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5

## AUTONOMY & CONSENT TO HIV TESTING

- Progression from paternalism to autonomy
- Shift from physician's obligation to disclose to emphasis on quality of user's understanding & consent
- Based on ethical value of respect for persons / autonomy
- IC = if capable, users are given opportunity to make their own decisions

A stylized illustration of a person with dark curly hair and sunglasses, wearing a yellow long-sleeved shirt and dark pants. They are holding a cane in their right hand and raising their left fist. Below them is a yellow banner with the word 'AUTONOMY' in white capital letters. The entire illustration is set against a white background with blue L-shaped corner accents.

6

## AUTONOMY & CONSENT TO HIV TESTING



Right to make decisions regarding her own body (autonomy rights)



Right to keep information about herself confidential or private (informational privacy rights)



Individual expressly must consent to all forms of medical treatment, incl. tests for HIV

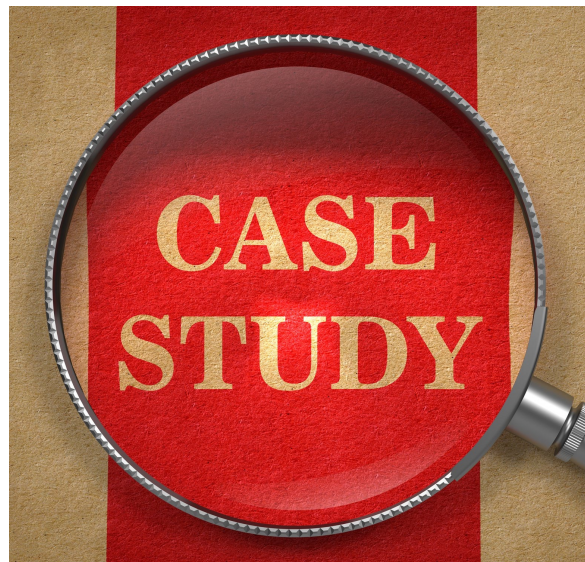


Information about herself remains confidential, incl. results of an HIV test

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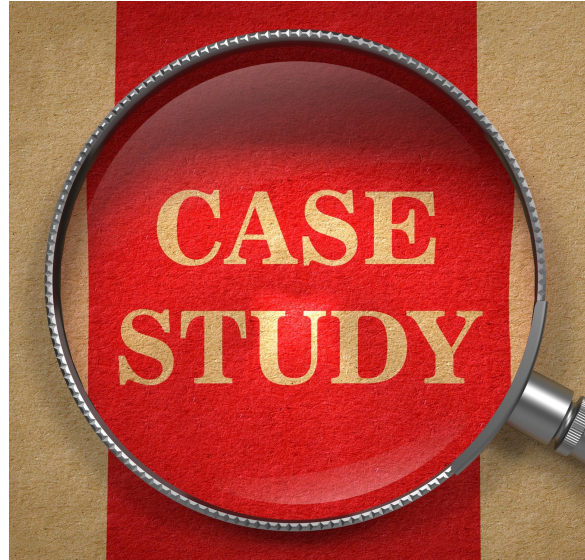
*Case of VRM v The Health Professions Council of South Africa TPD 1679/2002*  
10 October 2003

- In January 1999 VRM consulted Dr L in respect of the delivery of her baby
- She was 6 months pregnant with her 1<sup>st</sup> child
- Dr L drew blood for 'routine tests' - incl HIV test
- No pre- and post-test counselling as stipulated in the HPCSA's guidelines



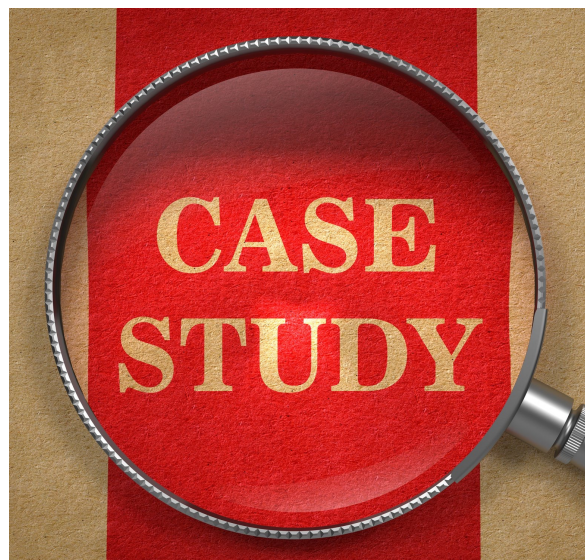
8

- VRM billed for R160 from Drs Buisson & Partners (pathologists)
- VRM's husband asked Dr L for an explanation of account: 'HIV ELISA'
- Details of Dr L's response in dispute - indicate he avoided informing VRM that her test results revealed that she is HIV+
- In April 1999 VRM gave birth by C/S to a stillborn baby



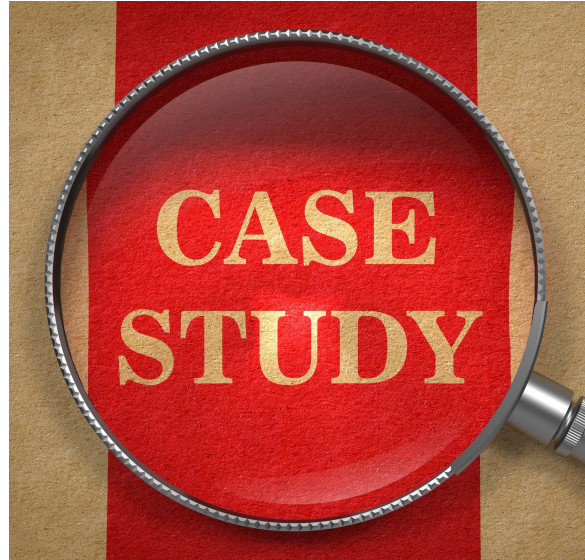
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- Dr L issued death certificate: cause of death - 'stillborn/HIV positive'
- Dr L informed VRM next day that she was HIV+
- VRM requested HPCSA to investigate conduct
- Dr L had not advised VRM on measures to reduce risk of MTCT of HIV during birth although he was aware of her HIV status



10

- 
- He did not perform C/S immediately after VRM's waters broke to reduce risk of transmission
  - Dr L claimed that '[VRM was] one month away from delivery and "I thought it in her best interest, from a psychological point of view not to inform her of her status at this point in time"'



