PositiveLifeNSW
the voice of people with HIV since 1988

DEVELOPING RESOURCES TO ASSIST PEOPLE LIVING WITH HIV ASSOCIATED NEUROCOGNITIVE DISORDER (HAND)

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Acknowledgements

Thank you to the people living with HIV in NSW who contributed to the valuable information in this research by taking time to answer the questionnaire and sharing of their experiences of HAND and the input and support of Denise Cummins, Clinical Nurse Consultant Sydney LHD, and Jane Costello, Craig Cooper, Lance Feeney and Craig Andrews of Positive Life NSW.

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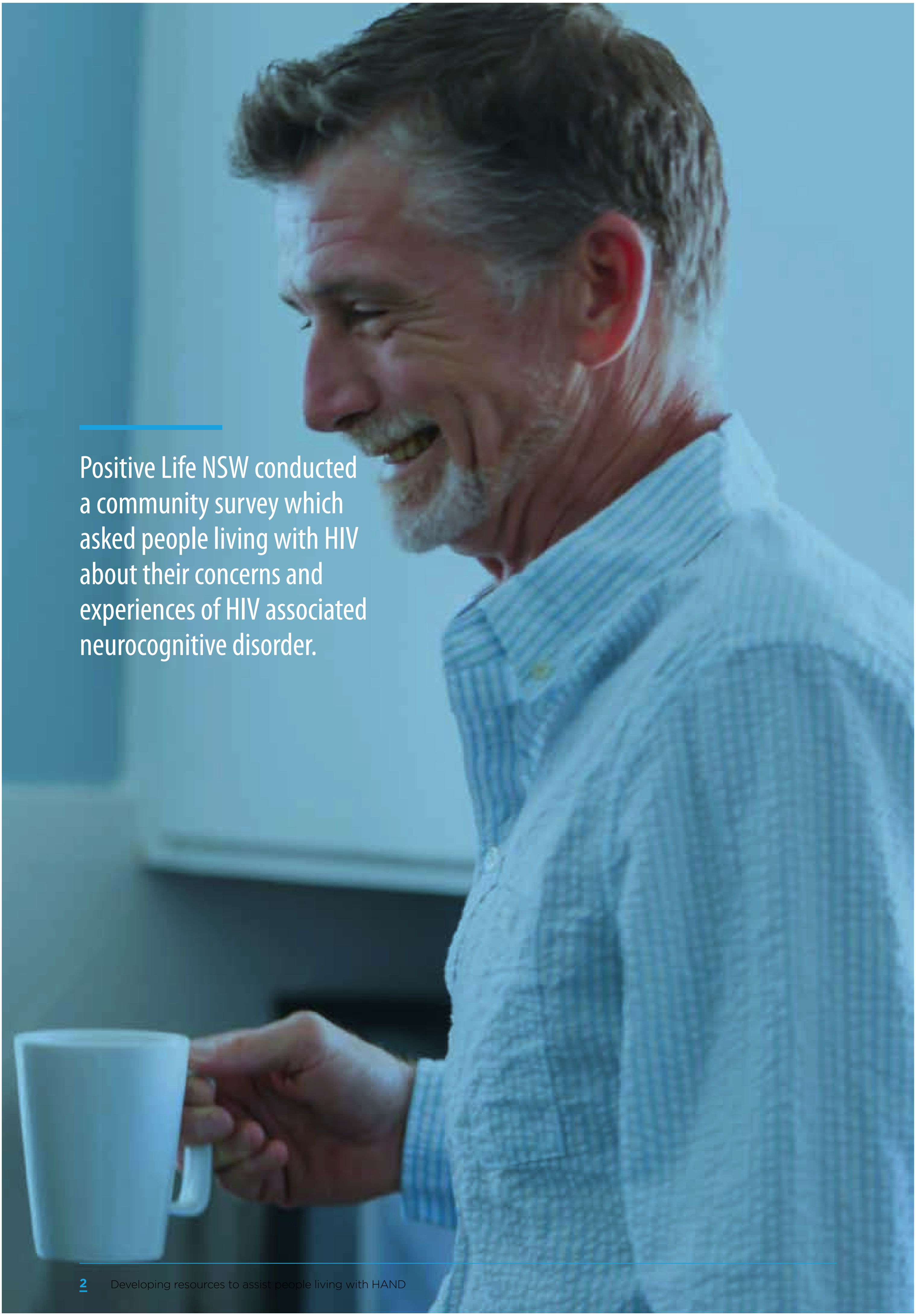


Positive Life NSW conducted a community survey which asked people living with HIV about their concerns and experiences of HIV associated neurocognitive disorder.

Summary of findings

In September 2015, Positive Life NSW conducted a community survey which asked people living with HIV (PLHIV) about their concerns and experiences of HIV associated neurocognitive disorder (HAND).

Of the PLHIV who completed the questionnaire, 77% said they were aware of HAND and 52% indicated they were concerned about it. The majority of people said that they were discussing these concerns with both healthcare professionals and their significant others. The majority felt their concerns had been listened to, although those who felt they had not been listened to were less likely to talk about their concerns again because some had received a negative response or were worried about being stigmatised. Some respondents commented that they are fearful of living with HIV in that it brings an uncertainty of the future. The results of this research have identified five key areas for resource development to assist both PLHIV to talk about HAND and for healthcare workers, service providers and significant others on how to respond meaningfully when addressing or raising concerns about the possibility of HAND with PLHIV.

Introduction

HIV enters the brain early at the time of systemic infection and possibly within eight days of infection(1). Mechanisms by which HIV gains entry into the central nervous system (CNS), that is the brain and spinal cord, is complex and multifactorial(1) (2). Prior to combined anti-retroviral therapy (cART) to control HIV replication within the CNS, HIV Associated Dementia (HAD) was observed in 20 to 30% of patients with uncontrolled HIV infection(1) (3). The incidence of HAD has dramatically reduced with the introduction of combined anti-retroviral therapy (cART)(1) (2) (4).

A key component of HIV in the brain is despite effective cART which crosses the blood brain barrier (BBB), inflammation persists albeit at lower levels(1) (4) (5). The mechanism for this persistent inflammation is not fully understood although some anti-retroviral combinations may have better CNS anti-inflammatory properties and lower the inflammation profile within the CNS(2). With effective cART it is still estimated that somewhere between 15 to 70% of PLHIV will have some degree of neurocognitive impairment from their HIV infection(2) (4) (6). This persistent inflammation has also been attributed to the broad range of early or premature aging and other neurological manifestations(2) (4) (7).

