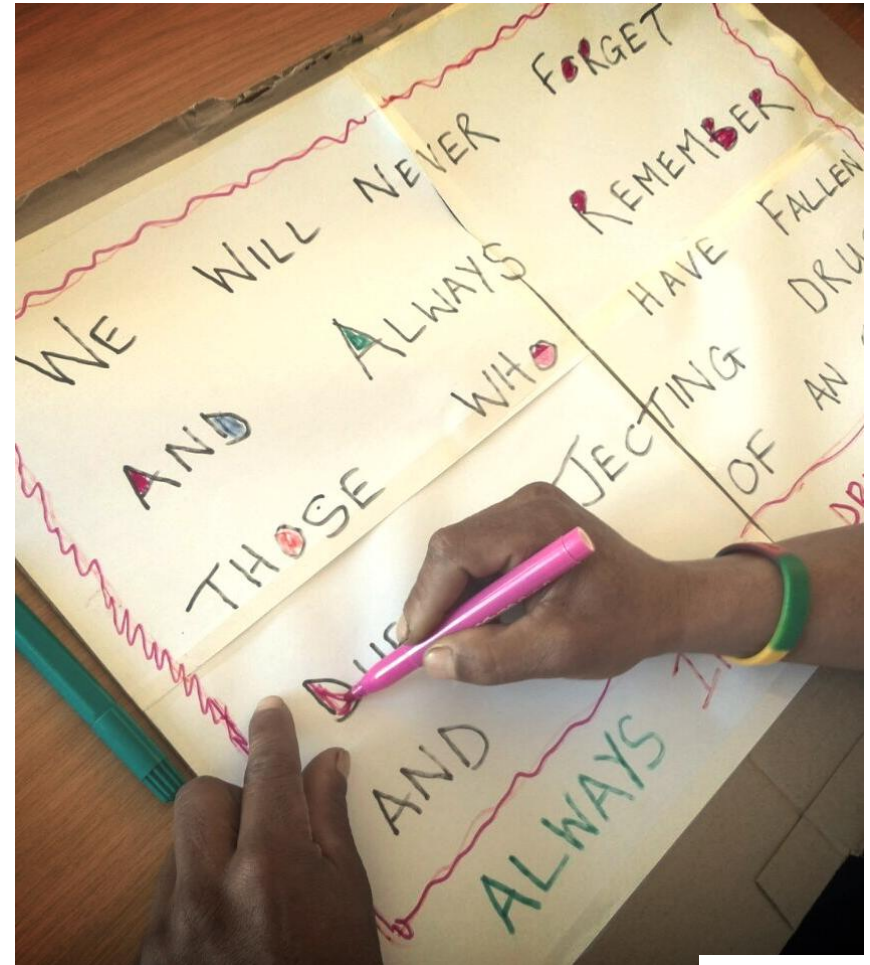
## Improved Comprehensive Health and Human Rights Service Delivery Tools

