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# CLINICAL APPROACHES TO SUPPORTING PATIENTS RETURNING TO HIV CARE

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COMMUNITY OF PRACTICE  
(HU-CCCoP)



**CME Disclosures:  
Planning Committee And Speaker**

**Speaker: The following speaker has nothing to disclose in  
relation to this activity: Dale Babb, MBBS, MSc, DTM&H**

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*Goulda A. Downer, PHD, RD, LN, CNS – Principal Investigator/Project Director*

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**Howard University Telehealth Training Center**

**Planning Committee: The following committee members have nothing to disclose in relation to this activity:**

**Goulda A. Downer, PhD, RD, LN, CNS**

**Walter Bland, MD**

**John McNeil, MD, FACP**

**Denise Bailey, M.ED**

**Speaker: The speaker Dr. Dale Babb disclosure statement is included in the presentation.**

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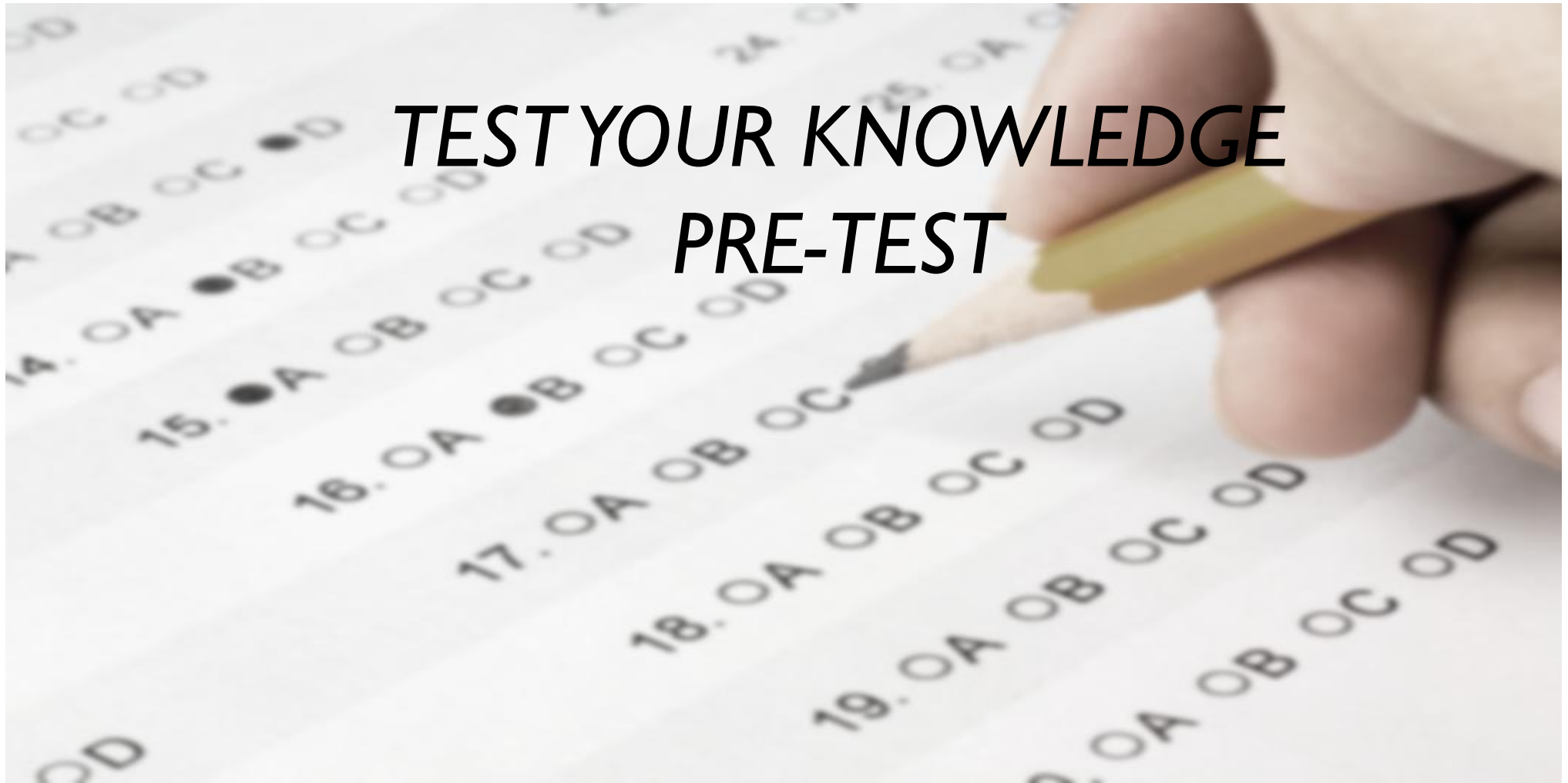
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A close-up photograph of a hand holding a yellow pencil, pointing at a multiple-choice test paper. The paper contains several questions, each with four options labeled OA, OB, OC, and OD. The text 'TEST YOUR KNOWLEDGE' and 'PRE-TEST' is overlaid in the center of the image.

**TEST YOUR KNOWLEDGE**  
**PRE-TEST**



## Test Your Knowledge

### Question #1

Which of the following statement is True? Choose the best response

- A. Retention in HIV care is not related to a client's continuous engagement with the health services or in medical care
- B. Retention in HIV is defined as a patient who misses less than 3 clinic visits per year
- C. Retention in HIV care is challenging to define and measure as there is no single accepted universal definition
- D. A and B



## Test Your Knowledge Question #2

**What factors may predict altered patient attendance for regular ongoing care in the Caribbean?**

- A. Female gender
- B. Higher socioeconomic status
- C. Belonging to a minority race or ethnicity
- D. A lack of health insurance

## Test Your Knowledge

### Question #3

**What are the most common reasons for non-retention in HIV care? Choose the best response.**

- A. Active substance abuse
- B. Advanced age
- C. Lack of social support
- D. Active psychiatric illness

## Test Your Knowledge

### Question #4

**Strategies to support retention of clients in HIV care includes which of the following? Choose the best response.**

- A. Reinforcing positive behaviours to adopt a positive relationship between clients and providers
- B. Making decisions without the clients as they are not compliant
- C. Stopping benefits for clients to force them to return to clinic to receive benefits
- D. Insisting on patient attendance at clinic to continue ongoing treatment