It has also been suggested that the presence of symptomatic HIV Associated Neurocognitive Disorder (sHAND) even in milder forms, may affect adherence to medications, workplace performance and quality of life(8). Broadly speaking, PLHIV often experience anxiety, depression, sleep disturbances and other cognitive disorders(5). HAND has been classified by the Frascati diagnostic criteria into two new terms – asymptomatic neurological disorder (ANI), and mild neurocognitive disorder (MND)(4) (9) (8). Both MND and HAD symptoms which affect and interfere with activities of daily living and are defined as sHAND(4).

Positive Life NSW's research into the level of knowledge and existence of HAND amongst PLHIV and how is it being perceived within this population within New South Wales (NSW), Australia, arose from questions raised at the meeting of HIV specialist clinicians, healthcare workers, nurses and community representatives in early 2015.
The primary questions were:

- 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?

The objective of the survey is to identify the next steps for the development of education, resources, and support for PLHIV when managing their experiences and concerns around living with HAND. These resources will be used to help PLHIV talk in a meaningful way with their service providers, clinicians and significant others about these concerns. The intention of this survey is to inform the development of resources for both healthcare professionals, significant others and partners on how to respond in a supportive way when the issue of HAND and other mental health related symptoms are raised by the PLHIV.

Resources will also be developed for healthcare workers, partners, friends and carers on how to raise concerns on what they are observing in the person's behaviour that may indicate they are at risk of HAND.

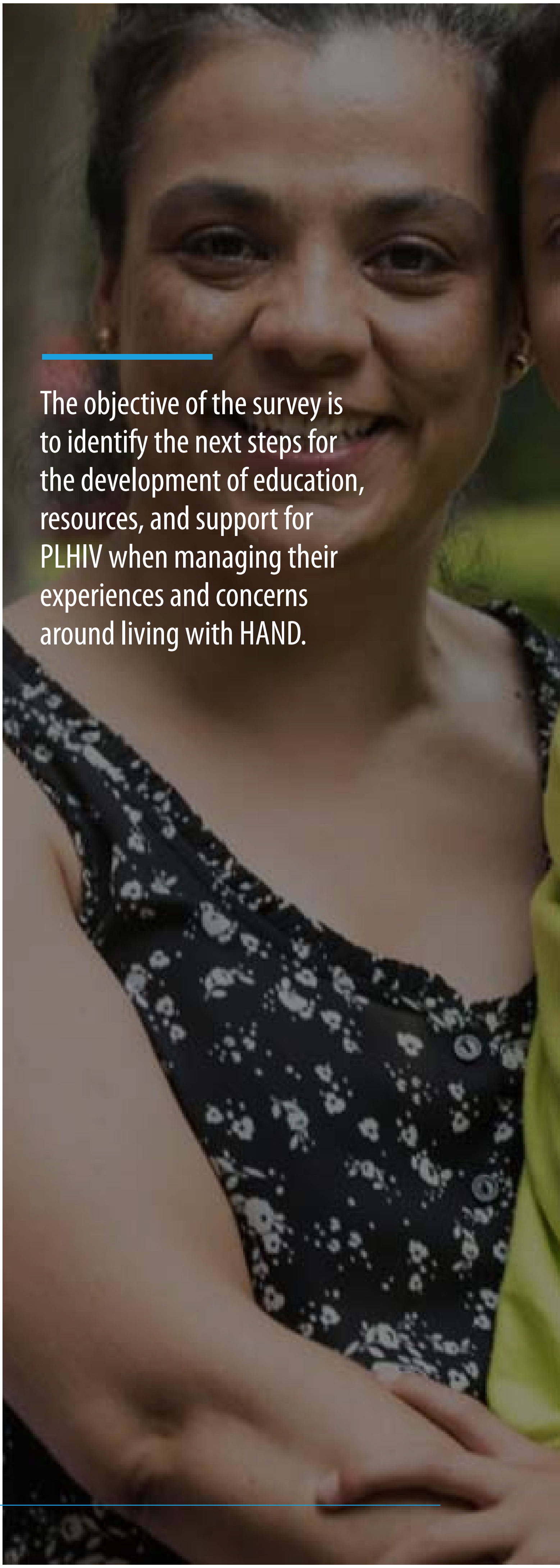
There was concern within the discussion at the 'Think Tank' that raising HAND with PLHIV may raise their levels of anxiety and fear. The association with dementia which is also highly stigmatised in the broader community may also raise anxiety(10). It was considered that this important topic also needs to carry a message of reassurance that sHAND is manageable if diagnosed early, is treatable with effective cART and that there effective strategies to manage activities of daily living with a diagnosis of sHAND.

Method

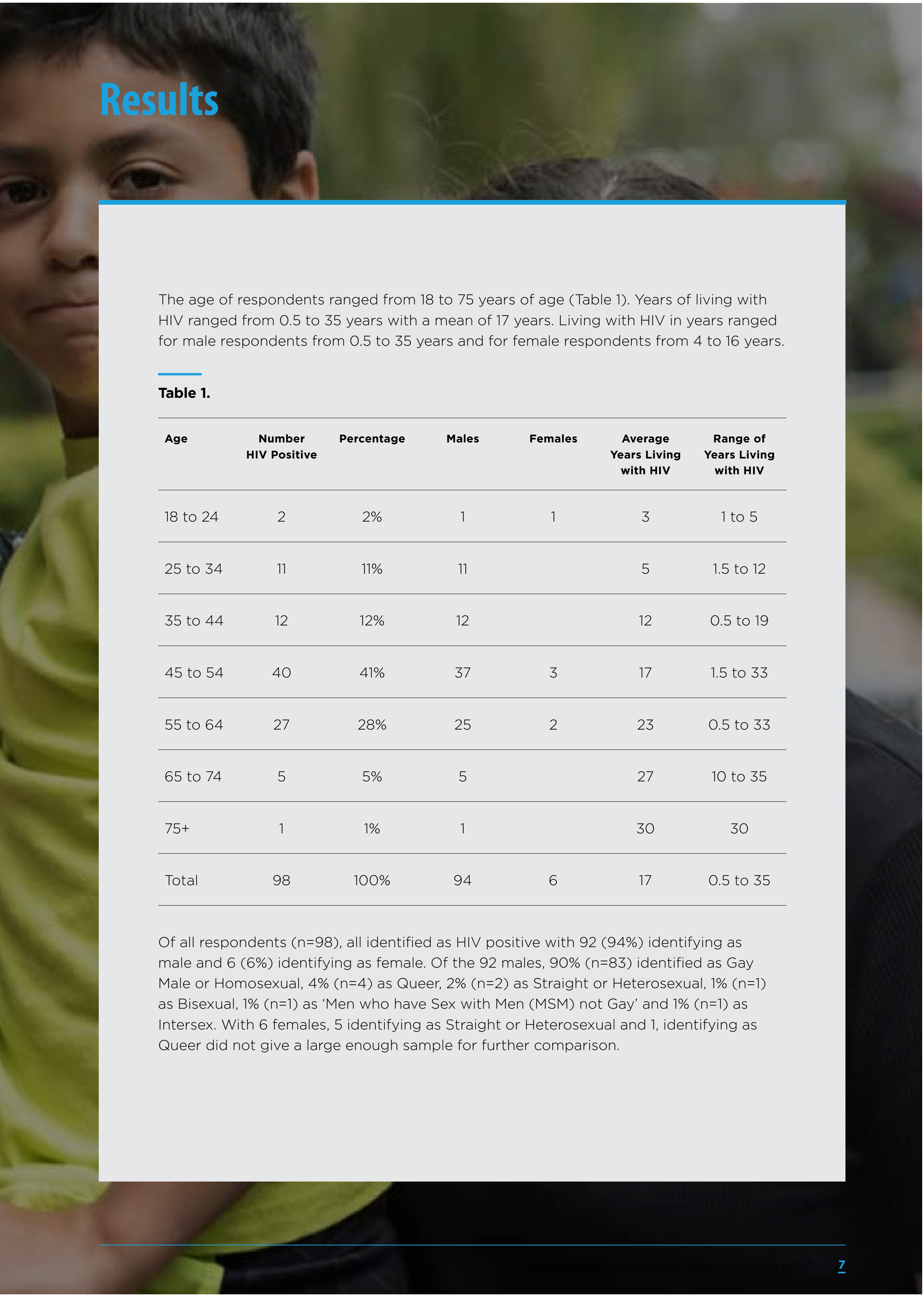
Ethics approval for this research was granted by the Human Research Ethics Committee (HREC) of the Sydney Local Health District in NSW, and endorsed by the HREC of the University of Sydney for a questionnaire to be distributed online via Surveymonkey through Positive Life NSW (PLNSW) social media platforms and electronic communication with members and subscribers.

