

# Monitoring the engagement in care of young people living with perinatally acquired HIV.

## Introduction

In 2011, a joint clinic for HIV seropositive young people was established by staff from the Sheffield Teaching Hospitals NHS Trust (STH) and the Sheffield Children's Hospital NHS Trust (SCH). Transition from paediatric to adult services can be a difficult time for HIV seropositive adolescents, with some disengaging from care and discontinuing antiretroviral therapy<sup>1</sup>.

BHIVA outlines the following standards of care<sup>2</sup>:

- 95% of patients should have had a viral load measured in the past 6 months.
- 95% of patients should have a viral load result <50 copies/mL (unless started treatment).
- 95% of patients should have attended their clinic appointment in the last 12 months.

## Aims

- To look at the patient outcomes after discharge from transition clinics to adult services.
- To assess the proportion of patients still engaged with adult health care and HIV services.
- To measure patient wellbeing; through HIV viral load and CD4 cell counts and concordance with ART.

## Method

- A retrospective case note review.
- Data was collected from e-records and patient's paper notes between 19/02/2018 and 13/03/2018.

## Results

11 HIV seropositive patients have transitioned in care from SCH to STH and attended the transition clinic.

**Table 1: Characteristics**

HIV seropositive attending STH (n=11).	n (%) or median (IQR)
Sex, female	7 (63.6)
Age at first appointment in transition clinic	16.4 (15.9-16.9)
Age at first independent appointment in adult services	18.3 (17.5-18.6)
Social Concerns documented:	
Yes	2 (18.2)
No	9 (81.8)
Level of Education Attained:	
Lower Secondary	1 (9.1)
Upper Secondary Education	1 (9.1)
Post secondary- non tertiary education	3 (27.3)
Tertiary Education	6 (54.5)
Employment status:	
Full time employment	0 (0)
Part time employment	3 (27.3)
Unemployed	1 (9.1)
In full time education	7 (63.6)
Pregnancy recorded in notes	1 (14.3)

**Table 2: Engagement in care**

	n (%) or median (IQR)
Latest appointment, attended within the last 12 months	10 (90.9)
Appointments in adult care services:	
Attended	117 (46.4)
Did not attend	78 (31.0)
Cancelled by trust	22 (8.7)
Cancelled by patient	35 (13.9)
Viral control:	
Most recent viral load taken within the last 6 months	10 (90.9)
Viral load taken in last 6 months <50 cells/mL	9 (81.8)
Number viral loads in adult services >400 cells/mL per patient	0 (0-2)
Latest CD4 cell count taken within 12 months	10 (90.9)
>500	4 (36.4)
200-500	7 (63.6)
<200	0 (0)
Anti-retroviral therapy (ART):	
Number of patients that changed regimen post-transition	9 (81.8)
Number of new regimens post-transition*:	
1	5 (45.5)
2	2 (18.2)
3	1 (9.1)
Concordance:	
No concern	7 (63.6)
Clinical concern	4 (36.4)
Last adherence recorded within notes in last 12 months	11 (100)

\*1 patient initiated ART in adult services.

**Table 3 Audit Standards**

BHIVA Standard	Audit Result	Standard met?
95% had a viral load measured in the past 6 months.	90.9%	No
95% had a viral load result <50 copies/mL.	81.8%	No
95% attended their clinic appointment in the last 12 months.	90.9%	No

## Conclusions

- The majority of patients are engaged in care; attended their clinic appointment in the last 12 months and have had an undetectable viral load measured in the last 6 months. The BHIVA standards of care are not met but this could be a result of the small sample size. The small study size is not a reliable estimate of a larger population.

- The non-attendance rate of young people for HIV clinic appointments is high, suggesting poor engagement in services.

- This cohort is engaged in care, but frequently miss their hospital appointments.

- It is recommended that adolescents and young adults may benefit from specific guidelines encouraging regular appointments to improve the relationship with adult services.

The PENTA guidelines recommend that children under the age of 16 have appointments every 3-4 months<sup>3</sup>. Adolescents and young adults could benefit from more frequent appointments to improve the relationship with adult services, address the barriers to and promote attendance.

## Recommendations

- Review the frequency and timing of clinic appointments, through discussion with patients.
- Ensure MDT reviews patients in the transition clinic quarterly.
- Discuss with other transition services how best to communicate with young people and encourage attendance.
- Qualitative research to determine why patients do not attend their clinic appointments.

## References:

1. Health outcomes and the transition experience of HIV infected adolescents after transfer to adult care in Québec, Canada. Kakkar et al. BMC Pediatrics (2016) 16:109 DOI 10.1186/s12887-016-0644-4
2. BHIVA Standards of Care for People Living with HIV 2013
3. Paediatric European Network for Treatment of AIDS (PENTA) guidelines for treatment of paediatric HIV-1 infection 2015: optimizing health in preparation for adult life. Bamford et al. HIV Med (2018) 19: e1-e42