

Research to Resource: Booklet for people living with HIV Associated Neurocognitive Disorder (HAND)

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Disclosures:

- No disclosures

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BACKGROUND/AIMS & METHODS:

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- ❖ Recent estimates of risk for symptomatic HAND range from 18-50% of those people living with HIV (PLHIV) including those on combined antiretroviral therapy (cART)

❖ Ethics approval

❖ **The objective of the survey** - identify the next steps for the development of education, resources, and support living with HAND

❖ **SurveyMonkey questionnaire** distributed to people living with HIV via Positive Life NSW (PLNSW) social media platforms and electronic communication with members and subscribers

We asked:

- **Is there an awareness of HAND** in the community of PLHIV?
- **Are PLHIV thinking about HAND?**
- **Have PLHIV tried talking to someone** about HAND? and what was the response to this conversation?
- **Are PLHIV worried and concerned** about HAND?



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RESULTS:

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- **77%** of respondents had **heard of HAND**
- **52%** indicated they were **'anxious'** about HAND
- **38%** of respondents indicated **talking to someone**
- **62%** had **not spoken** to anyone
- **16%** indicated that they would be **frightened and anxious discussing their concerns**
- 94% felt listened to and 6% they had not
- 35% had spoken to their partners and felt listened to
- Of the 2 who had spoken to a healthcare professional and not been heard 1 indicated they may not speak about it again
- **53%** indicated they would like **tips on how to talk about HAND**

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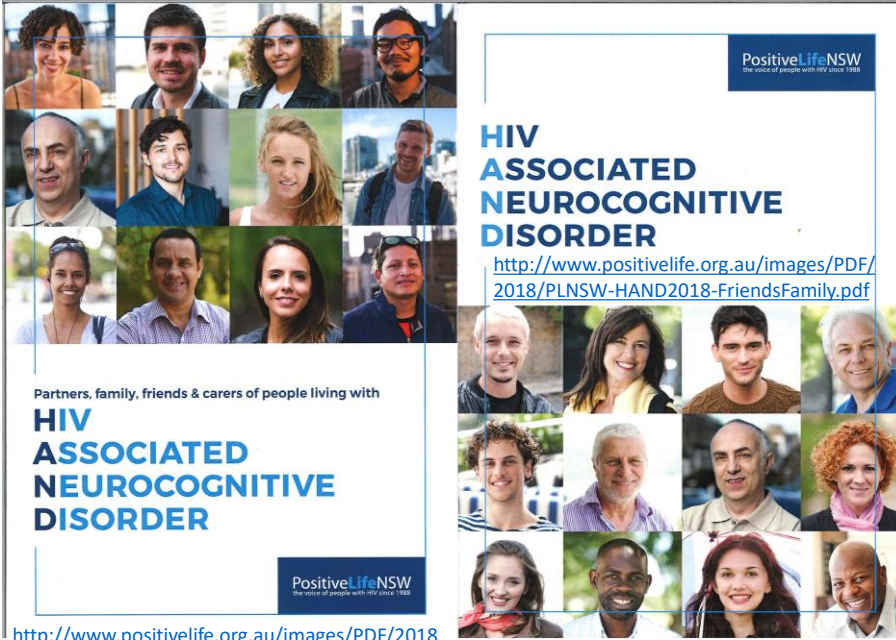
CONCLUSIONS/IMPLICATIONS:

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- Approximately 42% of PLHIV will be **living with some degree of sHAND**
- **Early recognition assessment** and **referral** will be important
- **People living closest** to the PLHIV will usually be the **first to recognise** these changes.
- ❖ **Objective of the resources:**
 - **Not to create an atmosphere of harm**
 - Focus on the **benefits of early detection and effective treatment**, interventions and **strategies to live with sHAND**
 - Talk to and **respond appropriately** at all levels when talking to someone about HAND
 - That a person diagnosed with HAND is managed within a **supportive framework** that promotes **meaningful engagement** and **affirmative outcomes**

<http://www.positivelife.org.au/images/PDF/2016/PLNSW-HAND-Report-2016.pdf>

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<http://www.positivelife.org.au/images/PDF/2018/PLNSW-HAND2018-FriendsFamily.pdf>

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