The questionnaire was available online throughout the period of 20 August to 20 September 2015 with a total number of 163 responses.

The data was cleaned by identifying duplicated responses (n=9) from the same IP address. Responses from postcodes of respondents from other states outside NSW (n=31) and those from overseas (n=28) were removed, which left a total of ninety-eight responses from NSW for analysis (n=98). Simple statistical analysis for this report was undertaken using Microsoft Excel. For more in depth statistical analysis refer to D Cummings who utilised data from the Australia wide responses (n=126).



The objective of the survey is to identify the next steps for the development of education, resources, and support for PLHIV when managing their experiences and concerns around living with HAND.



Results

The age of respondents ranged from 18 to 75 years of age (Table 1). Years of living with HIV ranged from 0.5 to 35 years with a mean of 17 years. Living with HIV in years ranged for male respondents from 0.5 to 35 years and for female respondents from 4 to 16 years.

Table 1.

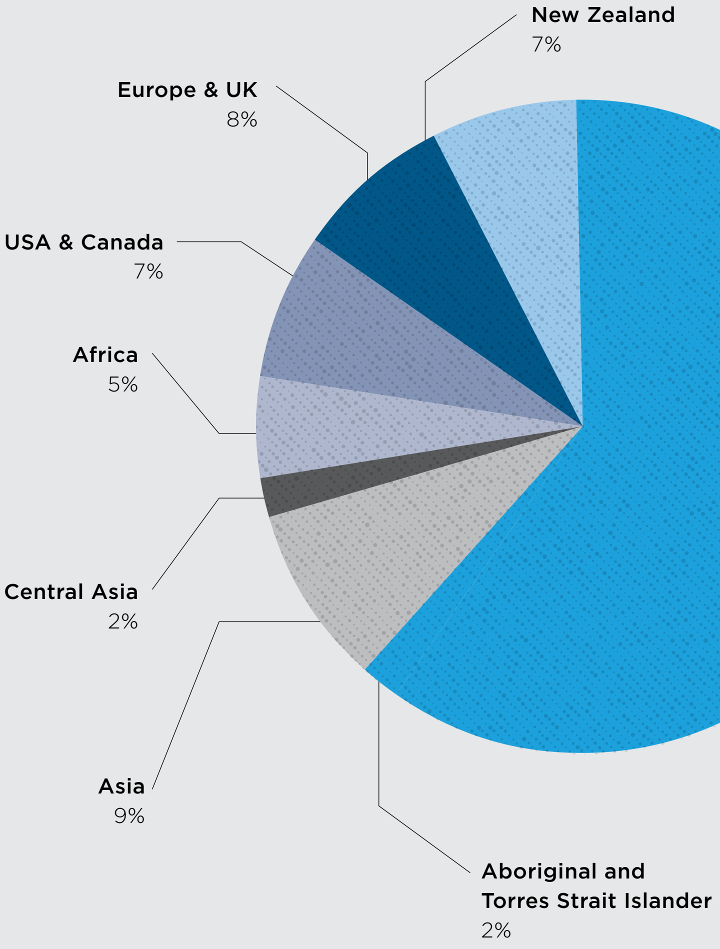
Age	Number HIV Positive	Percentage	Males	Females	Average Years Living with HIV	Range of Years Living with HIV
18 to 24	2	2%	1	1	3	1 to 5
25 to 34	11	11%	11		5	1.5 to 12
35 to 44	12	12%	12		12	0.5 to 19
45 to 54	40	41%	37	3	17	1.5 to 33
55 to 64	27	28%	25	2	23	0.5 to 33
65 to 74	5	5%	5		27	10 to 35
75+	1	1%	1		30	30
Total	98	100%	94	6	17	0.5 to 35

Of all respondents (n=98), all identified as HIV positive with 92 (94%) identifying as male and 6 (6%) identifying as female. Of the 92 males, 90% (n=83) identified as Gay Male or Homosexual, 4% (n=4) as Queer, 2% (n=2) as Straight or Heterosexual, 1% (n=1) as Bisexual, 1% (n=1) as 'Men who have Sex with Men (MSM) not Gay' and 1% (n=1) as Intersex. With 6 females, 5 identifying as Straight or Heterosexual and 1, identifying as Queer did not give a large enough sample for further comparison.

Country of birth

The majority of participant indicated they were born in Australia (62%) with only 2% identifying as Aboriginal and Torres Strait Islander. The remaining 38% were born overseas, originating from New Zealand (8%), Asia (8%), Africa (5%), Central Asia (2%), North and South America (7%), and Europe and the UK (8%) (Fig.1).