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# **CLINICAL APPROACHES TO SUPPORTING PATIENTS RETURNING TO HIV CARE**

## LEARNING OBJECTIVES

**By the end of this session participants will be able to:**

1. Discuss the terminologies used to describe non-retention in care
2. Describe the main predictors and reasons for non-retention in HIV care
3. Explain strategies and approaches for addressing non-retention of patients in HIV care
4. Demonstrate methods available to support noncompliant patients in their return to treatment and retention in care

## DEFINITIONS AND TERMINOLOGY

- Retention in care challenging to define and measure as there no single accepted definition, no “gold standard”
- Examples:
  - Remaining connected to medical care, once entered
  - Patients known to be alive and receiving treatment
  - Based on frequency of clinic visits (2 weeks to 1 year)
  - Based on number of viral load tests per year
- Additionally – varying terms used
  - Lost to follow up
  - Attrition
  - Defaulted

1. Mbugbaw L et al. Strategies to improve adherence to antiretroviral therapy and retention in care for people living with HIV in high-income countries: a protocol for an overview of systematic reviews. *BMJ Open* 2018;8:e022982
2. Stricker SM et al. Retention in care and adherence to ART are critical elements of HIV care interventions. *AIDS Behav.* 2014;18 Suppl 5:S465-75.

## DEFINITIONS AND TERMINOLOGY (2)

### Standard Operating Procedures for Returning HIV Clients to Care in Barbados

#### Definition of Default/Non-retention

- Missed  $\geq 2$  consecutive, scheduled clinic appointments over the past 12 months
- Has not attended any clinic appointments, had a viral load/CD4 test done, or picked up medication in 12 months
- Resilient defaulters, further defined as those who cannot be contacted, or located by telephone or house visit, after 6 months of active effort

# INTRODUCTION

- Poor patient retention undermines program and patient outcomes, including achieving sustained viral suppression
- The global effort to increase the number of people on Antiretroviral Therapy (ART) needs to ensure that people taking ART are retained in chronic care for life
- Sustained regular HIV care is critical for overall health of HIV infected patients and for prevention of HIV transmission
- Retention in ART programs is a major challenge in all settings and across populations, specifically pediatric and adolescent populations, postpartum women and men

1. World Health Organization. Retention in HIV programmes: Defining the challenges and identifying solutions. Meeting Report 13-15 September 2011. Geneva: 2011.

2. HIV – Retention in Care [cited 2023 Feb 14] . Available from: <https://www.cdc.gov/hiv/clinicians/treatment/care-retention.html>



## REVIEW OF EVIDENCE – RETENTION IN CARE

- Main predictors of non-retention
  - Developed countries - substance abuse, psychiatric illness, social issues
  - Developing countries - stage of illness, male sex, lower level of education, practical issues e.g., transportation and access
  - *Younger age* consistent across most studies
- Social and psychosocial support associated with good retention
- Early linkage to care was associated with longer term retention in care
- Many authors echoed the need for quantitative studies to bolster the abundance of qualitative evidence that exists

1. Bulsara et al. Predictors of Adult Retention in HIV Care: A Systematic Review. *AIDS Behav.* 2018;22(3):752-64.

2. Holtzman CW et al. Mapping patient-identified barriers and facilitators to retention in HIV care and ART adherence to Andersen's Behavioral Model. *AIDS Care.* 2015;27(7):817-28.

3. Yehia BR et al. Barriers and facilitators to patient retention in HIV care. *BMC Infect Dis.* 2015;15:246.

# RATES OF RETENTION

- Rates of retention and attrition vary widely across programmes
- In the United States, in 2018, approximately 58% of persons with HIV were retained in care, defined as having at least 2 CD4 cell counts, or HIV RNA levels obtained that year <sup>1</sup>
- One observational study in the US showed an attrition rate of 43% <sup>2</sup> while a Ugandan study of similar size demonstrated an attrition rate of approximately 30% <sup>3</sup>
- 20% of PLHIV in Canada have “discontinuous” care

1. Roscoe C et al. Retention in HIV Care. 2020 September 10, 2020. In: National HIV Curriculum. University of Washington. Available from: <https://www.hiv.uw.edu/go/basic-primary-care/retention-care/core-concept/all>.

