

# Understanding the lived experience research priorities for improving quality of life in people living with HIV and cognitive impairment

Kate Alford<sup>1,2</sup>, John Hammond<sup>3</sup>, Jaime H Vera<sup>1,2,4</sup> and Stephanie Daley<sup>5</sup>

<sup>1</sup>Dept. Global Health and Infection, Brighton and Sussex Medical School, <sup>2</sup>Brighton and Sussex University Hospitals NHS Trust, <sup>3</sup>Brighton and Hove LGBT+ Switchboard, <sup>4</sup>Dept. Of Medicine, Brighton and Sussex Medical, <sup>5</sup>Centre for Dementia Studies, Brighton and Sussex Medical School

## BACKGROUND

- Cognitive impairment (CI) is a common co-morbidity affecting people living with HIV (PLWH). It is seen at higher rates and at younger ages in PLWH compared to HIV-negative controls and prevalence is likely to increase as cohort ageing continues (1,2).
- PLWH report poorer health-related quality of life (HRQoL) than PLWH without CI and illness-specific conceptualisations of HRQoL have been developed (3,4). Important influencers of HRQoL in PLWH with CI include: physical functioning, cognition, social connectedness, HIV-stigma, self-concept, acceptance of and perceived control over cognitive health outcomes, and physical and mental health and wellbeing (4).
- In the last decade, there has been increasing recognition that the CIs seen in PLWH are frequently multifactorial, and often not synonymous or restricted to brain injury caused directly by HIV (5). Furthermore, for the majority of PLWH with CI, no pharmaceutical interventions which directly target cognition exist.
- Focusing on broader indicators of wellbeing, such as quality of life, may help to support individuals to live well with CI.

➤ **The aim of this study was to identify the lived experience research priorities for improving HRQoL in this population.**

## METHODS

- A research advisory group was established with 15 PLWH with CI and healthcare, community and academic partners (Table 1).
- Two semi-structured focus groups were conducted: one with PLWH with CI (lived experience participants) and one with relevant healthcare professionals and voluntary sector staff (staff participants).
- All participants were presented with the illness-specific domains identified as influencing HRQoL in PLWH with CI. Participants were asked to rank domain in order of importance and ask to discuss how each domain could be supported by intervention.
- Findings were analysed using content analysis and study findings were fed back to the Research Advisory Group.

## RESULTS





- Five PLWH with CI were recruited from community services (Male 4 (80%); median age 59 (range 56-78); White British 3 (60%), Mixed race 1 (20%), White other 1 (20%); men who have sex with men (MSM) 3 (60%), heterosexual 1 (20%)) and three healthcare and voluntary sector staff (2 (66%) voluntary sector staff; 1 (33%) healthcare staff) confirmed the relevance of domains identified as important to HRQoL.

**Table 1. Research Advisory Group members**

Research Advisory Group member	N
Lived experience	2
Community partner (AIDSMap, Lunch Positive, Sussex Beacon, B&H LGBT+ Switchboard)	4
Clinician (HIV consultant, Occupational Therapist, MAS manager, HIV nurse specialist)	4
Academics (Expertise in HIV, HIV and CI/ neurology and dementia)	5
MAS, Memory assessment service	

- All participants ranked interventions targeting improvement in social connectedness, cognition and physical function as being highly important. Furthermore, lived experience participants ranked acceptance of and perceived control over cognitive health outcomes as a priority (Table 2).
- All participants suggested potential interventions which could target the domains initially identified (Table 2).

**Table 2. Priority domain areas and interventional strategies from patient and professional focus groups**

HRQoL domain identified as priority	Intervention
Physical function 	<ul style="list-style-type: none"> <li>Help to maintain employment and signposting to advocates to support this</li> <li>Greater engagement with patient supporters (friend/family)</li> </ul>
Cognition 	<ul style="list-style-type: none"> <li>Clarity of information: easy language / written text (particularly following CI diagnosis to facilitate understanding of issues and their causes)</li> <li>Cognitive rehabilitation to help cope with cognitive symptoms and improve function</li> <li>Staff training on indicators of cognitive issues and when to screen for CI</li> </ul>
Social Connectedness 	<ul style="list-style-type: none"> <li>Mapping of available services in area</li> <li>Receiving and giving peer support</li> <li>Social groups (safe/non-judgmental space)</li> <li>Support to re-engage socially</li> </ul>
Acceptance of and perceived control over cognitive health outcomes 	<ul style="list-style-type: none"> <li>Collaborative development of strategies to mitigate cognitive difficulties</li> <li>Improved staff knowledge (e.g., at generic memory services). Including knowledge of the multifactorial causation of CI in PLWH and signposting to HIV-specific or CI services</li> <li>Clearer information for PLWH with CI on cognitive impairment diagnosis (written), along with causation and prognosis to facilitate understanding of issues and longer-term outcomes</li> <li>Information on how to support good cognitive health</li> </ul>

## CONCLUSIONS

- This is the first study to identify the research priorities and possible interventional strategies for improving or maintaining HRQoL in PLWH with CI.**
- Given the absence of interventions and support guidelines for PLWH with CI, this provides a roadmap for future research in this important and growing area of HIV clinical care.**

## FUTURE DIRECTIONS

- Based on the priority domains identified from the focus groups and the recommendations for intervention across the four key areas, the Research Advisory Group has identified two broad interventional strategies which could be developed to assist PLWH to live well with CI. These include:
- Cognitive rehabilitation interventions which deliver compensatory strategies to facilitate physical function and coping with cognitive symptoms in the context of daily life.
  - Information provision to support social connectedness and acceptance of and control over cognitive health outcomes. Including: booklets/website for staff and patients containing information on causes of CI in PLWH, prognosis, and guidance on maintaining good cognitive health; staff training (particularly in generic memory services); and mapping of local community services providing peer support, social groups and advocacy.