Figure 1



Employment and source of income

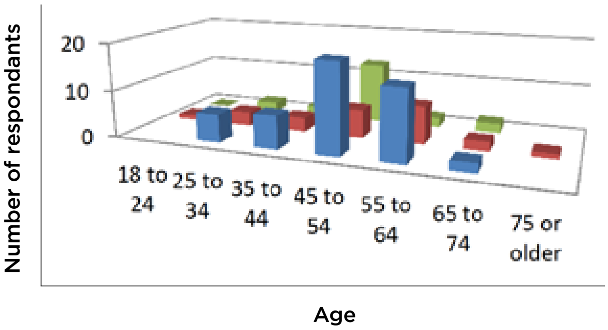
With regard to employment 22% of the respondents indicated they were not working, 42% stated they were employed and working full time, 18% were employed and working part time or casually, 16% stated they were retired, 1% were full time students and 1% stated they were part-time students.

With regard to earning an income 54% of participants were earning an income derived from a wage or salary, 35% were on a Disability or Aged Care Pension, 4% were being supported by a partner/spouse/friend and 6% indicated that their source of income was from other sources which included superannuation, income from investments, property rental income, a Disability Support Pension with supplementation from superannuation, savings or experiencing financial hardship.

Knowledge of HAND and concerns

When asked if they had heard of HAND, 77% of respondents answered 'Yes', 21% responded 'No' and 2% indicated they were 'Unsure'. Of those that responded in the affirmative 52% indicated they were 'anxious' about HAND, 26% stated that they were 'not anxious' and 22% indicated that they 'don't know'. The age groups that expressed the greatest concern about HAND were within the 45 to 54 age group (40%) followed by the 55 to 64 age group (27%) (Fig. 2).

Figure 2: Are you concerned about HAND by individual age group



Have you talked about HAND and were you listened to?

When asked if they had tried speaking to someone about their concerns regarding HAND 38% of respondents indicated they had tried talking to someone while 62% had not spoken to anyone about HAND. While 52% of respondents were concerned and anxious about HAND, of these, 16% indicated that they would be frightened and anxious about discussing their concerns with someone, with a majority leaving 84% willing to talk about their concerns.

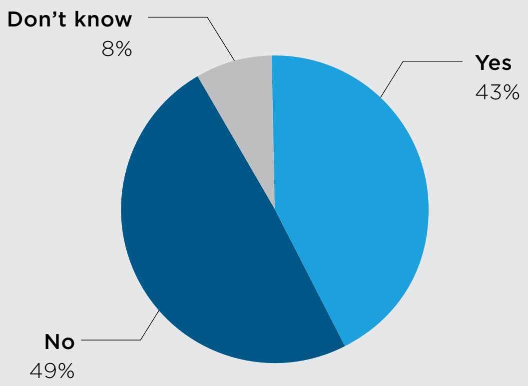
If they had spoken to someone, respondents (n=34) were asked who they had tried speaking to about their concerns, and could select more than one category from the options of a healthcare professional, partner friend and family. Of these 72% had spoken to a healthcare professional and 28% had spoken to a partner, family member or friend. Of those not speaking to anyone (n=62) 16% indicated that they would feel frightened and anxious about discussing their concerns with someone, with a majority (84%) willing to talk about their concerns.

For the 34 respondents who had spoken with someone about HAND, it was important to know if they felt listened to and how this might affect them seeking further support. Of all respondents who had spoken to someone, the majority (94%) felt they were listened to when they had talked about their concerns about HAND to someone. Of respondents who indicated they felt they had not been listened to 6% felt they had not been responded to appropriately. Of these 3% had spoken to a healthcare professional and 3% to a friend or family member. These respondents who had not felt listened to were asked if they would talk about their concerns again or would they seek to speak to someone else. Two respondents from the group who had spoken to family members about their concerns indicated they would not speak about it again but did indicated they were willing to speak to someone else. All respondents speaking to their partners 35% (n=12) felt they had been listened to. Of those who spoke with a healthcare professional two respondents felt they had not been listened to. Of these one indicated that they would talk to another healthcare professional and one indicated they would not talk about this again because the negative response.

Changes in behaviour and thinking

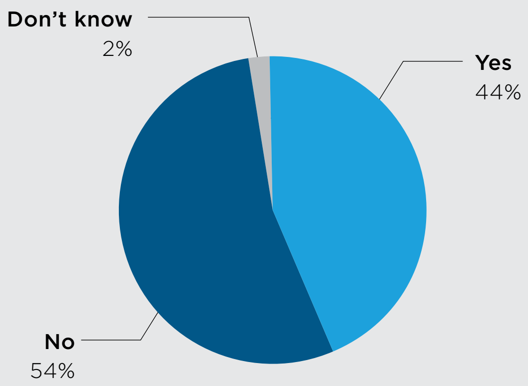
To find out if respondents were experiencing problems with thinking and behaviour, the question asked was, 'Has someone who knows you well commented that they have noticed any recent changes in you, such as you are more forgetful, more tired at the end of the day or a little more irritable?' In response to this question, 43% (n=41) respondents identified that someone had noticed them being more forgetful, tired or irritable while 49% (n=48) respondents indicated that no one had commented on any of these changes in memory, visible fatigue or being irritable (Fig. 3).

Figure 3: Has someone noticed changes (n=92)



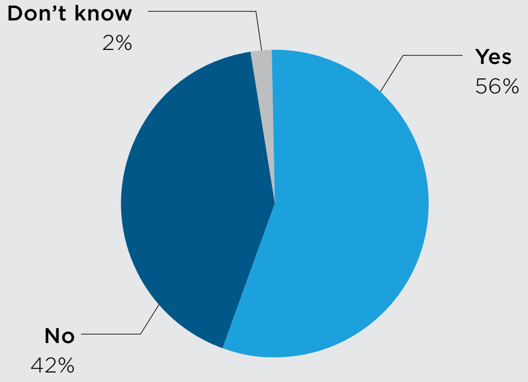
The question; 'Have you noticed that you are slower in your thinking than you used to be? (e.g. it takes you longer than usual to do something like cooking a meal)' was posed to compare what people might be feeling and noticing in their own behaviour subjectively compared to what others might have been noticing. Of the total responses (n=93) 44% (n=41) respondent had noticed that they were slower in their thinking, 54% (n=50) respondents indicated they had not noticed any changes and 2% (n=2) did not know if they had developed any problems with the speed of their thinking (Fig 4).

Figure 4: Are you slower in your thinking (n=93)



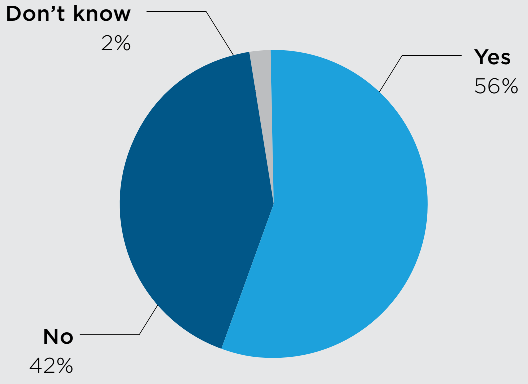
The question; ‘Have you noticed you are more forgetful than you used to be? (e.g. forget medications, where you put things like the keys)’ was asked to ascertain if people (n=93) were noticing problems with memory that may not have been noticed by anyone else or that they may not have subjectively noticed in their speed of thinking. Over half the respondents, 56% (n=52), identified that they are more forgetful while 42% (n=39) felt that they were not more forgetful with 2% (n=2) indicating that they did not know if they were more forgetful (Fig.5).

