

# RESEARCH TO RESOURCE: BOOKLET FOR PEOPLE LIVING WITH HIV ASSOCIATED NEUROCOGNITIVE DISORDER (HAND)

DAVID C. CRAWFORD<sup>1</sup>, DENISE CUMMINS<sup>2, 3</sup>.

<sup>1</sup>*Positive Life NSW, Sydney, Australia*

<sup>2</sup> Sydney Nursing School, University of Sydney, NSW, Australia

<sup>3</sup> Sydney District Nursing, Community Health, Sydney Local Health District, Sydney, Australia

## **Background/Purpose:**

Recent estimates of risk for symptomatic HAND range from 18-50% of those people living with HIV (PLHIV) on combined antiretroviral therapy (cART). Positive Life NSW's (PLNSW) research into the level of knowledge of HAND amongst PLHIV arose from questions raised at a meeting of HIV healthcare and community representatives in early 2015. Questions to be answered:

- Is there an awareness of HAND?
- Are PLHIV thinking about and are they concerned about HAND?
- Have they tried talking to someone about HAND?
- What was the response to this and the outcome?
- Did PLHIV want suggestions of how to talk about their concerns to others?

The research identified the next steps to develop resources and support programs for PLHIV managing their experiences and concerns living with HAND.

## **Approach:**

Ethics was granted for a questionnaire to be distributed online via SurveyMonkey through PLNSW social media and electronic media platforms. From total responses (N=163), postcodes of respondents from other states outside NSW (n=31), incomplete responses (n= 6) and those from overseas (n=28) were removed, leaving a total of ninety-eight responses from NSW for analysis (n=98).

## **Outcomes/Impact:**

A resource was drafted by healthcare professionals, reviewed by Multicultural HIV and Hepatitis Service (MHAHS) for those with low level literacy, the HIV/AIDS Legal Centre (HALC) covered legalities, and focused tested by PLHIV with HAND before publication. The booklet is now being distributed for use by PLHIV to talk in a meaningful way with healthcare providers and significant others about HAND. The booklet outlines signs and symptoms, seeking further assessment and support, legal assistance and practical advice on living with HAND.

## **Innovation and Significance:**

PLHIV and service providers alike reading the booklet have applauded the initiative are utilising the resource to speaking with friends and partners and seeking assistance from clinicians.

## **Disclosure of Interest Statement:**

<sup>1</sup>No disclosure of interests