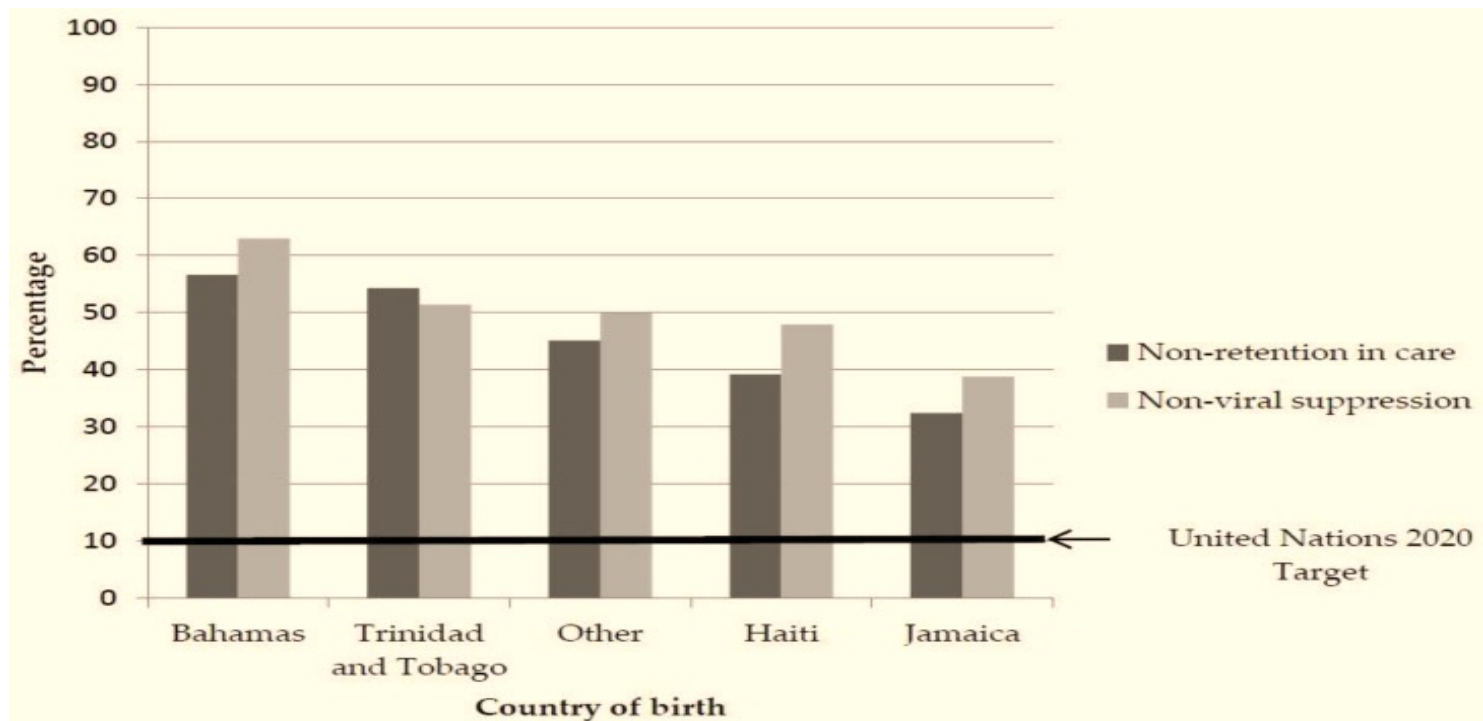
2. Crawford TN. Poor retention in care one-year after viral suppression: a significant predictor of viral rebound. *AIDS Care*. 2014;26(11):1393-9.

3. Boeke CE et al. Assessing linkage to and retention in care among HIV patients in Uganda and identifying opportunities for health systems strengthening: a descriptive study. *BMC Infect Dis*. 2018;18(1):138

## PREVALENCE OF NON-RETENTION

- The 2020 United Nations goal - 10% or less of HIV infected individuals being non-retained in care or achieving viral suppression, (non-Hispanic Caribbean immigrants are far from this goal)
- PLWHIV from **Bahamas, Trinidad and Tobago, and Haiti** had the highest percentages of non-retention: 56.6%, 54.3%, 39.2%;
- PLWHIV from **Bahamas, Trinidad and Tobago, and Haiti** - non-viral suppression (non-viral suppression: 63.0%, 51.4%, 47.9%).
- Cases from Jamaica did not differ statistically from any of the reference groups

# UNITED NATIONS TARGET VS CARIBBEAN COUNTRIES



# REVIEW OF EVIDENCE – RETENTION IN CARE

- Inconsistent with care or cycling in and out of care:
  - Female
  - Belong to a minority race or ethnicity
  - Lower socioeconomic status
  - Lack health insurance
  - Newly changed insurance company
  
- Drug or alcohol dependence
  
- Untreated depression

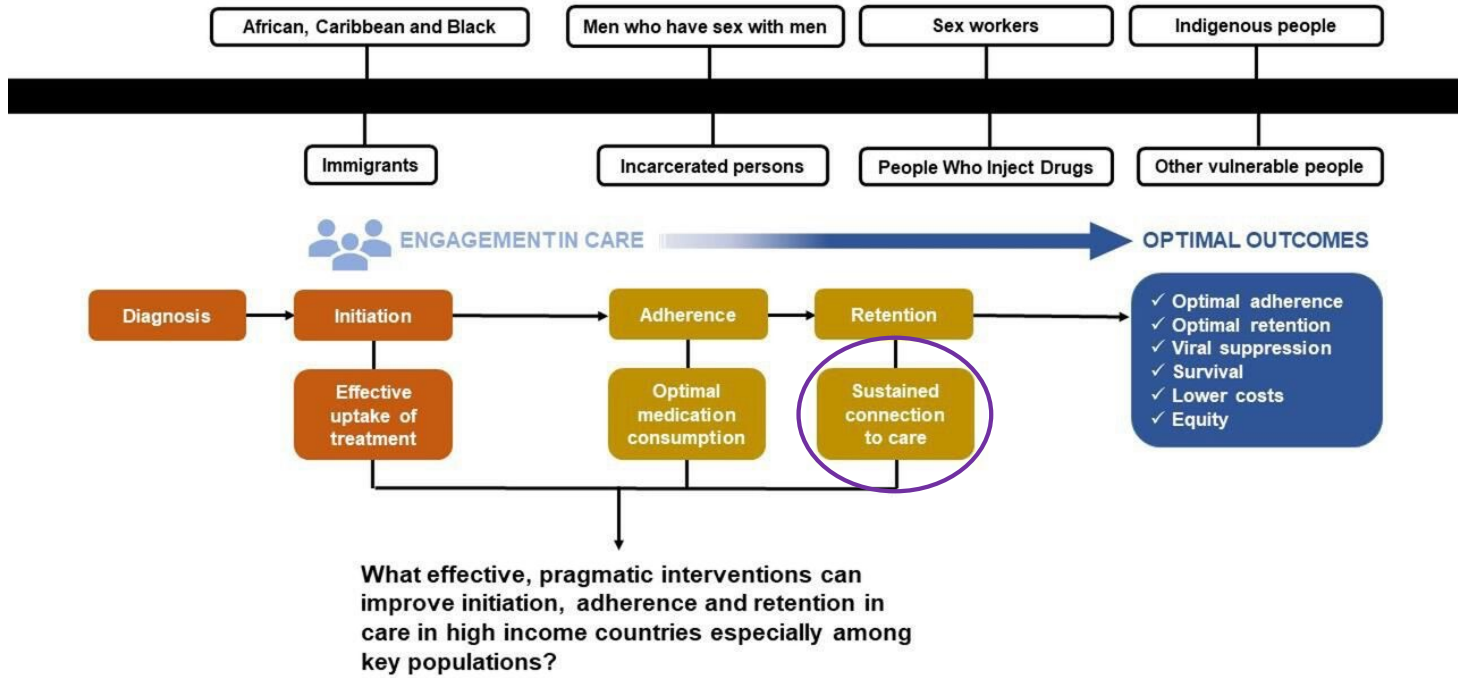
# PRIORITY POPULATIONS AND DISPARITY

Higher risk of poor retention, gaps in care

- Men who have sex with men
- Racial and ethnic minorities including indigenous peoples
- Individuals who use drugs
- Those with health insurance issues
- Other socially marginalised groups (e.g. immigrants, refugees)
- Women who face systemic risk and other groups known to have challenges with engagement in care