Figure 5: Are you more forgetful (n=93)



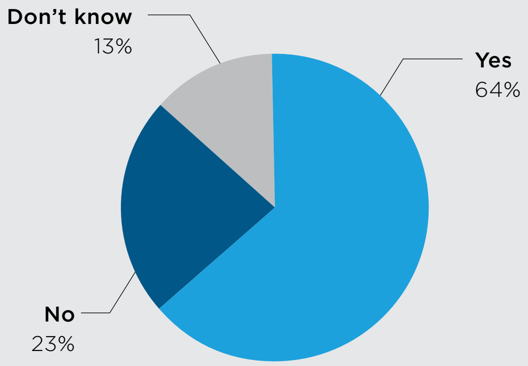
On the question ‘Have you found it harder to organise things than in the past? (e.g. need to use more reminders than in the past, e.g. notes, lists)’, 56% respondents (n=52)) have found it harder to organise things, 42% (n=39) respondents said they were not experiencing or noticing any difficulties and 2% (n=2) respondents were unaware of any difficulties in organising things (Fig. 6).

Figure 6: Difficulty organising things (n=93)



In response to the question 'Are you still able to find pleasure in the things you used to enjoy?', the majority of respondents, 64% (n=59) were still finding pleasure in the things they enjoy doing, while 23% (n=21) were not finding the same degree of pleasure in their activities they previously enjoyed. The remaining 13% (n=12) did not know if they were experiencing less pleasure in the things they used to enjoy doing (Fig. 7).

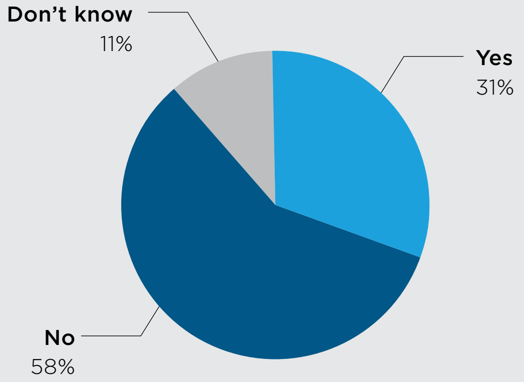
Figure 7: Finding pleasure? (n=92)



Noticing and talking about changes

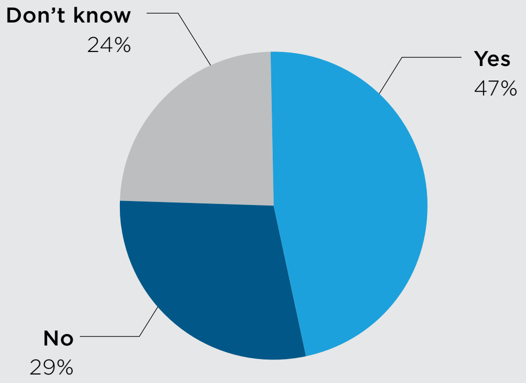
Participants were asked if they had noticed any unusual changes in their friends to explore if their friends where demonstrating any changes in behaviour 31% (n= 26) felt that they were seeing unusual changes in friends, while 58% (n= 49) were not noting any changes (Fig. 8). The remaining 11%) did not know if they had seen any changes within their friends' behaviour.

Figure 8: Changes in your friends (n= 84)



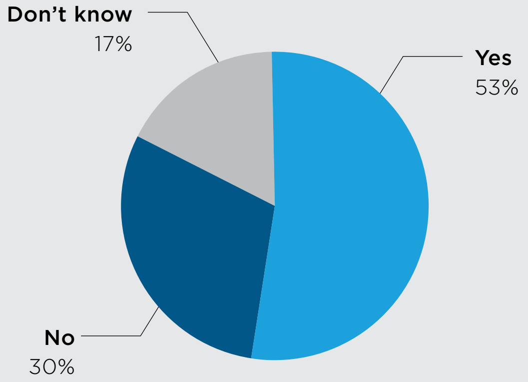
For respondents who noticed changes in their friends, it was important to know if they would feel comfortable discussing these changes with them (Fig. 9). Of the 31% (n=74) of respondents who had noticed changes in their friends behaviour, 47% (n=35) respondents felt they would be comfortable in discussing any changes with their friends. Of the remaining 53% (n=21) indicated that they would probably not talk to their friends and 24% (n= 18) didn't know if they would raise this with their friends if they were noticing changes in behaviour.

Figure 9: Talking to friends (n=74)



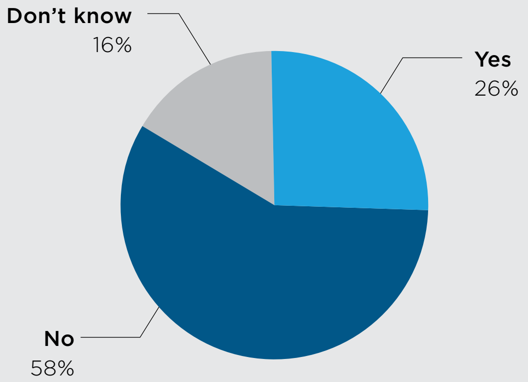
Asked if they would like some tips on how to talk to friends if they were noticing changes in their behaviour 53% (n=40) said that they would like tips on how to talk to their friends about the changes. Of those indicating they did not feel they needed tips on how to talk to their friends 29% (n=23) responded no and 17% (n=13) did not know if they would like talking tips (Fig. 10).

Figure 10: Talking tips (n=76)



In response to the question, 'Are your friends commenting that they are experiencing problems with their thinking?', intended to explore if respondents were discussing HAND at a community level (Fig.11) slightly over a quarter of respondents, 26% (n=22) indicated their friends were commenting on changes in their own behaviour. Over half, 58% (n=50) said that they were not hearing friends commenting on their own behaviour and the remaining 16% (n=14) did not know if their friends were commenting on any problems with their thinking.

Figure 11: Are friends commenting on problems? (n=86)



Respondents comments

People completing the survey were offered the opportunity to make any other comments ‘Please list any other issues or concerns you may have?’ Further comments were invited and made by 24 people. Within the 18 to 24 year age group no comments were made. Within the 25 to 43 year age group, two people responded, one said “I wish it would all end” and the second described feeling fatigued and exhausted.