11

- 
- The Pretoria High Court found that it was improper conduct for Dr L to test VRM for HIV without informing her of the purpose of the test
  - Case demonstrates the pitfalls facing a HCP who resorts to the defence of therapeutic privilege and to doing what 'doctor thinks best'



12

## OUTCOME

- The patient's informed consent must cover every aspect of the intervention
- Should a HCW test a person for HIV when she consults her, she must get her *explicit* consent for the test and inform her of its result



13



## *C v Minister of Correctional Services*

- HIV test performed on a prisoner without his informed consent
- The prisoner was twice informed that the test was for HIV and other STIs and that he had the right to refuse the test
- However, the Constitutional Court found that the prisoner's consent had not been *informed* as he was not given the information in private, nor had the prisoner been given sufficient time to consider whether to refuse the test

14

## What About Children?



15

## Children's Act 38 of 2005

Secs 130, 132 & 133:  
130(1) Subject to sec 132, no child may be tested for HIV except when  
(a) it is in the **best interests** of the child and consent has been given in terms of subsection (2); ...

16



## Children's Act 38 of 2005

### (2) Consent for a HIV-test on a child may be given by

(a) the child, if the child is

(i) **12** years of age or older; or

(ii) under the age of 12 years **and** is of sufficient maturity to understand the benefits, risks and social implications of such a test

17

## Children's Act 38 of 2005

(b) the **parent or care-giver**, if the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a test;

(c) the **Provincial Head of Social Development**, if the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a test;

(d) a **designated child protection organisation arranging the placement of the child**, if the child is under the age of 12 years and is not of sufficient maturity

18

## Children's Act 38 of 2005

(e) the **Superintendent** or person in charge of a hospital, if

(i) the child is under the age of 12 years and is not of sufficient maturity to understand the benefits, risks and social implications of such a test; and

(ii) the child has no parent or care-giver and there is no designated child protection organisation arranging the placement of the child; or (i) consent in terms of paragraph (a), (b), (c) or (d) is unreasonably withheld; or

(iii) the child or the parent or care-giver of the child is incapable of giving consent

19

## National Health Act 61 of 2003

- **Confidentiality:** Importance of medical confidentiality, including for children
- The HIV status of a child must remain confidential, and disclosure of the results must only be made with the appropriate consent, whether from the child or a guardian, depending on their age

20

## Ethical Guidelines by the HPCSA

- **Counselling and Support:** Importance of pre- and post-test counselling for children undergoing HIV testing
- Orphaned children, in particular, should be provided with psychosocial support to ensure they understand the process and to mitigate the emotional impact of the results
- **Informed Consent and Testing of Vulnerable Children:** Need for sensitive handling of HIV testing for vulnerable populations, such as orphaned children
  - Proper consent
  - Ensuring the child's best interests are prioritized

21

## South African National AIDS Council (SANAC) Guidelines

- **Prevention and Early Diagnosis:** Promote early HIV diagnosis in children, particularly in high-risk populations, such as orphans and vulnerable children
- Aligned with public health goals to reduce the burden of paediatric HIV infections and to ensure early access to ART

22

## South African Human Rights Framework

- **Non-Discrimination:** The Constitution of South Africa prohibits discrimination based on health status, including HIV status
- Children are protected from discrimination and stigma, and policies or practices related to HIV testing must ensure that children are treated with dignity and without prejudice


23



## Benefits & Harms of Testing All Orphaned Children for HIV

24


## Benefits



### Early Diagnosis and Treatment

**Proactive Care:** Timely intervention with ART  
Significantly improve health outcomes, reduce disease progression & extend life expectancy

**Reduction of Transmission:** Reduce risk of HIV transmission  
Especially in care settings where orphaned children may live in close quarters

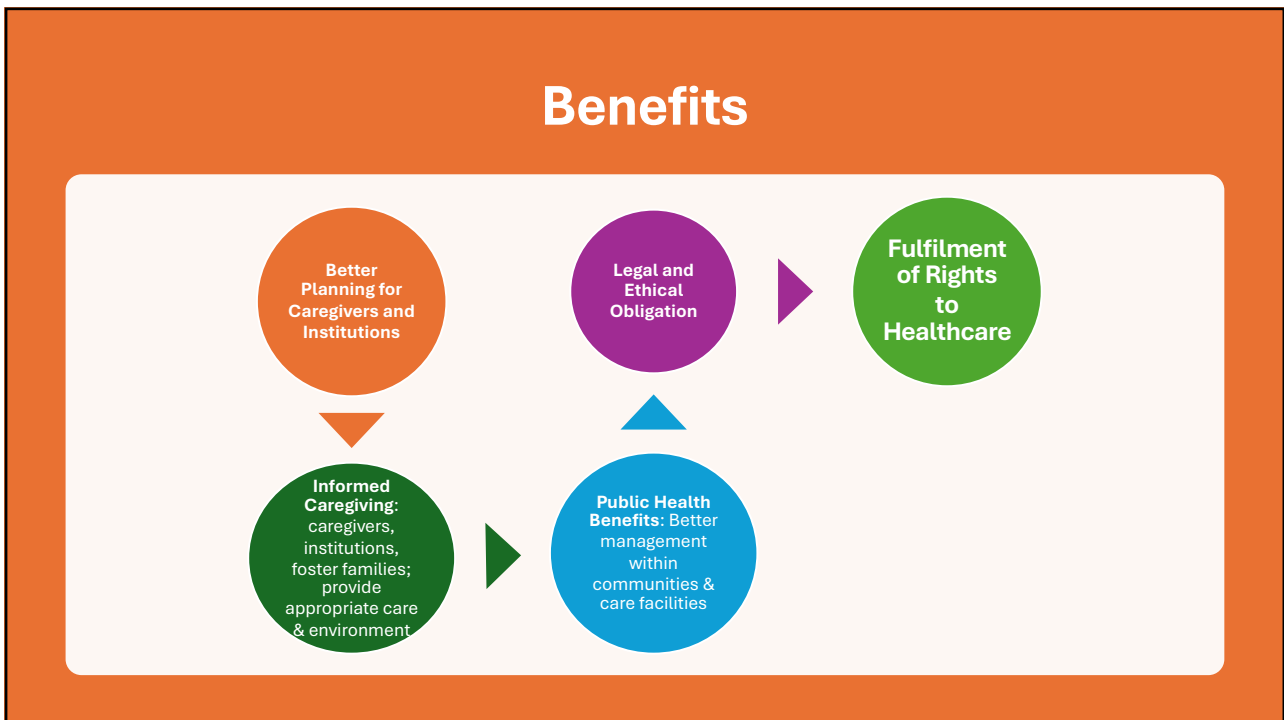


### Improved Health Monitoring

**Continuous Health Support:** Proper medical attention & monitoring; better management of OIs; improved general well-being.