1. Mbugbaw L et al. Strategies to improve adherence to antiretroviral therapy and retention in care for people living with HIV in high-income countries: a protocol for an overview of systematic reviews. *BMJ Open* 2018;8:e022982
2. Cunningham CO et al. Factors associated with returning to HIV care after a gap in care in New York State. *J Acquir Immune Defic Syndr*. 2014 Aug 1;66(4):419-27.

## Outline of the HIV Care Cascade





# **CASE STUDY#I**



## CASE #1: SE

SE, a 29-year-old female attended treatment clinic in July 2008 having been brought in by her father. She had been in care for 2 years. He gave a history of his daughter testing positive for HIV in October 2006 while on remand at the Psychiatric Hospital. She has a h/o - active substance abuse (cocaine) & was drowsy at time of visit.- She was given a follow up to return – but did not return at slated time.

October, 2008 – Returned to clinic independently, advised of HIV status – states she was not previously aware of status

October, 2008 - In patient of the Psychiatric Hospital for detox– brought by Psychiatric Nurse

### **At baseline:**

CD4 190 cells/mm<sup>3</sup> (30%) – July 2008

VL 18,800 copies/ml – October 2008 (earliest available VL)

Clinically: Mild anemia, pruritic papular eruptions, intermittent diarrhea

B3 & Not on HAART

To be reviewed in 2 weeks



## CASE #1: (CONT'D)

- Did not return for the review appointment
- Defaulted for 8 months (from October 2008 to June 2009)
- On return
  - Referred for social assessment, Food Bank assistance and welfare assistance
- Counselling concerning the need for Antiretroviral Therapy (ART)
- Attended next 3 scheduled visits
- Discussion re ART continued
- Decision to have her attend with a relative before starting ART

## CASE # 1: (CONTD.)

- SE and her 2 children (aged 9 and 4) moved in with her mother
- SE reported no cocaine use in the 3/52 prior and felt she could “manage her addiction”
- Open to the idea of non-residential rehab
- Started on ART, June 23, 2009 (TDF/FTC/NVP) and referred to MSW to organize entry to rehab
- SE maintained 100% adherence for 2/12
- Then defaulted after 3/12, for - > 2 years...

## CONSIDER...

- Information from her history & examination should include
  - Contact tracing
  - Her level of competence/ability to adhere
  - Psychiatric History – severity/control
  - Family Support
- HIV management – ART – Oral vs Long acting Injectables, feasibility?

## REASONS FOR POOR RETENTION AND ADHERENCE

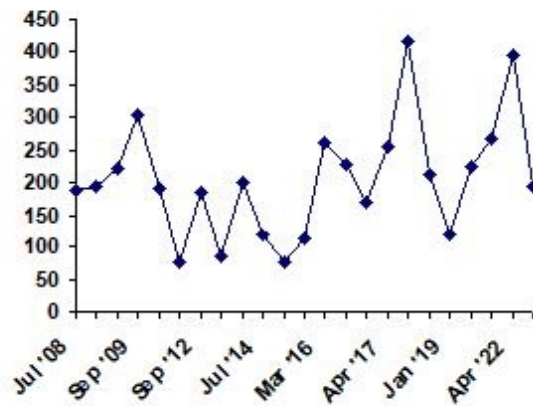
*Crack cocaine use*

*Lack of support* (when she lived with her mother and attended visits with relative, adherence and retention improved)

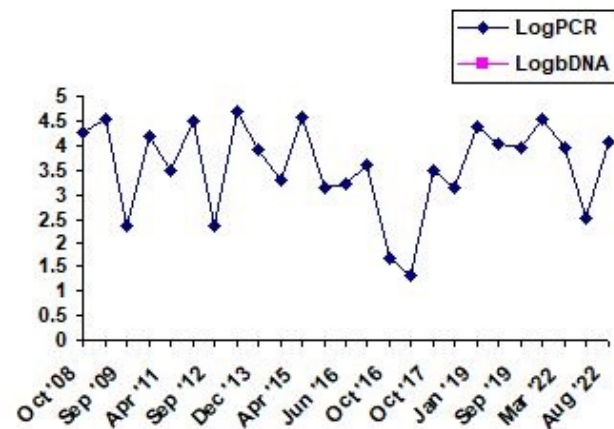
*Forgetting* (medication and appointments)

# SUMMARY OF RESULTS, 2008 TO 2022

CD4



Viral load



## REGIMENS USED

- 2009 - TDF/FTC/NVP (initial response)
- 2012 - TDF/FTC/ATV/r (initial response with pill distribution support)
- 2016 - ABC/3TC/ATVr (initial response)
- 2022 – ABC/3TC/ATV/r (response with pill distribution support)
  
- Resistance test requested – results not available

## CURRENT STATUS

- On ABC/3TC/ATVr currently
- Adherence maintained when supports are in place (mother, residential drug rehabilitation)
- Pill boxes distributions being utilized
- VL 326 copies/ml (12/04/2022) and 12,100 copies/ml (17/08/2022)
- Last clinic attendance November 2022



## STRATEGIES EMPLOYED

- Strengthening of support mechanisms (family support, external social support)
- Drug Rehabilitation
  - Non-residential and residential care
- Use of weekly pill distributions
- Resistance testing and change of regimen



# **CASE STUDY #2**

## CASE #2: J.H

J.H. 47-year-old male was diagnosed HIV positive in 2001 in late-stage disease.