Observations and comments within the 35 to 44 year age group were made by four respondents. A broader lack of the awareness of HAND within the community was raised by one respondent identifying the need for psychological testing to identify those at risk of HAND and that this was important to ensure that people were on the right antiretroviral combination. Also within this age group, two indicated they were experiencing difficulties, one mentioned poor dexterity (“always dropping things”) and one noted difficulty with thinking. The fourth respondent identified the need for attention to general health over the long term and that there are things that can be done to minimise the risk of losing brain function.

There were 11 responses within the 45 to 54 year age group. Of these, two respondents indicated they had nothing more to add. Of the remaining nine respondents, three discussed the things they are noticing within themselves. These included fatigue, difficulties with visual-spatial coordination and problems with executive functioning. Fear of developing and living with a neurocognitive deficit was expressed by two respondents where one participant expressed the intention that they would not want their family and friends witness their mental decline and would plan "an escape option… I would rather go before any long term, visibly embarrassing traits develop… I just don't want my family seeing me like that". In the context of this survey, we interpret this as the option of suicide being considered. This respondent countered this by saying they would need a lot of support from services if they were to develop "dementia", in which case they expressed their desire to be in a facility that treated them with dignity and respect. The second person expressed fear in relation to being discounted when speaking with medical staff about their concerns in that they may be seen as raising another issue with their health on top of other co-morbidities they may have already discussed with their doctor. Themes raised by the remaining two respondents in this age group discussed the importance of friends being confident to raise concerns about observed unusual behaviour. One participant stated, their friends were "too polite to bring up inconsistencies in my behaviour" and that they are concerned about some of their friend's behaviours they have observed that may not be being assessed. Both of these respondents identified the need to raise this issue by talking more about HAND, needing more publications, the importance of testing, and to recognise this as a 'real' problem. The last respondent in this age group indicated they were "good" and not noticed any of these "things" within themselves nor had they been noticed by their partner.

Within the 55 to 64 year age group there were six responses. Of these, two indicated nothing specific to add. One respondent drew attention to the terminology of HAND and identified that 'HIV dementia' is an old term and that 'dementia' should not be used as it is "quite different". This respondent and another identified aging as an issue and that there needs to be a clearer differentiation between decline of cognitive function and aging and those associated with HAND. On observing behaviour of friends, one respondent identified the problem of methamphetamine use amongst "a couple" of friends making them "irritable and erratic" and attributed their memory loss to substance use.

A quote from the final respondent encapsulates the primary reason for this research:

"*Some family and friends have 'heard' me when I bring up my sense that I am in early cognitive decline, but most doctors just look at you; say little, or dismiss it as not being all that bad. This makes me feel unheard; dismissed; invalidated; like I'm a hypochondriac; I'm over-exaggerating it all. When that comes from the very people who should be doing more – medicos – or at least be asking more questions, it makes me feel very alone; lost, and anxious as to where this process is taking me.*"

Current and future HAND in NSW

People living with HIV are living longer with effective cART and are expected to live as long as people without HIV(11). This may not equate to a similar expected quality of life with PLHIV who are experiencing a greater number of co-morbidities including neurological symptoms(4) (11). Within the general population of Australia, three in ten people over the age of 85 years and 1 in 10 over the age of 65 years will be living with dementia(12). The challenge will be to identify those PLHIV who are at risk of HAND and those who might be developing other causes of age related neurocognitive impairment such as dementias, e.g. Parkinson's disease and Alzheimer's disease, which will be an important distinction when considering approaches to treatment, care and life planning. At the end of June 2015, there was an estimated 9,970 people living with HIV in NSW(12). Based on a mean estimate of the prevalence(2)(4) (6), approximately 42% of PLHIV will be living with some degree of sHAND(5) (7) (9). It will be important to ascertain the degrees by which PLHIV are experiencing sHAND, how they are responded to when discussing concerns of neurocognitive functioning, particularly when speaking with healthcare providers, how they are supported, and the resources that are made available.

The qualitative comments from participants are evidence for the ongoing burden on those aging and living longer term with HIV. Fatigue and impacts on mental health that result from multiple co-morbidities and the risks that emerge from these experiences highlight the results of previous surveys undertaken by Positive Life NSW(29) (30). This is further compounded by the multi-morbidities related to 'general' aging that bring increased risks for polypharmacy, drug interactions, poor adherence or ceasing to take medications and will require a broad range of specialist care (Alcorn). It is envisaged that PLHIV living in NSW will require an increasing level of care coordination and support particularly when sHAND affects executive functioning.

Current and identified needs for resources

Alzheimer's Australia produced a resource in the 'Dementia and Chronic Conditions Series'(13) 'Living with HIV Associated Neurocognitive Disorders (HAND)'. The association with dementia is stigmatising(10) and the association of sHAND with dementia may also be anxiety producing when the disorder when diagnosed and assessed early is manageable with cART that effectively crosses the blood brain barrier. Milder forms of sHAND might not limit people in their work and general activities of daily living. As has been identified from feedback of participants in this research, the language, definitions and responses towards PLHIV are an important consideration in any response or resources developed for PLHIV about HAND. Resources must reflect these sensitivities for PLHIV when talking to health care providers, partners, family and friends so as not to add to the stigma, panic or fear about HAND. This is a critical consideration given the degree of concern expressed by some participants about their response when one participant considered suicide as an option. Equally important will be how the subject of HAND is raised by healthcare professionals and significant others with PLHIV. As this survey shows, a negative response can be damaging to the individual and may shut down any further discussion about the subject. The progression of the disorder from mild to acute to chronic can be subtle and lead to permanent damage or HAD. Being able to identify those at risk of sHAND has required intensive and time consuming neurocognitive screening by neuropsychologists(8). A modified assessment tool, CogState-based screening procedure, with a high specificity for doctors assessing and identifying those with sHAND has been recently publishe (8).

Resource development

Four domains have been identified for resource development and to build the capacity of those affected by or impacted by HAND.

1) Health Care Professionals

- How to recognise, assess and talk about HAND.
- How respond to HAND when it is raised by PLHIV or by a partner, family member or carer.
- Where to refer for further support.

2) For PLHIV at risk of HAND and sHAND

- What is HAND, symptoms, treatment and prognosis particularly if detected early.
- The importance of neurocognitive assessment, is the diagnoses HAND or could it be something else – identifies strengths and weaknesses.
- How to manage living with possible deficits to allow for the development of strategies.
- What strategies do people currently use when living with anxiety, depression, thoughts of suicide and other mental health conditions (bipolar disorder, schizophrenia).
- How to respond when someone raises concern regarding your behaviour.
- Support groups for PLHIV with sHAND.
- Protecting yourself legally, Power of Attorney, Enduring Guardianship, Will and Living Will distinguishing and defining the role of each legal document.