**Comprehensive Care:** Nutritional support; psychosocial counselling & other resources that improve quality of life

25



26

## Harms

### Violation of Privacy and Consent

- **Lack of Informed Consent**
  - Violation of right to privacy & autonomy
- **Confidentiality Concerns**
  - Testing may lead to breaches in confidentiality, especially in institutional settings, where the child's HIV status may be unintentionally or intentionally disclosed, leading to stigma

27

## Harms

### Stigmatization and Discrimination


- **Social Stigma**
  - Within care institutions & wider community
  - Can negatively affect their mental health, social integration & future opportunities
- **Discriminatory Practices**
  - Some institutions or caregivers may treat HIV-positive children differently – segregation; limiting access to care, education, or adoption opportunities

28

# Harms

## Psychological Impact

- **Emotional Distress**
  - Especially if they lack adequate psychological support
  - Feelings of isolation, anxiety, or depression
- **Impact on Childhood**
  - Difficulties in accepting their diagnosis
  - Challenges in maintaining mental & emotional well-being as they navigate the complexities of living with a chronic illness



29



## Ethical Dilemmas in Mandatory Testing

- **Autonomy and Choice**
  - Ethical concerns about autonomy & potential for coercion in healthcare
- **Cultural Sensitivities**
  - Could conflict with local beliefs or attitudes towards HIV
  - Further tension or resistance to care

30

## Conclusion

Effective policies should aim to balance the rights of the child, the need for medical care, and the broader public health benefits of early HIV detection and treatment



31

### South African Legislation and Guidelines on Testing for HIV After Death

Consent

Confidentiality

Public health

32



## 1. Consent for HIV Testing After Death

- **General Rule:** NHA 61 of 2003: HIV testing should be conducted with the informed consent of the individual
    - After death, this principle remains important
  - **Consent from Next of Kin or legal representative**
  - HPCSA: Testing without consent may only be justified in limited circumstances
- 

33

## 2. Confidentiality and Respect for the Deceased

- **Confidentiality:** NHA & HPCSA: confidentiality extends beyond death
  - Deceased's medical information (e.g. HIV) handled with respect & confidentiality
  - Only disclosed to authorized individuals (e.g. family members or legal representatives) or if required by law
  - **Ethical Obligations:** Health professionals must maintain the dignity & confidentiality of the deceased
  - Unauthorized testing or disclosure of an individual's HIV status after death is a violation of medical ethics
- 

34

### 3. Public Health Concerns

- **Mandatory Testing in Special Cases:** NHA allows for certain exceptions where HIV testing may be performed without consent after death
  - Determining the cause of death is crucial for public health reasons
    - Disease outbreaks
    - Deceased was involved in an accident with blood exposure that could affect others
- **Forensic and Legal Contexts:** Coroners may test for HIV if it is relevant to the cause of death or has implications for public health or legal proceedings
  - Must be done in accordance with legal procedures
  - Results must be handled confidentially - strictly within context of autopsy report

35

### Disclosure of HIV Status

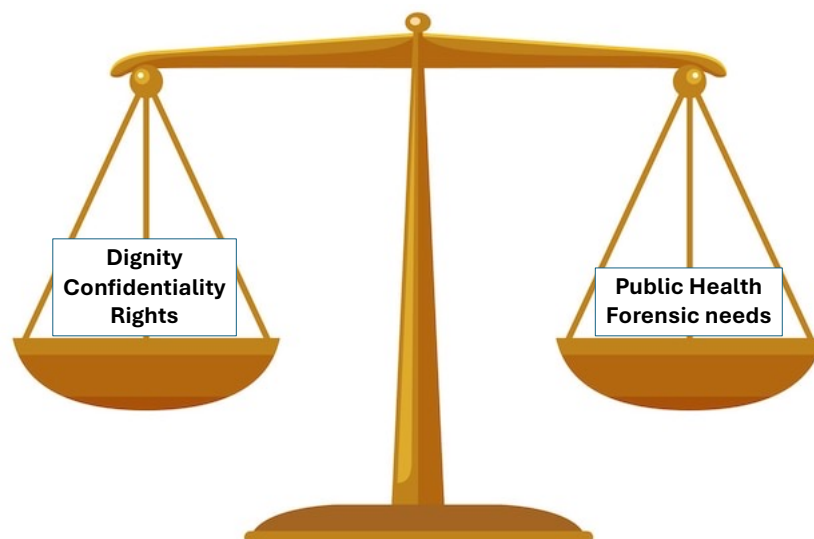
- The results of any HIV testing conducted during an autopsy should only be disclosed to relevant parties
  - Family members
  - Law enforcement
  - Legal, medical, or public health reasons

36

## Protection of Health Workers

- In certain cases, e.g. healthcare worker exposed to HIV during the care of a deceased person, testing may be permitted to assess risk
- Still requires following due legal and ethical processes.

37



38

## Protections That Extend Beyond Death



39

## Dignity & Respect

- **Right to Dignity**
  - South African law, esp. Constitution, acknowledges the inherent dignity of every person, which extends to their treatment after death
  - Respectful handling of the body and remains
  - Funeral and burial practices should uphold this dignity
- **Legal Protections**
  - Although the *Constitution* applies to living persons, courts have recognized that certain rights, like the right to dignity, are still relevant in the posthumous context

40

## Privacy & Confidentiality

- **Confidentiality of Medical Records**
  - NHA & HPCSA protect confidentiality of a person's medical records, including after their death
  - Medical professionals are bound by law to maintain the privacy of a deceased individual's health information, e.g. HIV status, unless disclosure is legally required or consent is obtained from the next of kin
- **Public Health Exceptions**
  - Contagious diseases
  - Forensic investigations
    - Handled with strict legal oversight

41

## Reputation

- **Defamation of the Deceased**
  - SA defamation law protects the living
  - Reputation of a deceased person can still be legally protected in some circumstances
  - Close family members or the estate may bring action if defamatory statements made about the deceased negatively affect their legacy or the emotional well-being of the family
- **Infringements After Death**
  - Courts have dealt with cases where the defamation of a deceased person has impacted the rights of their family or estate
  - Not straightforward, but allows for legal redress if deceased's good name unduly harmed