Earliest available results

CD4 – 40 cells/mm<sup>3</sup> (April 2001); VL 190,000 copies/ml (March 2002)

Admitted to hospital March 2002 with seizures

Main diagnoses - Cerebral Toxoplasmosis and AIDS Dementia Complex

ART commenced April 2002 (AZT/3TC/EFV)

Client's ART was administered by his family (son, daughter and wife)

100% adherence reported by son

## CASE #2: CONT'D

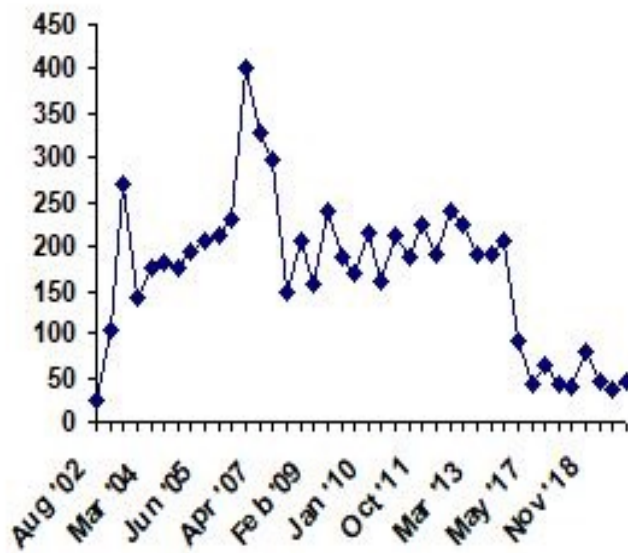
- Assisted by family with meds and attending appts
- Of note, June 04 wife died, but family support continued from his children
- Between 2003 – 2008, missed some appointments and collection of medication repeats dues to transportation issues
- Interventions:
  - Strong support from family, with meds administered by them daily
  - Decision was made to start pill boxes weekly
  - Community visits were commenced by nurse
  - Driver was asked to deliver medications to J.H. residence
- Adherence averaged 95-100% over that time period, and reflected in virologic response to ART

## GAPS IN CARE

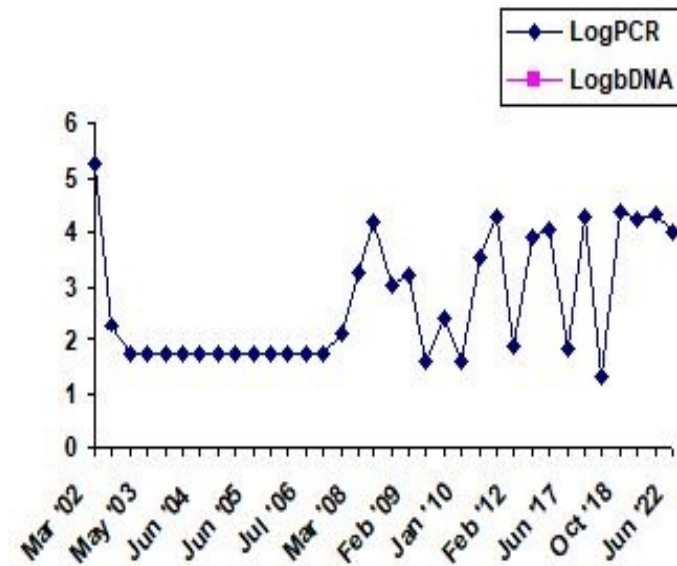
- In 2008, things began to go awry
- Main issues highlighted:
  - Intellectual deficit
  - Cognitive impairment, with increasingly poor memory
  - Need for transport from home to clinic and for delivery of medications
  - Less support from family (occasional relationship tension)
  - Alcohol abuse (refused support to decrease or stop)
  - Developed HTN, peripheral neuropathy
- Repeated episodes of defaulting, 4 months, 1 year, 18 months, 10 months, 7 months
- Additionally, h/o of a fall 2020, injury to lower back, resulting in further reduced mobility (previously used a walker at clinic appointments, now progressed to wheelchair)

# SUMMARY OF RESULTS, 2002 - 2022

CD4



Viral load



## REGIMENS USED

- AZT/3TC/EFV – 1<sup>st</sup> Line ( April 2002)
- TDF/FTC/LPV/r – 2<sup>nd</sup> Line (March 2009)
- TDF/FTC/LPV/r/ABC
- TDF/FTC/ATV/r/ABC
- TDF/FTC/DTG (current) – Simplification

## AT PRESENT

- Recently returned to care after a 7/12 gap
- Adherence sub-optimal
- Daughter “helps with medications” – less supportive compared to before
- CD 4: 47 cells/mm<sup>3</sup>; VL 9,780 copies/ml
- Physical and mental decline noted
- Support reinforced with respect to:
  - Transportation to clinic
  - Establishing the main point of contact within the family
  - Re-engaging with social worker
  - Assistance with medication refills and collection or transport when clinic vehicle is functional



## DISCUSSION

1. What are the support needs of this patient? Mentally/Physically/ socially?
2. How much intervention is acceptable in a limited resources situation?
3. Are resources being wasted?
4. How do you rationalize your management? E.g. Intensity/Cost
5. Compared to the previous case study where were the successes gained?

## STRATEGIES EMPLOYED IN THIS CASE

- Involvement of family, strengthening of family support
- Home visits by community nurse and medical social worker to monitor and support adherence, discuss any issues with family
- Providing transport for client to and from clinic
- Delivery of medications
- Use of pillboxes (one week supply at a time)
- Referral to MSW (social assessment and support, substance use counselling)