3) Family, partners and friends of PLHIV

- How to recognise and talk sensitively about HAND.
- How to respond to concerns about HAND.
- What is it like to live with a PLHIV with HAND – how to support them, strategies and tips on managing at home.
- Where to get further support and information.

4) Employers and the Workplace for PLHIV

- What are the needs within the workplace and how to support someone.
- How to manage someone's workplace performance if they have sHAND.
- Where to get further support and information.

5) Service Providers for PLHIV (Department Housing, Centrelink, and NGOs)

- How to manage at reception
- Do and don'ts for managing people with sHAND.

Where resources exist e.g. 'Dementia and Chronic Conditions Series: A toolkit for community care workers', these need to be focus tested, if not previously done so, for accuracy and relevance to ensure that they meet the objectives of not causing harm, reinforcing stigma and lead to isolation.

The objectives will be:

1) to ensure that resources do not create an atmosphere of harm, negativity and needs to maintain a focus on the benefits of early detection and effective treatment, interventions and strategies to live with sHAND;

2) to 'normalise' symptoms, and demonstrate that seeking further support will prevent further deterioration, and could possibly reverse symptoms if assessed early enough. Resources must be written without reinforcing the stigma and/or shame associated with memory deficits or negating concerns when they are raised by PLHIV;

3) resources will be underpinned by the importance of being able to talk to and respond appropriately at all levels when the topic HAND is raised either with the PLHIV or by the PLHIV and their significant other/s and healthcare professionals; and

4) that when a person is diagnosed with sHAND that they are managed within a supportive framework that promotes meaningful engagement and affirmative outcomes.

To ensure that the resources meet these objectives they will be focus tested by representatives from each resource group and PLHIV will have input into all resource development and testing.

> The objectives will be to ensure that resources maintain a focus on the benefits of early detection and effective treatment, interventions and strategies to live with sHAND.

Conclusions

The aim of this research was to gain insight into the concerns, experiences, perceptions and ability of PLHIV within NSW to engage in discussions about HAND with healthcare professionals. The responses from the population for this research is heavily weighted towards 45 to 65 year age group (69%) with a greater representation of MSM and an under-representation of heterosexual males and females, and transgender people. The findings are more likely to be representative of the Anglo-Australian born MSM population. The research has shown that PLHIV are concerned about HAND and are willing to discuss these concerns with healthcare professionals or significant others with the right support. It has also highlighted the importance of the response by healthcare professionals, partners and significant others when the topic is raised. It is important that when the topic is raised that the response be receptive and validating. Given the benefits of assessment, diagnosis and appropriate treatment which can reverse or slow neurocognitive decline with effective antiretroviral therapy(1) (2) (4), a negative response can close the person off from following up on what may be legitimate concerns.

While a minority of participants indicated that if a response is perceived to be negative by the person raising their concerns, they may not raise the topic again. This response can damage the relationship with healthcare professionals should never discount a person's concern about their neurocognitive function. Given that symptoms of sHAND can also be indicators of other mental health diagnosis, it is important to ensure that any concerns are assessed. Negative or dismissive responses from significant others may reflect the level of discomfort in not having the skills to respond appropriately and lead to a closing down of the discussion. This indicates the need for resources to be developed for partners, friends and significant other to both raise and respond appropriately to concerns about neurocognitive function and behaviour. 53% of the respondents indicated that resources to help with discussion would be helpful. In addition requests were made for greater support in living with sHAND via support groups.

With 16% of respondents indicating that they were fearful of discussing their concerns, it will be important to ensure that resources being developed do not create further stigma or fear and highlight the importance of early assessment and that unlike other neurocognitive disorders this is not a progressive dementia when on effective antiretroviral therapy. The resources will need to affirm that with sHAND, the right supports within the community and the workplace are important contributors to living an engaged and productive life. These resources will also need to focus on the role of remaining engaged in either work or volunteer activities, exercise, diet and relaxation as important strategies to maintain neurocognitive functioning(11) (14) (15) (16). The proportion of those at risk of sHAND remains broad and requires a more definitive range. Recent estimates of risk for sHAND still range from 18–50% of those PLHIV on cART(1). This broad estimation of risk is reflected in the complexity of the clinical presentation, how it is diagnosed and treated(1). What is of paramount importance is that any concerns raised by the person be listened to and addressed in a responsive manner to ensure that they are not left feeling unsupported or stigmatised.

Bibliography

1. *Neuropathogenesis of HIV: From Initial Neuroinvasion to HIV-Associated Neurocognitive Disorder (HAND).* Zaina, Z., Spudich, S. 2015, Current HIV/AIDS Reports, Vol. 12, pp. 16-24.
2. *Viral and Inflammatory Markers in Cerebrospinal Fluid of Patients With HIV-1-associated Neurocognitive Impairment During Antiretroviral Treatment Switch*. Tiraboschi, J., Muñoz-Moreno, J., Puertas, M., Alonso-Villaverde, C., Prats, A., Ferrer, E., Rozas, N., Maso, M., Ouchi, D., Picado, Martinez-Picardo, J., Podzamczer, D. 6, 2015, HIV Medicine, Vol. 16, pp. 388-392.
3. *Neuropsychological Impairment in Acute HIV and the Effect of Immediate Antiretroviral Therapy*. Kore, I., Ananworanich, J., Valcour, V., Fletcher, J., Chalermchai, T., Paul, R., Reynolds, J., Tipsuk, S., Ubolyam, S., Rattanamanee, S., Jagodzinski, L., Kim, J., Spudich, S. 2015, Journal of Acquired Immune Deficinecy Syndrome, Vol. 70 (4), pp. 393-399.
4. *Virologically Suppressed Patients With Asymptomatic and Symptomatic HIV Associated the Same Pattern of Immune Activation*. Vassallo, M., Durant, J., LebrunFrenay, C., Fabre, R., Ticchioni, M., Andersen, S., DeSalvador, F., Harvey-Langton, A., Dunais, B., Cohen-Codar, I., Montagne, N., Cua, E., Fredouille-Heripret, I., Laffon, M., Cottalorda, J., Dellamonica, P., Pradier, C. 2015, HIV Medicine, Vol. 16 (7), pp. 431-440.
5. *Cognitive Functioning, Wellbeing and Brain Correlates in HIV-1 Infected Patients on Long-term Combination Therapy*. Marloes, J., Olga, M., Steens, S., Bozena, G., Bosch, M., Koopmans, P., Kessels, Roy. 29 (16), 2015, AIDS, pp. 2139-2148.
6. *Multivariate normative comparison, a novel method for more reliably detecting cognitive impairment in HIV infection*. Su, J., Schouten, J., Geurtsen, Wit, F., Stolte, I., Prins, M., Portegies, P., Caan, M., Reiss, P., Majoie, C., Schmand, B.,. s.l. : AIDS, 2015, Vol. 29 (5), pp. 547-557.
7. *The Montreal Cognitive Assessment: A Pilot Study of a Brief Screening Tool for Mild and Moderate Cognitive Impairment in HIV-Positive Veterans*. Chartier, M., Crouch, P., Tullis, V., Catella, S., Frawley, E., Filanosky, C., Carmody, T., McQuaid, J., Harry Lampiris, H., K. Wong, K. 14(3), 2015, Journal of International Association of Providers of AIDS Care, pp. 197-201.
8. *A Screening Strategy for HIV-Associated Neurocognitive Disorders That Accurately Identifies Patients Requiring Neurological Review*. Bloch, M., Kamminga, J., Jayewardene, A., Bailey, M., Carberry, A., Vincent, T., Quan, D., Maruff, P., Brew, B., and Cysique, L. July 15, 2016, Clinical Infectious Diseases, pp. 1-7.
9. *A Better Screening Tool for HIV associated Neurocognitive Disorders*. Brouillette, M., Mayo, N., Fellows, L., Lebedeva, E., Higgins, J., Overton, E., Ances, B., Koski, L. 2015, AIDS, Vol. 29 (8).
10. Anderson, P. *World Alzheimer's Report* 2915: Global Impact of Dementia. s.l. : Medscape, August 27, 2015.
11. American Academy of HIV Medicine, AIDS Community Research Initiative of American, and the American Geriatrics Society. *The HIV and Aging Consensus Project: Recommended Tretament Startegies for Clinicians Managing Older Patients with HIV*. 2012. pp. 1-76.