42



## Disclosure to Family Members (Spouse, Children)

- **Informed Consent and Legal Guidelines**
  - HIV status only disclosed to family members if deceased had given explicit consent
    - Documented in advance directives or discussions prior to death
  - If no prior consent exists, healthcare providers must carefully weigh the decision to disclose against the legal and ethical obligation to maintain confidentiality
- **Immediate Health Concerns**
  - Specific ethical considerations that may justify disclosure
    - Spouse or child could be directly impacted by the deceased's HIV status
      - Risk of exposure (e.g. sexual contact or breastfeeding)
      - Disclosing the HIV status of the deceased could help prevent further transmission or ensure timely testing and treatment for the family member
- **Ethical Dilemmas of Non-Disclosure**
  - Non-disclosure of HIV status may lead to harm, esp. if family members unaware of their own potential exposure

45

## Legal Opinion

McQuoid-Mason argues that such a disclosure can be regarded as being in the public interest, that there is a legal duty on medical practitioners to warn the intimate partners of HIV-positive deceased persons, and that failure to do so may result in legal action by the dependants of such spouses or sexual partners should they incur any loss or damage as a result of being unaware of their HIV status

46

# Legal Opinion

Roehrs argues that various factors will have to be taken into consideration, including whether there is a legal duty on the healthcare practitioner to act, whether there is a special relationship between the healthcare practitioner and the particular patient's intimate partner, what the boni mores of the community warrants in such a situation, what the particular patient's responsibilities are towards their intimate partner(s), and whether these responsibilities may be conferred upon healthcare practitioners by their patients

47



48



## Balancing Beneficence & Autonomy

- **Beneficence (Doing Good)**

- Disclosure of HIV status may benefit surviving family members
  - Enables testing and early treatment
  - Esp. important if family members were unaware of their risk

- **Autonomy of the Deceased**

- Respecting autonomy of the deceased means honouring their decisions & preferences regarding disclosure
- If the deceased had explicitly requested non-disclosure of their HIV status, healthcare providers are ethically bound to respect these wishes unless there is a compelling reason not to

49

## Psychological & Emotional Considerations

- **Impact on Surviving Family Members**

- Emotional and psychological impact on surviving family members
  - Feelings of shock, betrayal, or guilt
  - Sensitive to these potential effects
  - Provide appropriate counselling and support

- **Timing and Sensitivity**

- Timing and manner of the disclosure are critical
- Sensitive communication, counselling, and support for the spouse or child must be provided to help them cope with the information and make informed decisions about their own health

50



## What If the PLWH Is Still Alive?



51

**Disclosure of  
a person's  
HIV status to  
their spouse**

Privacy

Confidentiality

Informed Consent

52



## Confidentiality & Informed Consent

- Legislation & Ethical guidelines
  - NHA
  - Promotion of Access to Information Act
  - HIV & AIDS and STI Strategic Plan for South Africa
- **HCW:** legal & ethical obligation to maintain confidentiality
- Cannot disclose a person's HIV status without their explicit consent, even to a spouse or family members
- The person living with HIV must give **informed consent** for their HIV status to be disclosed
  - They must understand the implications and voluntarily agree to the disclosure

53

## Legal Framework

- **NHA**
  - Ensures the protection of patient information and requires consent for disclosure unless legally required or necessary to protect public health
- **Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA, 2000)**
  - Protects individuals from discrimination based on their HIV status, including in situations of disclosure

54

## Ethical Duty to Warn

- Ethical dilemma: patient refuses to disclose HIV status to spouse/ sexual partner
- SAMA & HPCSA recognize a duty to protect third parties from serious harm
- Only under specific conditions:
  - HCW made all reasonable efforts to persuade patient to disclose their status voluntarily
  - Third party (e.g., the spouse) must be at serious risk of HIV infection
  - Disclosure limited to what is necessary to protect the 3<sup>rd</sup> party's health
  - Patient informed of the intention to disclose
  - HCW should seek guidance from legal and ethical bodies before doing so

55

## Testing and Partner Notification

**VCT** is encouraged

HCW support individuals in making informed decisions regarding disclosure of their HIV status to partners

No automatic right for a spouse to know the other's HIV status

HCWs may have an ethical obligation to inform a spouse under extreme circumstances to prevent serious harm

56

## SAMA

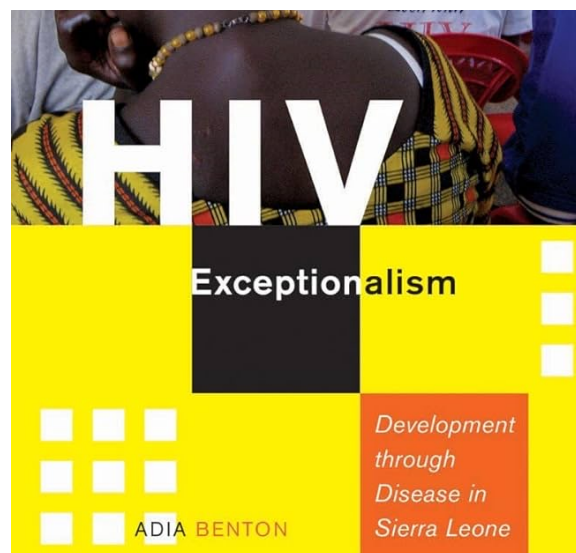
- HCW may breach confidentiality only if:
  - The partner of that patient is clearly identified
  - There is a real risk that the partner will be infected
  - There is no other way to protect the partner other than to disclose the patient's HIV status
- Where the patient reasonably believes that disclosure entails a risk of harm, the HCWs primary duty will be to protect the patient and not disclose their status at all



57

## Are We Guilty of AIDS Exceptionalism?

- Many calling for an end to "AIDS exceptionalism"
- They argue that:
  - Public health interests, & interests of PLWH, will best be served if HIV is regarded as any other STI, such as syphilis
  - Individual privacy & autonomy rights should be limited for the sake of the uninfected



58

## BUT

- HIV and AIDS still stigmatised
- A HIV+ diagnosis has far-reaching effects for patient's future
- Because of these implications, HIV ≠ other diseases
- Therefore, special protection in South African law & ethics



