

**Title: Quality of life in people living with HIV with neurocognitive impairment**

**Background:** Neurocognitive disorders are a common issue impacting those living with human immunodeficiency virus (HIV). Effective antiretroviral treatment has lessened the severity but not the frequency of these impairments, with estimates of over 20% of people living with HIV (PLWH) having a neurocognitive impairment (NCI) which is associated with their HIV at least partly. NCI is likely to become an increasingly important issue as the HIV population ages. NCI in PLWH is associated with reduced employment, poorer medication adherence, lower mortality and is independently associated with significant reductions in perceived quality of life (1-3). Quality of life (QoL) is increasingly being recognized as an essential end point in the disease management of chronic condition: widely adopted within the NHS, measuring QoL examines a healthcare system's ability to produce health gains, rather than just health care. Indeed within HIV care there have been recent calls to include good QoL as a 'fourth 90' in the 90-90-90 testing and treatment target introduced by the World Health Organization in 2016 (4). Despite research examining QoL in PLWH generally, few studies have examined this concept in PLWH who also have a cognitive disorder. Exploring the experiences of PLWH with NCI and understanding factors influencing QoL in conditions impacting cognition is particularly important given the multiple areas of functioning affected and challenges patients likely face with regard to self-report. With estimates of 73% of PLWH over the age of 50 by 2030, along with the high number of comorbidities and polypharmacy, likely impacting cognition, seen in PLWH at younger ages (5), the need for thorough assessments of QoL outcomes in this population has become important. Equally important is the development and assessment of a theoretical framework in which QoL is conceptualised for studying NCI in PLWH. It is anticipated that in exploring the experiences and identifying the components influencing QoL, and how they relate to one another, we will gain an understanding of NCI in PLWH which will inform the development of patient-reported outcome tools and assist with the development of interventions which have a 'real-world' benefit for this population.

**Study aims:**

1. To explore the experiences of PLWH with NCI using a qualitative methodology
2. To understand the determinants of QoL, and their relationship to one another, in PLWH with NCI
3. To use this data to develop a theoretical framework in which QoL in PLWH with NCI is conceptualized

**Methodology:** Qualitative interview methodology will explore factors influencing QoL in PLWH with NCI. 25-35 interviews will be conducted with PLWH with NCI over the age of 18 and who attend HIV services in Brighton and London. Participants will have a current clinically significant cognitive impairment considered to be currently related (completely or at least partly) to HIV disease. Thematic analysis will be conducted to explore factors related to QoL. Thematic analysis is a flexible method of analysis which allows for rich, detailed and complex

descriptions of data (6). The first 2-3 transcripts will be manually coded by the PI and by the qualitative supervisor. These will be used to develop an initial coding framework. Further interviews will be analysed and the fit with the narrative synthesis from a prior literature review will be reviewed. New components will added and existing components amended based on discussion and consensus from regular reflexivity sessions. The remaining transcripts will be coded using constant comparison techniques, where existing and new transcripts are continually reviewed to identify new components, check for consistencies and explore relationships between components. The final interviews will employ theoretical sampling to refine understanding and disprove emerging themes and produce a finalized conceptual framework. Validity of components structures will be ensured through regular academic supervision and review.

## **References**

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