12 *The HIV Diagnosis and Care Cascade in NSW as of June 2015*. The Kirby Institute. 2015.

13. Alziehmers Australia . Statistics: key facts and statistics 2016. *Alzhemier's Australia*. [Online] 2016. https://fightdementia.org.au/about-dementia/statistics.
14. *Addressing the burden of mental, neurological, and substnace use disorders: key messages from Disease Control Priorities, 3rd Edition*. Patel, V., Chisholm, D., Charlson, F., Dgenhart. L., Dua, T., Ferrari, A., Hyman, S., Laxminarayan, R., Levin, C., Lund, C., Mora, M., Petersen, I., Scott, J., Shidaye, R., Vijayakumar, L., Thornicroft, G., Whiteford, H.,. Jan 11, 2016, Lancet, Vol. 387, pp. 1672-85.

15. *Chronic Diesase Self-Management by People With HIV*. McDonald, K., Slavin, S., Pitts, M., Elliott, J. (6), 2016, Qualitative Health Research, Vol. 26, pp. 863-870.

16. *Taming HIV-Related Inflammation with Physical Activity: A Matter of Timing*. d'Ettorre, G., Ceccerelli, G., Giustini, N., Mastroainni, C., Silvestri, G., Vullo, V. 10, 2014, AIDS Research and Human Retroviruses , Vol. 30.

17. AIDSmeds. *A New, More Reliable Way to Gauge HIV-Related Cognitive Dysfunction*. 2015.

18. *It's not in the notes!* Cummins, D., Trotter, G., Murray, K. 2014, HIV Nursing, Vol. Spring, pp. 25-27.

19. Rani, P., Singh, N. Central Nervous System Complications in HIV: Overview, Pathophysiology, Differential Diagnosis. *http://emedicine.medscape.com/article/1167008-overview*. [Online] Dec 23, 2015.

20. *Geriatric Syndromes in Older HIVinfected*. Greene, M., Covinsky, K., Valcour, V., Miao, Y., Madamba, J., Lampiris, H., Cenzer, I., Martin, J., Deeks, .G. 2015, Journal of Acquired Immune Deficiency Syndrome, Vol. 69 (2), pp. 161-167.

21. *HIV and Aging: Insights From the Asia Pacific HIV Observational Database (APHOD)*. Han, N., Wright, S., O'Connor, C., Hoy, J., Ponnampalavanar, S., Grotowski, M., Zhao, H., Kamarulzaman, A.,. 2015, HIV Medicine, Vol. 16 (3), pp. 152-160.

22. *The Effect of Antidepressant Treatment on HIV and Depression Outcomes*. Pence, B., Gaynes, B., Adams, J., Thielman, N., Heine, A., Mugavero, M., McGuinness, T., Raper, J., Willig, J., Shirey, J., Ogle, M., Turner, E., Quinlivan, E. 2015, AIDS, Vol. 29 (15), pp. 1975-1986.

23. *HIV Encephalopathy and AIDS Dementia Complex*. Thomas, F., Singh, N. Feb 23, 2016, http://emedicine.medscape.com/article/1166894-overview.

24. *Risk of Clinically Significant Depression in HIVinfected*. Gutiérrez, F., García, L., Padilla, S., Álvarez, D., Moreno, S., Navarro, G., Gómez-Sirvent, J., Vidal, F., Masiá, M. ;. 2014, HIV Medicine, Vol. 15 (4), pp. 213-223.

25. Wilson, D. *Mapping HIV outcomes: geographical and clincal forcasts of numbers of people living with HIV in Australia*. s.l. : The University of New South Wales, 2011.

26. *Virologically Suppressed Patients With Asymptomatic and Symptomatic HIV-Associated Neurocognitive Disorders Do Not Display the Same Pattern of Immune Activation*. M Vassallo, M., Durant, L., Lebrun-Frenay, C., Fabre, R., Ticchioni, M., Andersen, S., DeSalvador, F., Harvey-Langton, A., Dunais, B., Cohen-Codar, I., Montagne, N., Cua, E., Fredouille-Heripret, L., Laffon, M., Cottalorda, J., Dellamonica, P., Pradier,C. 16(7), 2015, HIV Medicine, pp. 431-440.

27. The Kirby Institute. *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2015*. Australia, Sydney NSW 2052 : s.n., 2015. 1838–5559.

28. *Geriatric Syndromes in Older HIV-infected Adults*. Meredith Greene, MD, et al., et al. 2015, Journal of Acquired Immune Deficiency Syndrome, pp. 161-167.

29. Feeney, L. *Better Outcomes for People with Chronic and Complex Health*. s.l. : Positive Life NSW, 2015. pp. 1-7.

30. —. *People living with HIV and access to health care in NSW-A Community Survey*-2015. Positve Life NSW and Australian Society for HIV Medicine (ASHM). 2015. pp. 1-27.

31. 2014 Alcorn, K. *French study reveals the growing complexity of medical need as people with HIV age*. 2016.

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