59

## Breach of Confidentiality

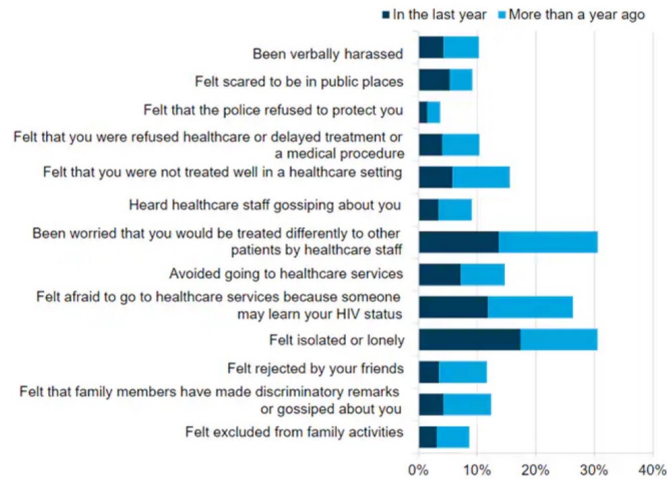


- Different forms of harm
  - Stigmatisation
  - Impact upon individual's ability to obtain insurance
  - Employment, etc

60

## UK Positive Voices 2022: Survey Report Stigma in Different Settings

Percentage of People Living With HIV Reporting Stigma in Different Settings, 2022

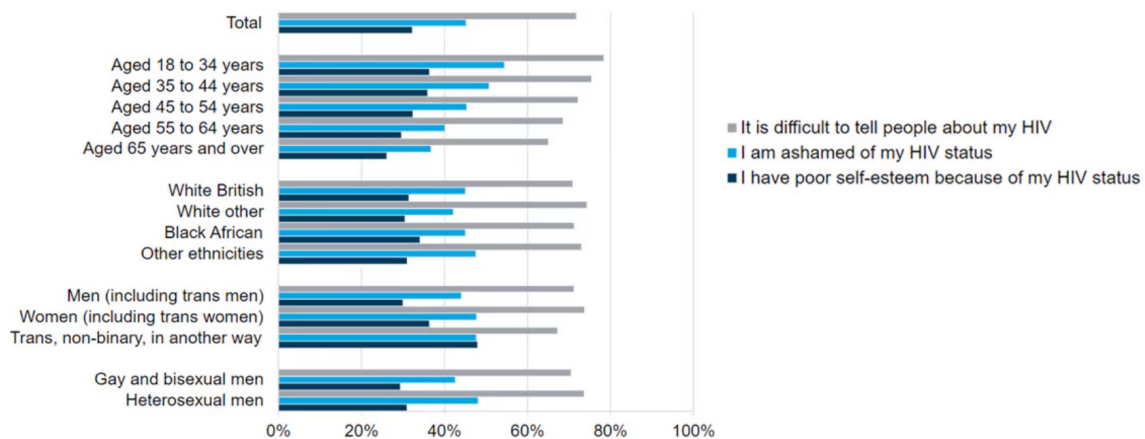


UK Health Security Agency. Accessed February 1, 2024. <https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report#Stigma>

61

## UK Positive Voices 2022: Survey Report Experience of Stigma

Percentage of People Living With HIV Reporting Types of Self-Stigma by Age, Ethnicity, Gender, and Sexuality, 2022

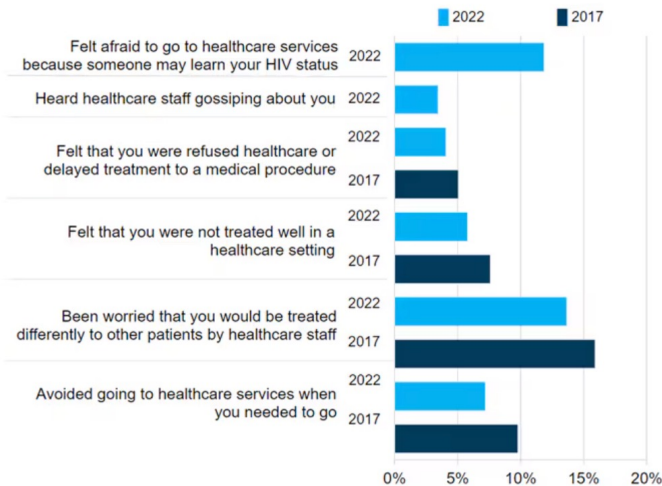


UK Health Security Agency. Accessed February 1, 2024. <https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report#Stigma>

62

## UK Positive Voices 2022: Survey Report Stigma in Healthcare Settings

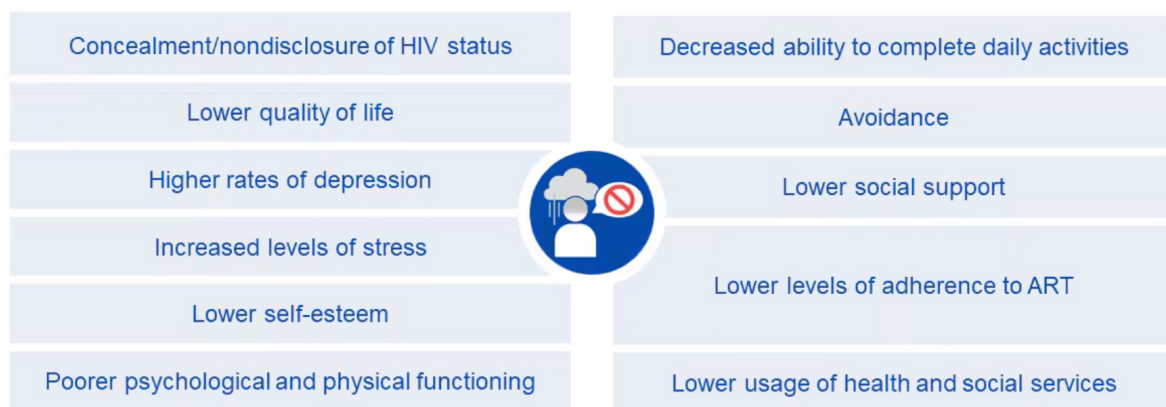
Percentage of People Living With HIV Reporting Stigma in Healthcare Settings in the Past Year, 2017 and 2022



UK Health Security Agency. Accessed February 1, 2024. <https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report#Stigma>

63

## Consequences of HIV Stigma



ART, antiretroviral therapy.  
Camacho G, et al. *Curr Opin Psychol.* 2020;31:28-32; Rueda S, et al. *BMJ Open.* 2016;6:e011453; Turan B, et al. *AIDS Behav.* 2017;21:3431-3439; Holzemer WL, et al. *J Assoc Nurses AIDS Care.* 2009;20:161-168; Larios SE, et al. *Ethn Dis.* 2009;19:65-70; Wingood GM, et al. *Women Health.* 2007;46:99-112; Logie CH, et al. *Prev Med.* 2018;107:36-44.