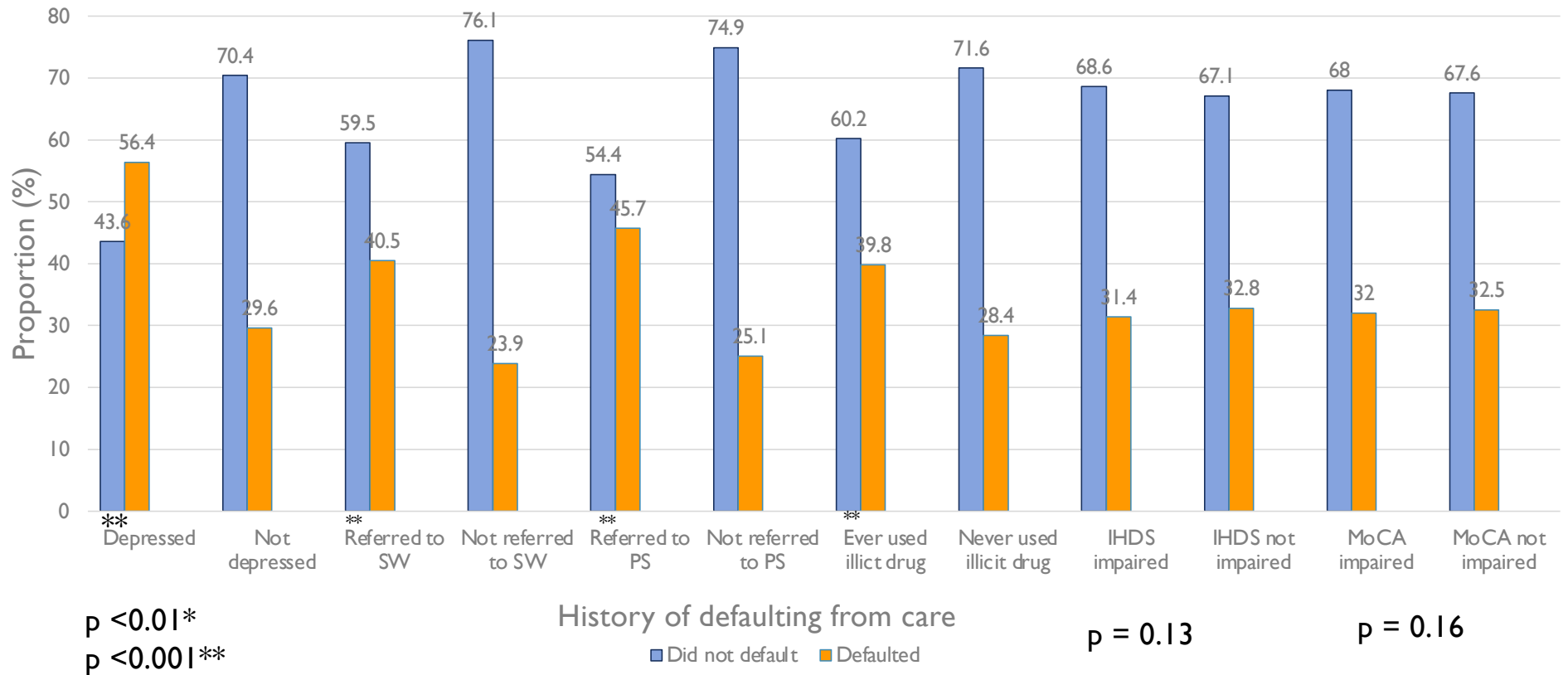
# RETENTION IN CARE – HIV PROGRAM BARBADOS

- First attendance:
  - Within 1 month (46.9 %)
  - Within 6 months (34.2%)
  - 6 months – 2 years (15%)
  - > 2 years (3.8%)
  
- Never defaulted, 67.9% ; Ever defaulted, 32.1%
  - Once 14.6%
  - Multiple occasions 17.5%
- Overall rate of default: 17% (2022)

1. Babb D. (2022) An Assessment of Adherence to Antiretroviral Therapy and Retention in Care among persons living with HIV in Barbados. Dissertation.

2. HIV/STI Programme, Routine Surveillance Data (preliminary), 2022

## Relationship between default and specific factors

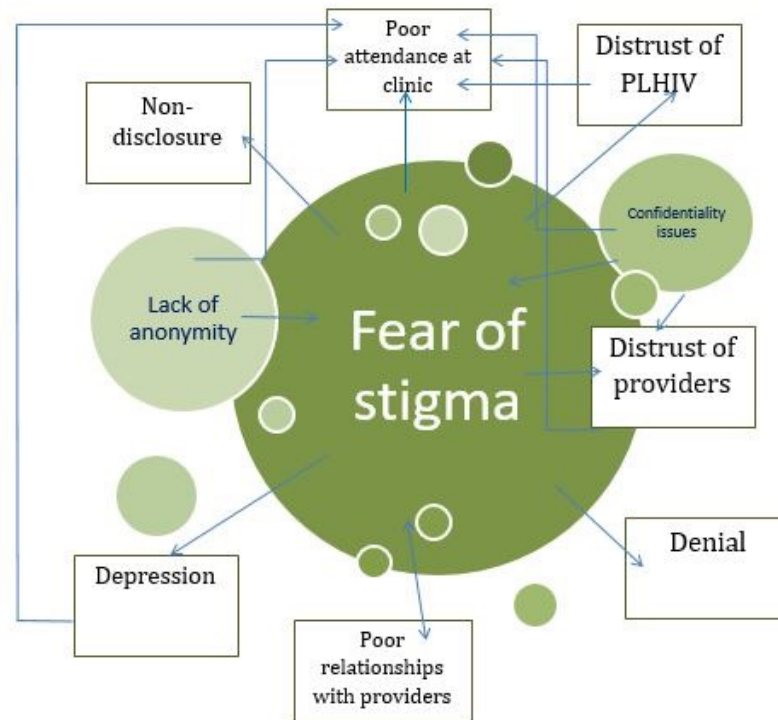
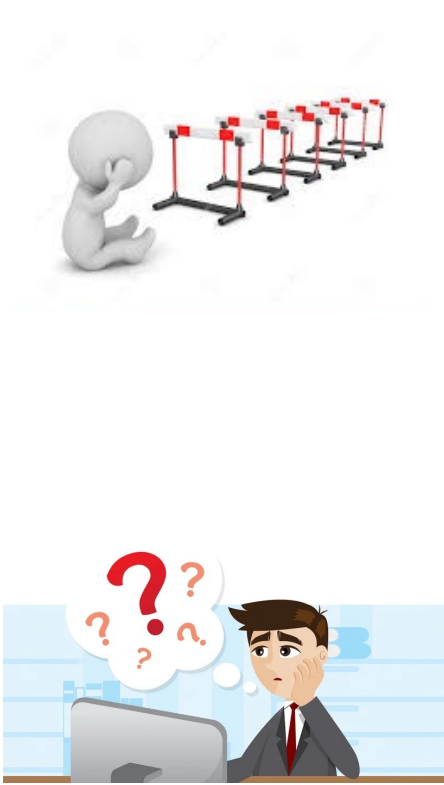


