Appendix A

## Consultation List

i. Initial meeting with the Positive Life NSW CEO Craig Cooper and the HIV Complex Care Advisory Group on 25 September 2017

ii. Consultation meetings (either face-to-face or teleconference) were conducted between 12 October and 16 November 2017with the following stakeholders:

- Adahps (Jenny Thompson)
- Albion Centre ( Dr Don Smith, Ruth Hennessy)
- Multicultural HIV & Hepatitis Service (Barbara Luisi, Dash Gray)
- Pozhet (Susan McGuckin, Maxine Lewis)
- Positive Central ( Alison Colwell)
- SESILHD HIV Outreach Team (Leo Barreto, Ross Duffin)
- St Vincent's IBAC (Prof Andrew Carr, John William McAllister)
- Liverpool Sexual Health (Dr Chis Carmody, Lisa Severin, Sandhya Goundar)
- Nepean & Blue Mountains Sexual Health (Dr Eva Jackson, Kerrie McCallum, Joanne Gough)
- Liverpool Hospital HIV Clinic (Velma Parkinson, CNC; Karen Keating, CNC; Thuy Tien To, Social Worker)
- John Hunter Hospital Social Worker (Richard Riley)
- NSW Ministry of Health (Tim Duck, Marlene Velecky)
- SNSWLHD & MLHD (Alison Nikitas, Dr Katherine Turner, Alison Kincade, Sally-Anne Brennan, Margaret Trail, Catherine Maher, Gemma Hartmann, Ally Davoren,
- BGF (Andrew Buchannan, Sue Wood, Lauren Foy, Troy Dunn)
- SLHD HIV Outreach Team (Kurt Andersson, Denise Cummins)
- Clinic 16 (Vicki Gibb, Christopher Sewell)
- WNSWLHD & FWNSW LHD (Dr Anna McNulty, Ann Ryan, Kim Grant, Donna Middleton, Margaret Crowley, Roisin Steward, Ann Bolton)
- Positive Life NSW ( Craig Cooper, David Crawford, John Carr
- ACON ( Nicolas Parkhill, Sarah Lambert)
- Parramatta Sexual Health ( Dr Catriona Ooi, Andrew Everingham, Lara Goulding
- Lismore Sexual Health (Dr David Smith, Ariane Minc, Dr Natalie Edmiston
- *Mid North Coast LHD HARP Unit (no response to multiple contact requests)*

## Definition of PLHIV and Complex Care Needs

Healthcare needs are complex if they are the product of a co-existing set of interrelated morbidities that are severe and protracted. In the case of HIV healthcare needs, complexity typical involves a range of relatively serious and persistent health conditions that have resulted from or coincided with people living with HIV (PLHIV) for a number of years.

The number, type and severity of conditions experienced by people with HIV and complex healthcare needs will vary among individuals, and the overall impact of those conditions will in turn be affected by the range of social and other external factors impacting on each person's life. In all cases however they will experience multiple, relatively serious and interrelated health and social factors over an extended period. These can be ameliorated or compounded by the complexity of health care service delivery.

Complexity for PLHIV can be thus characterised as: any set of co-occurring and interrelated medical conditions of varying severity and chronicity (medical complexity); compounded by ageing, frailty and socio-economic factors, as well as cultural, environmental and behavioural issues (situational complexity); together with systemic factors relating to access, delivery and coordination of health services (systemic complexity).

### Medical Complexity

People living with HIV (PLHIV) experience higher rates of multiple co-occurring medical conditions including: non-AIDS related cancers, neurocognitive disorders, mental health conditions, cardiovascular disease, osteoporosis and osteopenia, diabetes and frailty. PLHIV who were diagnosed with HIV prior to the advent of ART and older PLHIV are particularly prone to complexity, due in part to years of living with an immune-compromised system.

The severity of co-occurring medical conditions, the degree of impairment, and the level of health care, treatment and service coordination required will all impact upon the level of medical complexity for PLHIV. For example, the medical complexity for a PLHIV with cancer, or a catastrophic event such as stroke, or HIV associated dementia and frailty, will be significantly different to a PLHIV with well controlled HIV, hypertension and depression. Each of these examples involves a different array of generalist and specialist services.

### Situational Complexity

Non-medical factors such as gender, race, culture and language, age, sexual identity, education, self-agency, poverty, and place of residence can all impact on situational complexity. Lifestyle and behavioural factors, including excessive alcohol consumption, drug abuse and nicotine smoking also contribute to this complexity. As a result, the situational complexity of a heterosexual middle aged woman with HIV living alone in rural NSW will be substantially different to a gay man living in the inner city with HIV and alcohol and drug abuse issues, or a bisexual CALD PLHIV refugee living in outer suburban Sydney.

### Health care system complexity

The inherent complexity of the healthcare system is magnified for those with complex needs who must navigate generalist and a range of specialist health service providers. As well as creating consumer confusion with an array of public and private health service providers, systemic complexity can contribute to inadequate or uncoordinated health care responses and disengagement of PLHIV from health care.