64



## Evolving Understanding of the Consequences of Stigma

“

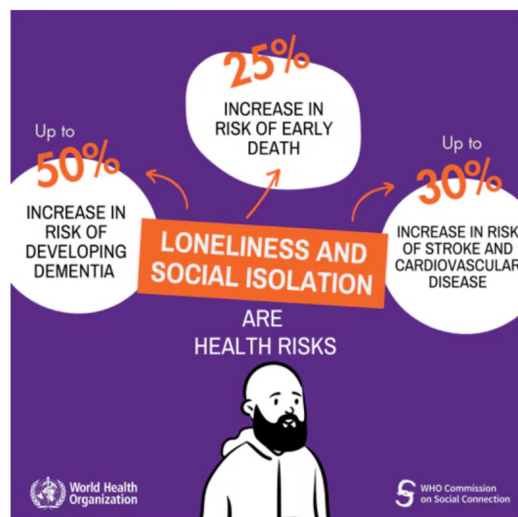
We are growing in our understanding that **mind-body dualism** is actually **not a very helpful paradigm.**

”

“We often have thought of things that are **social constructs**, like **loneliness**, as **something that people experience, but not really entirely connected it to health outcomes**”

65

## The Isolating Experience of Stigma



Reproduced from the WHO "Loneliness and social isolation are health risks," 2023. Accessed February 26, 2024. <https://www.who.int/multi-media/details/loneliness-and-social-isolation-are-health-risks>

66



## Confidentiality & Trust

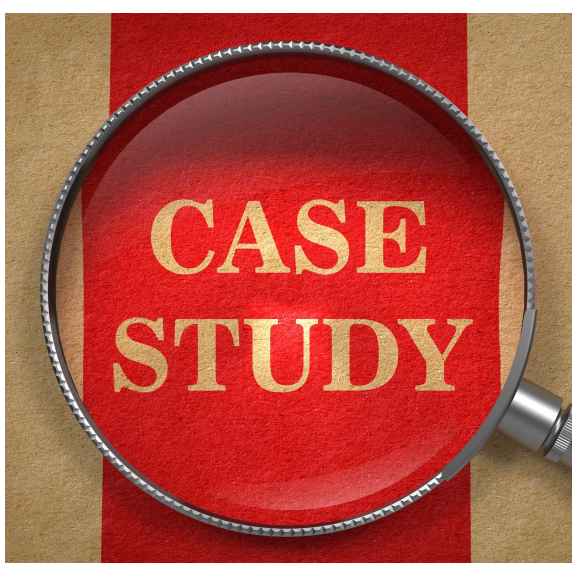
**HPCSA principles of confidentiality**

“Patients have a right to expect that information about them will be held in confidence by health care practitioners. Confidentiality is central to trust between practitioners and patients. Without assurances about confidentiality, patients may be reluctant to give practitioners the information they need in order to provide good care”

67

## Jansen van Vuuren v Kruger

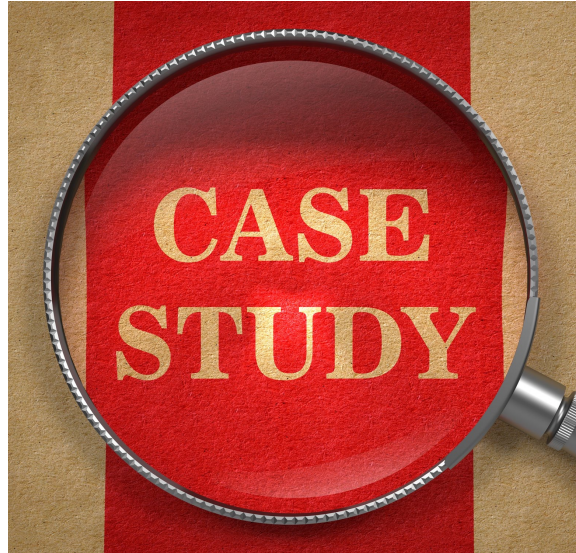
- Medical practitioner disclosed the HIV status of his patient — after an explicit request by the patient to keep the information confidential — to other health practitioners during the course of a game of golf
- The patient/plaintiff instituted proceedings claiming that the medical practitioner owed him a duty of confidentiality in regard of their doctor-patient relationship and regarding any knowledge of the plaintiff’s medical and physical condition



68

## Jansen van Vuuren v Kruger

- Plaintiff: Suffered invasion of privacy & injured in his rights of personality
- Medical practitioner: Disclosure had been made on a privileged occasion, that it was the truth, made in the public interest
- Social & moral duty to make the disclosure to the other health practitioners
- They had a reciprocal social & moral right to receive the information & apply due diligence when again dealing with or treating the plaintiff



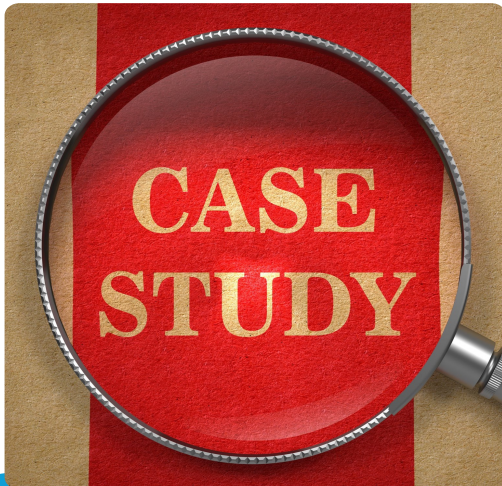
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## Judgement

- Importance of maintaining confidentiality about the information acquired in a medical practitioner's professional capacity even predated Hippocrates and should always be honoured at all costs
- Protect the privacy of patients
- Only way of securing public health, as doctors would otherwise be discredited
- Not merely an ethical duty but also a legal duty recognised by South African common law



70



## ***NM and Others v Smith and Others***

- Applicants claimed their rights to privacy, dignity & psychological integrity had been violated as their names & HIV status had been disclosed, without their prior consent, in the biography of Ms Patricia de Lille, a publication that had been authored by Ms Charlene Smith
- Applicants' details were included in the book in a chapter discussing Ms de Lille's work in campaigning for the rights of PLWH
- Ms Smith made use of an external report, that had been e-mailed to Ms de Lille that detailed information on the clinical trial, the complaints & the ethical enquiry into the trial

71



## ***Judgement***

- "The disclosure of an individual's HIV status, particularly within the South African context, deserves protection against indiscriminate disclosure due to the nature and negative social context the disease has as well as the potential intolerance and discrimination that result from its disclosure. The affirmation of secure privacy rights within our Constitution may encourage individuals to seek treatment and divulge information encouraging disclosure of HIV which has previously been hindered by fear of ostracism and stigmatisation. ***The need for recognised autonomy and respect for private medical information*** may also result in the improvement of public health policies on HIV/AIDS."