## FACTORS ASSOCIATED WITH DEFAULT (NON-RETENTION) ON LOGISTIC REGRESSION

Default	Odds Ratio	Std. Err.	Z	P > z	(95% Conf. Int.)
<b>Depression</b>	2.47	0.73	3.06	0.002	1.39 – 4.40
<b>Referral to a social worker</b>	2.20	0.42	4.16	0.000	1.52 – 3.18
<b>Age</b>	1.03	0.01	4.16	0.000	1.02 - 1.04
<b>_cons</b>	0.164	0.07	-4.23	0.000	0.071 - 0.378

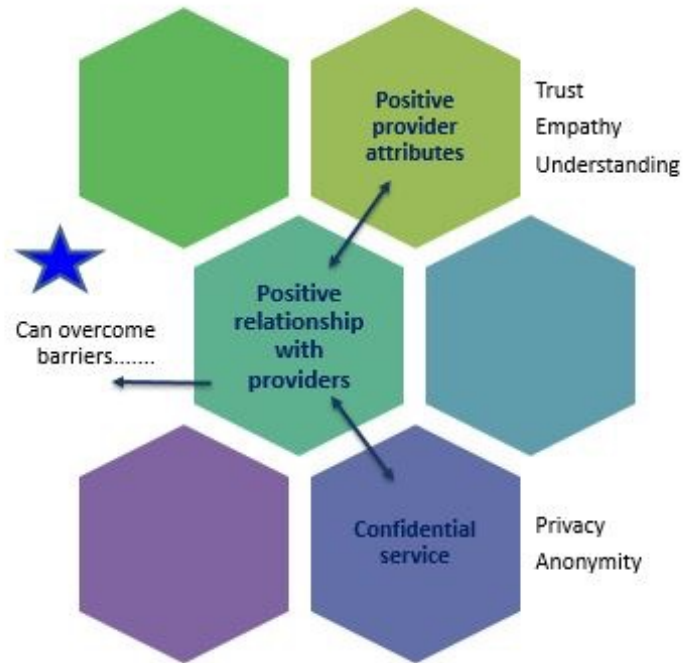
No. of observations = 582; LR chi sq = 48.6; Prob > chi2 = 0.000; Pseudo R2 = 0.0665

# BARRIERS TO RETENTION IN CARE ARE INTERCONNECTED



1. Babb D. (2022) An Assessment of Adherence to Antiretroviral Therapy and Retention in Care among persons living with HIV in Barbados. Dissertation.

# FACILITATORS OF RETENTION IN CARE



***Relationship between the health care facilitators of retention in care***

1. Babb D. (2022) An Assessment of Adherence to Antiretroviral Therapy and Retention in Care among persons living with HIV in Barbados. Dissertation.

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## ADDITIONAL APPROACHES FOR SUPPORTING CLIENTS RETURN TO HIV CARE

- Locating those who have defaulted – calls, text messages, house visits
- Addressing the specific issue where possible
  - Active psychiatric illness – referral and treatment
  - Substance abuse – referral to rehab programs
  - Social issues – MSW assessment and appropriate support (welfare, housing, food assistance etc.)
  - Addressing the environment and convenience of clinic services to reduce stigma associated with accessing the service
- Differentiated care programs e.g. after hours clinics (evenings and weekends)
- Ongoing efforts e.g. calls and contact when an appointment is missed
- Individual and collective social and psychological support must be maintained



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## GENERAL STRATEGIES TO SUPPORT RETENTION IN HIV CARE

- Assist patients in modifying their behaviour
- Gain the patient's trust
- Have good communication between the patients and HCWs to collaborate in the decision-making
  - Show empathy
  - Address health care system constraints
  - Incorporate psychosocial, sociocultural, gender, age, and chronic illness factors
  - Have an interest in the barriers that patients have
  - Mutually agree on a plan
  - Reinforce positive behaviours

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## GENERAL STRATEGIES TO SUPPORT RETENTION IN HIV CARE

- Enable access to services and resources as needed
- Use of mobile health (mHealth) applications to provide support with engagement in care
- Include use of video social media platform to help meet patients' needs
- Use of real time patient tracking systems to determine non- compliance/ non retention
- Discuss consent to intervention and observe HIPAA and privacy laws

1. Cohn WF et al. An Implementation Strategy to Expand Mobile Health Use in HIV Care Settings: Rapid Evaluation Study Using the Consolidated Framework for Implementation Research. JMIR Mhealth Uhealth. 2021 Apr 28;9(4)

2. Fonner, V.A. et al. (2021) Patient-provider text messaging and video calling among case-managed patients living with HIV: Formative acceptability and Feasibility Study, JMIR Formative Research. Canada.

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## GENERAL STRATEGIES TO SUPPORT RETENTION IN HIV CARE

- Set up and maintain a simple standardized monitoring system
  - Track the number of patients in care (every month, quarter, etc.)
- Reliably ascertain true treatment outcomes
  - Death, stopped treatments, loss to follow-up, transferred patients
- Ensure uninterrupted ART drug supplies
- Use simple non-toxic, and economical ART regimens
- Decentralize ART clinics and reduce the number of visits for stable patients
- Reduce indirect patient costs (e.g. socioeconomic interventions)
  - Provide transportation, social support, home-based care, welfare support, food, etc.
- Strengthen ART links within and between health services and the community
  - Community links e.g. nurses, family members, etc.
- Use Innovative Interventions

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## LESSONS LEARNED

- Non-retention is a complex issue
  - There are no “easy” solutions for complex issues
- Reasons for poor retention evolve over time as circumstances/stages of life change
- Efforts to return persons to care and retain them in care should:
  - Be individually tailored to the clients specific need
  - Utilise multiple approaches
- The process is often highly labour intensive



