

Defining research priorities for people living with HTLV-1 through patient/public involvement and engagement (PPIE) workshops

Authors:

Adonis A¹, Russell AM^{2,3}, Cassidy E⁴; Ashford, S^{5,6}; Taylor, GP^{1,3}

¹ National Centre for Human Retrovirology, Imperial College Healthcare NHS Trust, London, UK

² University of Exeter Medical School, College of Medicine and Health, Exeter, UK

³ Faculty of Medicine, Imperial College Healthcare NHS Trust, London, UK

⁴ Freelance Academic

⁵ The Regional Hyper-acute Rehabilitation Unit, London North West University Healthcare NHS Trust, Northwick Park Hospital

⁶ Department of Palliative Care, Policy and Rehabilitation, King's College London, London, UK.

Background/Purpose:

Human T-cell Lymphotropic Virus type1(HTLV-1) affects 5-10 million people worldwide, with up to 300,000(2.5-4.5%) developing HTLV-1-associated myelopathy(HAM). Asymptomatic carriers may or may not develop HAM and live with the associated lifelong uncertainty. Active PPIE in health research brings focus to the relevant person-centred questions and priorities. Little is known about how HTLV-1 impacts on everyday life and what patients need from healthcare services. We explored patient's unique perspectives to better understand their lived experiences and how to configure healthcare services to optimally meet patients' and families' needs.

Approach:

Patients were invited to participate through HTLV clinics in England. We conducted six 90minute virtual workshops over 10 months with two additional consolidation workshops. All were video-recorded with consent. The content of each sequential workshops' was informed by the previous group discussion, transcribed verbatim and thematically analysed.

Outcomes/Impact:

Twenty-two people participated, attending >80% of the workshops. The majority diagnosed with HAM. Analysis identified thirteen themes including: diagnosis, 'not been seen or heard', fragmented care and health-service mis-configuration. Information and knowledge underpinned all themes. In the consolidating workshops participants rated and ranked their six most important themes, further prioritising these top three: disease progression; management; psychosocial wellbeing.

Innovation and Significance:

What matters to each unique individual living with HTLV1 and health-related quality-of-life(HRQoL) is worthy of enquiry. This is the first of this type of research in HTLV-1 in the UK and identifies several avenues of investigation to improve healthcare services and HRQL. Participants described the impact of HTLV-1 on everyday life,

identified unmet needs and offered solutions for health service re-configuration. They recognised that participation in these workshops formed a community and the start of the conversation to progress person-centred and meaningful research. Participants appreciated the value of their individual and collective voices to advocate for research important to them, for tangible change to happen.

Disclosure of Interest Statement

Adine Adonis, NIHR Pre-doctoral Fellow, NIHR301126, is funded by Health Education England (HEE) / National Institute for Health Research (NIHR) for this research project.