72

The Court referred to the case of *NM and Others v Smith and Others 2007 CC*, in which the Constitutional Court held, 'There is nothing shameful about suffering from HIV/AIDS. HIV is a disease like any other; however, the social construction and stigma associated with the disease make fear, ignorance and discrimination the key pillars that continue to hinder progress in its prevention and treatment. These pessimistic perceptions persist to fuel prejudice towards people living with HIV/AIDS.'

73

In this case ([K.A.B v National Union of Metal Workers of South Africa \(NUMSA\) and Others \(1438/2021\) \[2023\] ZAFSHC 288 \(21 July 2023\)](#)) the plaintiff instituted a defamation action against the employer after the employer's supervisor disclosed the plaintiff's HIV positive status in a work grievance meeting with 14 attendees, colleagues of the plaintiff, including the plaintiff.

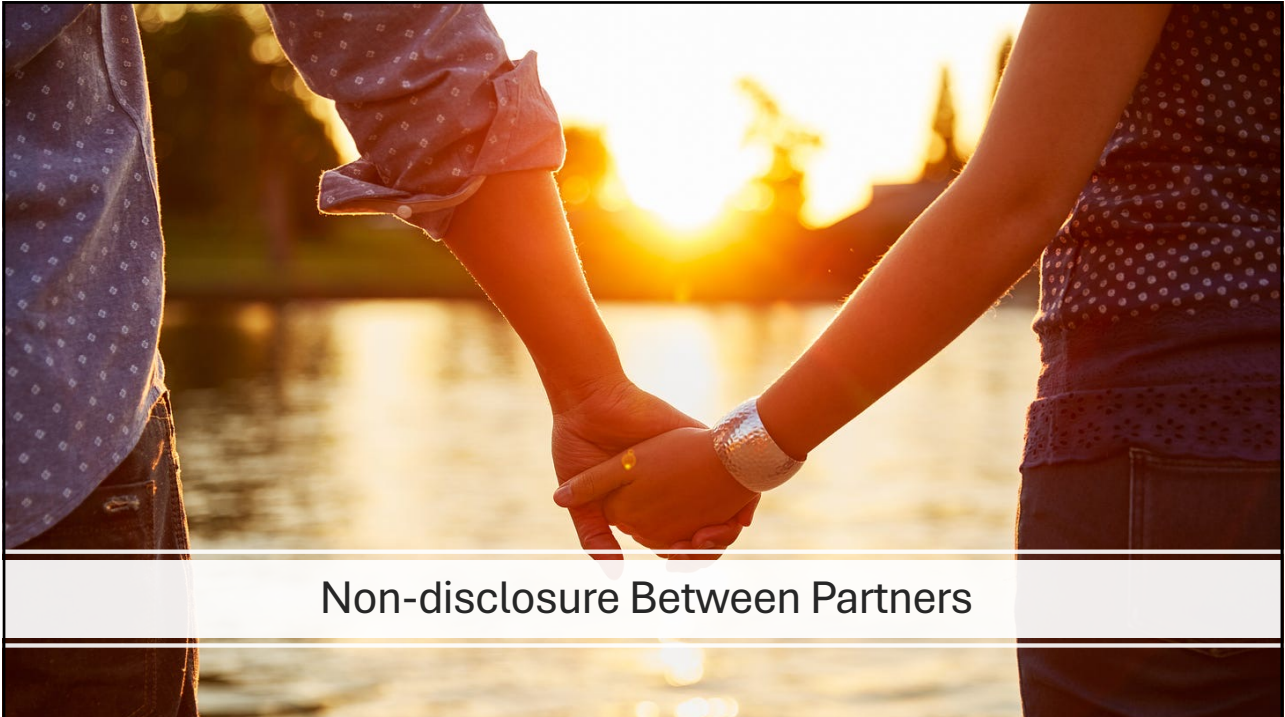
The second defendant disclosed the plaintiff's HIV status in the meeting and later apologised to the plaintiff in the same meeting.

The court had to assess whether the defendants' disclosure of the plaintiff's HIV status constitutes defamation and whether the plaintiff's subjective feelings had been violated and her dignity had been impaired.

The court held that the defendant's disclosure of the HIV status of the Plaintiff in a meeting with 14 people should be regarded as public violation of her privacy, dignity, reputation, and therefore defamation. The supervisor's apology came after the harm had already been done and was delayed. The plaintiff did not consent to the disclosure of her HIV status and that the manner in which the plaintiff testified, even crying during her testimony, clearly showed that the plaintiff sustained injuries to her reputation and dignity.

The court held that the more sensitive the information about a person, the more important it is to protect that information. The disclosure was defamatory of the plaintiff and damages of R100 000.00 were awarded.

