

## **The UK's HTLV National Register: a unique cohort to inform disease progression**

KL Davison<sup>1</sup>, H Harvala<sup>2</sup>, R Wilkie<sup>1</sup>, SR Brailsford<sup>2</sup>, GP Taylor<sup>3</sup>

<sup>1</sup>UK Health Security Agency, London, UK

<sup>2</sup> NHS Blood and Transplant, London, UK

<sup>3</sup> Imperial College, London, UK

### **Background:**

HTLV infection is rare in the United Kingdom (UK) but infections are more common in people originating from endemic countries. After the introduction of anti-HTLV screening of all blood donations in 2002, individuals affected by HTLV were identified and prospectively recruited to the HTLV National Register to inform onset and progression of HTLV associated disease.

### **Methods:**

Recruitment by clinicians at blood centres and specialist clinics began in July 2003. Initially this included non-infected and infected adults at different stages of disease, from 2013 recruitment focused on asymptomatic infected individuals. Clinicians report details of diagnosis, clinical history, and probable source. All participants complete a baseline self-completion health questionnaire (SCQ), and a follow up SCQ every 2-3 years. Details of cancer or deaths are obtained from national registries.

### **Results:**

By December 2021, 287 people had consented to take part; 124 HTLV-infected asymptomatic donors, 9 recipients of blood transfused before screening and 154 clinic attendees (76 asymptomatic and 78 symptomatic). Most participants were HTLV-1 positive (n=248); 13 HTLV-2, 2 indeterminate and 24 were HTLV-negative. Most were female (73%), of non-white ethnicity (68%) with a mean age of 49 years. Baseline self-completion questionnaires were received for 82% and at least one follow-up completed for 67%. At the most recent follow-up, onset of HAM-like symptoms was reported by 1%. Cancers and deaths were reported in low numbers and none were associated with HTLV.

### **Conclusion:**

This cohort has enabled descriptions of HTLV-associated disease progression amongst people recruited from varying sources; it is the first prospective study of its kind in Europe. The 2022 follow-up is due to commence and will include questions about Covid-19 infection and immunisation.

### **Disclosure of Interest Statement:**

Nothing to disclose.