G. Lifestyle (all)		1. Height m	2. Weight kg	3. BP mmHg
4. BMI (w/ hgt)		5. Glucose mmol/L	6. Cholesterol	
H. Clinical assessments				
f. Pregnancy screening (woman)				
1.1 Pregnant?		1.2 LMP	1.3 Pregnant test?	1.4 Pregnancy test result
2. Children and parenting (all)				
2.1 # < 12		2.2 Age (youngest)	2.3 Lives with	2.4 Who decides on health care?
2.5 Are their health needs met?				
3. Contraception screening (all)				
3.1 Using contraception		3.2 Method	3.3 Assessed for contra-indication	3.7 New Apt
4. STI symptom screening (all) over the last month				
4.1 Sores/ulcers on genital/anus?		4.2 Burning on passing urine?	4.3 Discharge genital/anus?	
5. PAP smear screening (woman)				
5.1 Date of last PAP		5.2 PAP smear needed?	5.3 PAP smear by PNC?	
6. TB symptom screening (all)				
6.1 Have you had TB before?		6.2 Completed TB treatment?	6.3 On TB Rx now?	
6.4 Drenching night sweats		6.5 Unexplained weight loss (> 1.5 kg/month)	6.6 Cough of 2 weeks or more OR of any duration if HIV positive	
7. Viral hepatitis (all)				
7.1 Have you been vaccinated against hepatitis B?		7.2 Have you been tested for hepatitis C?		
8. Medical male circumcision (men)				
8.1 Is client circumcised?		8.2 Type?	8.3 Type confirmed (examined)?	
9. Post exposure prophylaxis (all)				
10. Psychosocial problems (all) reported in last 3 months				
10.1 Violence from client?		10.2 Sexual assault/ rape		
10.3 Violence from intimate partner?		10.4 Trafficking?		
10.5 Police harassment		10.6 Harassment from general community?		
11. Key pop code (X all that apply)				
L. Health behaviour interventions				
a. Health talks (x if provided)		b. Psychosocial support (x if provided)		c. Sexual risk pack
1. Condom demonstration		1. LGBTI support & rights		1. NSP pack
2. Condom genital tube		2. Gender Based Violence		2. Needle syringe
3. HIV PMCT education		3. Gender norms		3. Alcohol swab
4. HIV substances & risks		4. Services support for Key Population		4. PWUD pack
5. HIV partner testing		5. Services provided (x if done or provided)		5. IEC materials
6. HIV sexual risk reduction		6. STI/TSU info		6. Spoon
7. HIV condom negotiation		7. STAs		7. Sharps cont.
8. HIV MMC promotion		8. Emergency contraception		8. Hepatitis info
9. STI/TSU testing & treatment		9. Heavy drinking		9. Hygiene
10. ARVs health checks		4. Safer sex		1. Wound care
11. PWUD safer injecting		5. STI syndromic management		2. Goshbruh
12. PWUD 2x/2d method		6. PAP smear testing		3. T. paste
13. PWUD drug/injecting risks		7. Specimen taken for TB tests		4. Soap
14. PWUD overdose		8. PEP (PPEP oral/topical)		5. Overdose care
15. PWUD safe NS disposal		9. DOTs (specify)		6. Hand sanit.
		10. Wound care		7. Women's services
				8. Human rights
M. Referrals				
Type of referral (circle)		Referral site/clinic	Comments	LTFU
1. HIV Pre-ART / ART				SFU Client
2. TB investigations				SFU Clinic
3. STI treatment				
4. Contraception				
5. PAP smear / MMC				
6. PMCT				
7. PEP / PPEP (oral/topical)				
8. Psycho-social				
9. Wellness Centre				
10. Referral for MA				
11. Hepatitis referral				
12. Other				
N. Next health screen date				
Form completed by		Referral log by	DC	Site entry
			Date	Date