74



75

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INTERNATIONAL AIDS SOCIETY

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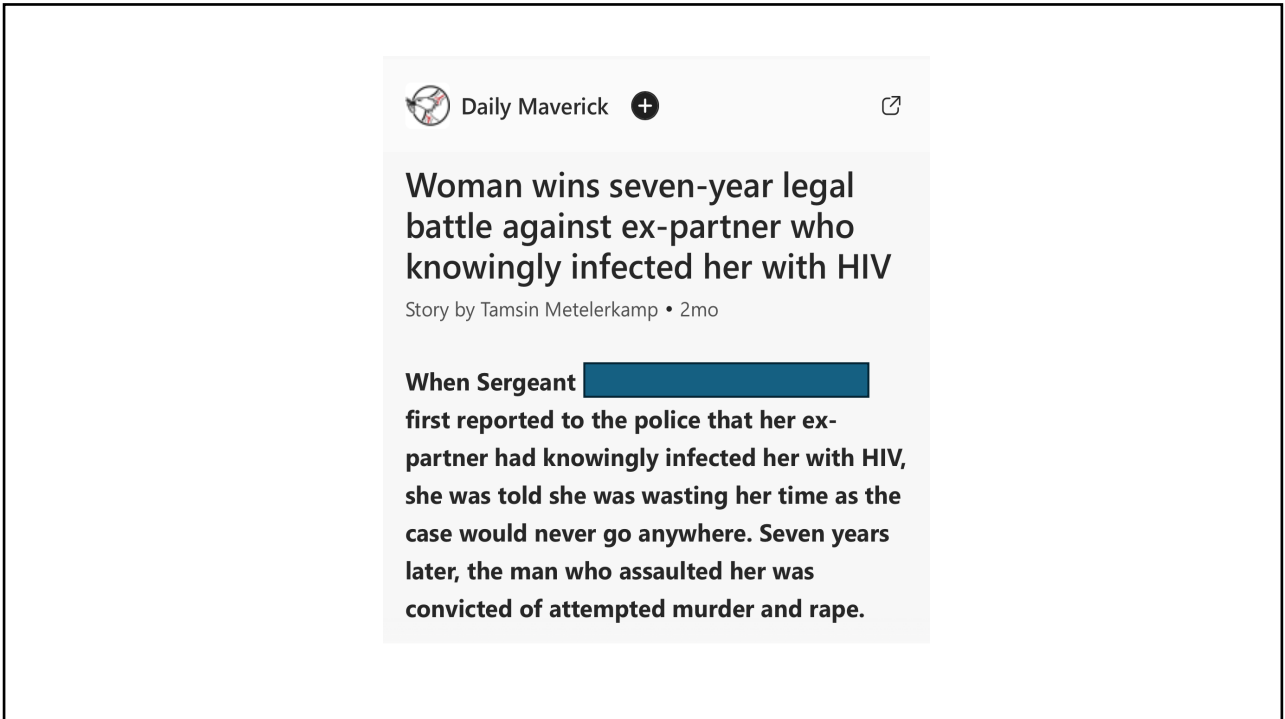
**Expert Consensus Statement on the Science of HIV in the Context of Criminal Law from the *Journal of the International AIDS Society***

The *Journal of the International AIDS Society* (JIAS) has just published the “Expert Consensus Statement on the Science of HIV in the Context of Criminal Law”.

At least 68 countries have laws that specifically criminalize HIV non-disclosure, exposure, or transmission and 33 countries are known to have applied other criminal laws in similar cases. These unwarranted and discriminatory laws could worsen the spread of the virus by stigmatising people living with HIV thus discouraging them from disclosing their status and entering the HIV care continuum.

Concerned that HIV criminalization laws are partly driven by a poor appreciation of the science around HIV, 20 leading scientists, including Nobel Laureate Françoise Barré-Sinoussi and International AIDS Society President Linda-Gail Bekker, developed a Consensus Statement describing the best medical and scientific evidence around HIV transmission to inform the justice system.

76



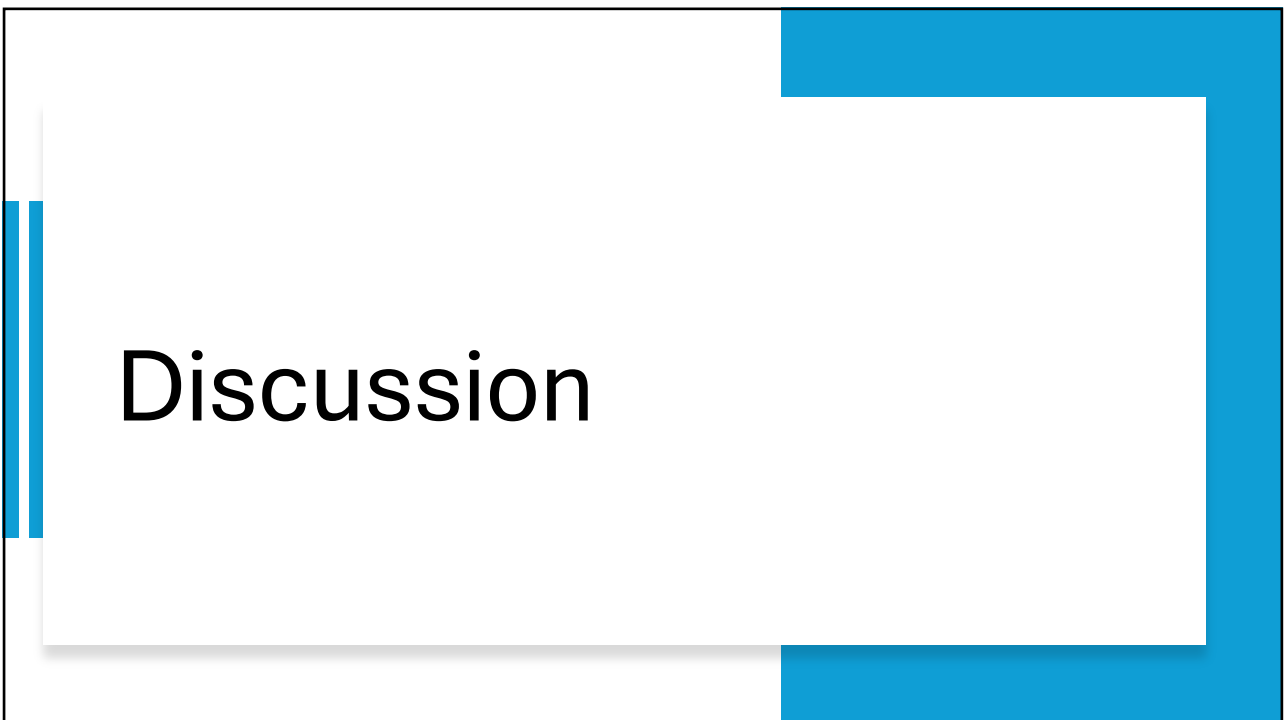
Daily Maverick

### Woman wins seven-year legal battle against ex-partner who knowingly infected her with HIV

Story by Tamsin Metelerkamp • 2mo

**When Sergeant [redacted] first reported to the police that her ex-partner had knowingly infected her with HIV, she was told she was wasting her time as the case would never go anywhere. Seven years later, the man who assaulted her was convicted of attempted murder and rape.**

77



# Discussion

78