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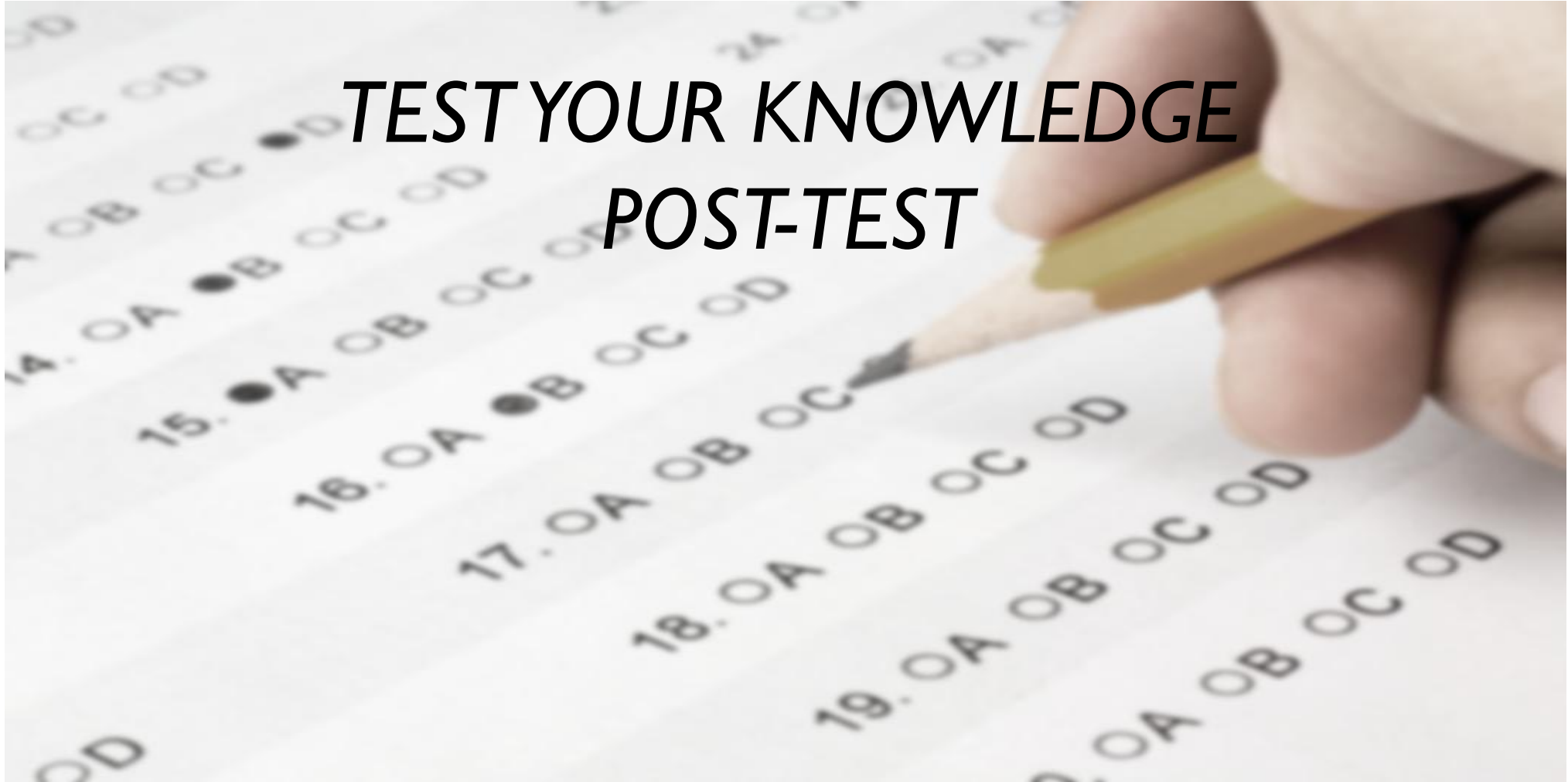
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# ***QUESTION & ANSWER SESSION***



*Thank You*

**TEST YOUR KNOWLEDGE  
POST-TEST**





## Test Your Knowledge Question #5

Which of the following statement is True? Choose the best response

- A. Retention in HIV care is not related to a client's continuous engagement with the health services or in medical care
- B. Retention in HIV is defined as a patient who misses less than 3 clinic visits per year
- C. Retention in HIV care is challenging to define and measure as there is no single accepted universal definition
- D. A and B

## Test Your Knowledge Question #6

**What factors may predict altered patient attendance for regular ongoing care in the Caribbean?**

- A. Female gender
- B. Higher socioeconomic status
- C. Belonging to a minority race or ethnicity
- D. A lack of health insurance

## Test Your Knowledge Question #7

**What are the most common reasons for non-retention in HIV care? Choose the best response.**

- A. Active substance abuse
- B. Advanced age
- C. Lack of social support
- D. Active psychiatric illness

## Test Your Knowledge

### Question #8

**Strategies to support retention of clients in HIV care includes which of the following? Choose the best response.**

- A. Reinforcing positive behaviours to adopt a positive relationship between clients and providers
- B. Making decisions without the clients as they are not compliant
- C. Stopping benefits for clients to force them to return to clinic to receive benefits
- D. Insisting on patient attendance at clinic to continue ongoing treatment

## REFERENCES

1. World Health Organization. Retention in HIV programmes: Defining the challenges and identifying solutions. Meeting Report 13-15 September 2011. Geneva: 2011.
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7. Yehia BR et al. Barriers and facilitators to patient retention in HIV care. *BMC Infect Dis*. 2015;15:246.
8. Mbuagbaw L et al. Strategies to improve adherence to antiretroviral therapy and retention in care for people living with HIV in high-income countries: a protocol for an overview of systematic reviews. *BMJ Open* 2018;8:e022982
9. Cunningham CO et al. Factors associated with returning to HIV care after a gap in care in New York State. *J Acquir Immune Defic Syndr*. 2014 Aug 1;66(4):419-27.
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11. HIV/STI Programme Ministry of Health and Wellness. Standard Operating Procedures for Returning HIV Clients to Care in Barbados. 2017. 7 p.
12. Babb D. (2022) An Assessment of Adherence to Antiretroviral Therapy and Retention in Care among persons living with HIV in Barbados. Dissertation.
13. HIV/STI Programme, Routine Surveillance Data (preliminary), 2022
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