

## THE NATIONAL CENTRE FOR HUMAN RETROVIROLOGY: HTLV HUB AND SPOKE CARE PROVISION IN THE UK

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**Background:** HTLV sero-diagnostics were introduced in the UK in 1987 and the HTLV- research clinic opened in 1993. The introduction of UK HTLV blood donation testing in 2002 led to the establishment of a national HTLV service, the National Centre for Human Retrovirology ([www.HTLV1.eu](http://www.HTLV1.eu))

**Methods:** Description of service provision including cross-sectional data on demographics and longitudinal data on diagnosis of HTLV-1 infection and associated diseases.

**Results:** 1987-2016: 2024 HTLV seropositive persons diagnosed. Prior to 1993: ~ 38 diagnoses per annum (pa); 1993–2001: 54 pa and 2008–2016: 88 pa. 50% of patients have been seen by the NCHR. London clinic serves as a clinical hub and provides specialised diagnostic services. Three regional HTLV satellite clinics have been established (Birmingham, Manchester, York) to improve access and disseminate knowledge with regular joint clinics at all sites. Services are multidisciplinary reflecting the broad spectrum of HTLV-1 associated diseases. Patients are predominantly female (64%); median age at diagnosis is 52 years; the majority are of black Caribbean origin (60%), followed by white (19%); In 2016, 320 HTLV infected patients attended the services, 28% had HTLV-1-associated inflammation, mostly HTLV-1 associated myelopathy (HAM) and 12% Adult T-cell Leukaemia/Lymphoma (ATLL). Significant sub-groups are patients with end-stage renal disease, HIV/HTLV co-infection, uveitis or polymyositis. Newer indications for testing and referral are cord blood storage and in-vitro fertilisation. HTLV-specific diagnostics include molecular tests to detect, type and quantify HTLV infections and immune-phenotyping of T-cells for activation markers in patients at risk of HAM and prognostic markers of ATLL. Patient pathways: Donors are referred directly by national blood donor services, all Public Health England reports confirming HTLV infection recommend referral, patients self-refer and contact-tracing is advocated.

**Conclusion:** The hub and spoke model of centralised care in the UK has allowed highly specialised services to be developed and delivered nationally.

**Disclosure:** Nothing to declare.