Health screening tool							
A. Visit information							
1. Date		5. Location #		7. Consents for data use			
2. Project		6. Type of Wellness Service		8.1 Indoor		If does not consent, why	
3. Team/zone		6.2 Outdoor/mobile clinic		6.3 Wellness Centre/Clinic			
B. Client information							
1. Name		2. Initials		7.1 Manual PID			
3. Gender		4. D.O.B		7.2 Digital PID		8. Contact no:	
5. Race		6. Housing		9. Referred by			
C. Health screening assessment							
1. Last health screening		2. Location of last health screen (choose one)					
D. Substance use assessment							
1. How many units (250 ml glass of wine/ 340 ml can of beer/ shot of spirit) of alcohol do you normally drink a week?		units					
2. How many times you have used any of the following substances in the last month (X all that apply)							
3. Have you been on medication assisted treatment or opioid substitution therapy for the last 30 days or more?							
4.1 Have you injected a drug in the last 12 months?							
4.2 Have you injected a drug in the last month?							
4.3 If yes, what drug did you inject? (tick all that apply)							
4.4 On average, how many times a day did you inject in the last month?							
4.5 Did you use a new needle/syringe the last time you injected?							
4.6 If not, did you clean your needle/syringe with bleach the last time you injected?							
4.7 Did you share your needle/syringe with anyone else the last time you injected?							
E. Sexual health assessment							
1. Have you been sexually active last month?							
2. How many people did you have sex with in the last week?							
3. Penis-vaginal sex		3.1 Used condom last time?		3.2 Used lube last time?			
4. Anal sex - insertive		4.1 Used condom last time?		4.2 Used lube last time?			
5. Anal sex - receptive		5.1 Used condom last time?		5.2 Used lube last time?			
6. Oral sex		6.1 Used condom last time?		6.2 Used lube last time?			
7. Did you have sex with someone of the same gender in last month?							
8. Did you receive drugs / goods in the last month in exchange for sex?							
9. Did you receive money in the last month in exchange for sex?							
10. Did you pay for sex in the last month?							
11. Did you use alcohol or substances the last time you had sex?							
F. HIV screening and testing							
1. Known HIV (X if apply)		Not in care		In care, pre-ART		In care, on ART	
1.1 Last CD4 count		1.1.1 Date of last CD4 count					
1.2 Last clinic visit		1.2.1 Which clinic?					
1.3 Is in a support group?		1.3.1 Where?					
2. HIV status negative or unknown (X if apply)		2.1 When was the last time you had an HIV test?					
2.2 Would you accept an HIV test now?		CONSENT TO HIV TESTING (consent of parent or guardian if <12 years)					
I hereby consent to having an HIV test:		Signature: _____		Date: _____			
Ngayavuma okokube igodi lem linphotholewa lefelo sengautso (HIV/AIDS).		Signature of counsellor: _____		Date: _____			
Ek verleen hiermee toestemming vir 'n HIV toets.		Signature of counsellor: _____		Date: _____			
Name of counsellor: _____		Signature of counsellor: _____		Date: _____			
3. Test Client		Performed by		Date			
3.1 Screening Test		3.2 Confirmatory Test		3.3 CD4 Count Test		4. Results (mark with x)	
4.1 WHO Stage		4.2 CD4 Count		4.3 Refused date		4.4 Referred for ELISA	
4.5 Client accepted HIV results		4.6 Client accepted CD4 results					

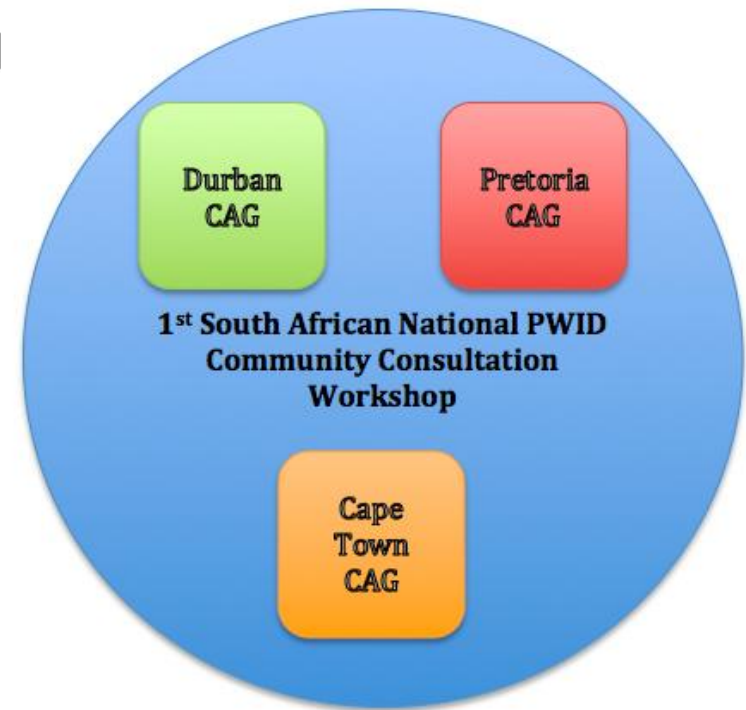
# CAG Outcomes

- PWID Safe space
- Group Advocacy (LEA)
- Programme and research protocol input and review
- PWID led community engagement
- PWID HIV± and other health related support groups
- Human rights reporting, interventions and support
- PWID Ambassador programme
- Peer outreach staff creation
- Media (PWID CAG member)



# CAG Outcomes:

- UNODC funded National Community Consultation Workshop
- Beginning of National PWID/UD Advocacy movement
- The birthplace of SANPUD
- First 2 months of NSP and service delivery (began June 2015) reach **±800 PWID**



# Next Steps

- Expand further to PWUD
- Increase participation of female PWUD
- More Autonomy



Thank you



