

## **HTLV-Covid-19 online survey: A novel experience through the pandemic for those living with HTLV**

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### **Background:**

During the Covid-19 pandemic, digital technology was key in gathering clinical information to shape an effective response globally.

The National Centre for Human Retrovirology and International Retrovirology Association (IRVA) developed a digital system to collect real time data on the effects of Covid-19 on those living with HTLV. The results are discussed.

### **Methods:**

An online anonymous survey was developed, available on the IRVA website and related social media pages, from June 2020. This was subsequently translated into three further languages: Portuguese, Japanese and Spanish. Socio-demographic status, Covid-19 infection, effects on routine HTLV care and social life were included. This data was analysed and displayed on the same website for public access.

### **Results:**

To the present date, there were 165 responses from 8 countries. The majority were from Brazil, female and aged 41-50 years.

77% had known HTLV-1 infection. 62% were in HTLV medical care services and only 11.5% reported an appointment cancelled by the hospital or patient. 19% had a virtual consultation instead.

The confirmed Covid-19 prevalence was 13%, with 5 hospitalizations.

The biggest social concern was inability to meet friends and family.

### **Conclusions:**

Prevalence of confirmed infection with SARS-CoV-2 is likely to be an underestimate due to variable access to testing, especially early in the pandemic.

Most in the study reported access to continuing HTLV specific medical care.

Whilst responses are limited to those with internet access, patients welcomed a portal to report their experiences.

Whilst translated questionnaires increased the response rate, this was still relatively low, given the global burden of HTLV infection.

With wider availability and access to a central global digital portal, patients with HTLV infection worldwide would be able to respond in larger numbers to issues of concern to them and the health care clinicians who provide their medical management.

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

Nothing to disclose.