Moreover, systemic complexity increases the risk of service duplication, increasing service gaps and inadequate coordination and personalisation of care. In a complex system involving generalist and various specialist health care professionals, clinicians may also struggle to diagnose and manage the various conditions PLHIV with complex healthcare needs experience.

Appendix C

# PLHIV and Complex Care – Literature Review & Desktop Analysis

## 1. Population profile and diversity - PLHIV in NSW

### 1.1 Introduction

This desk-top review examines published literature on the demographic profile, medical, psycho-social and contextual issues facing people living with HIV (PLHIV) in NSW who experience chronic and complex health conditions. The literature review primarily focuses on source documents identified by the HIV & Complex Care Project Advisory Group and other Australian published research on the subject of HIV, multi-morbidity and complex care. Some international literature has been sourced and included where there is a useful population parallel.

The overall purpose of the literature review is to identify the scale and scope of the range of interrelated and compounding medical, situational and health systems factors that contribute to the complexity of health care for individuals with HIV and which adversely impact on their quality of life, health outcomes and mortality. It is intended that the literature review will inform consideration of the health care needs of PLHIV with complex health, psychosocial and support requirements through a needs assessment, service mapping exercise and gap analysis. The purpose of this process is to enhance engagement in health care, retention in health care and improve the future health outcomes of PLHIV in NSW.

### 1.2 Key findings

**Number of NSW residents with diagnosed HIV**

- In June 2015, it was estimated by the Kirby Institute that there were approximately 11,500 people living with HIV (PLHIV) in NSW. Of these, 86% (9,890) had been diagnosed.[1]
- In October 2016, The Kirby Institute recalculated and revised the number of people living with diagnosed HIV (PLDHIV) as part of a 2015 NSW HIV Care Cascade. The number of PLDHIV equalled the estimated number of PLDHIV, minus (-) the number of deaths, +/- overseas migration, +/- interstate migration. At that time (2015), it was estimated that the number of PLHIV equalled 9,947 (range 8,834 – 11,085), the number of PLDHIV in NSW equalled 9,222 (range 8,338-10,121), the number of PLDHIV in care equalled 8,761 (range 7,632 – 10,000), the number receiving ART 7,882 (range 7,497 – 8,647), and the number with supressed HIV viral load equalled 7,089 (range 6,659 – 7,874).[2]
- There were 317 NSW residents diagnosed with HIV between January and December 2016,[3] and 144 NSW residents diagnosed with HIV between January and June 2017.[4]
- Therefore, there were approximately 9,683 PLDHIV in NSW as at June 2017.

**Proportion of PLHIV by transmission route**

- Of the 317 NSW residents notified with newly diagnosed HIV infection in 2016, HIV risk exposure was reported as male to male sex for 82% (n=259), heterosexual sex for 15% (n=47), injecting drug use (PWID) for 1% (n=4), another type or unknown exposure for 2% (n=6) and vertical transmission for <1% (n=1), which occurred outside Australia. This was a similar breakdown of HIV risk exposures as was reported for people newly diagnosed in 2010-2015.[5]

[1] NSW HIV Strategy 2016-2020, NSW Ministry of Health, 2016, pviim
[2] The NSW 2015 HIV Cascade, R Gray, Kirby Institute UNSW, October 2016
[3] NSW HIV Strategy 2016-2020, Quarter 4 & Annual 2016 Data Report, pvi
[4] NSW HIV Strategy 2016-2020, April – June 2017 Data Report, pvi
[5] NSW HIV Strategy 2016-2020 Quarter 4 & Annual 2016 Data Report, pxv

- Between 2007 and 2011, the profile of newly diagnosed HIV infections in NSW included: men who have sex with men (72.3%), heterosexual contact (19%), injecting drug use (3.3%), and other/undetermined (5%).[6]

**NSW Distribution of PLHIV**

- In 2011, the Kirby Institute conducted modelling to forecast the number of Australian people living with diagnosed HIV by statistical region and year.[7] It was estimated that in 2015 there would be 10,867 people living with diagnosed HIV in NSW. This figure is 324 more than the current 2017 estimate of NSW residents with diagnosed HIV calculated above.
- Wilson went on to calculate the numbers of PLHIV by Australian Bureau of Statistics (ABS) statistical regions in Sydney and regional NSW in 2015. He estimated that approximately 78% (8,461) people with diagnosed HIV lived in the Sydney metropolitan area and 22% lived in regional and rural NSW.[8]

**PLHIV age distribution**

- The PLHIV population is ageing. In 2000, 11.2% of PLHIV were 55 years and over. In 2010, 25.7% of PLHIV were 55 years and over and in 2020, 44.3% of PLHIV will be 55 years and over. The proportions of 55-64, 65-74 and 75 years and older are all increasing.[9]

**Proportions of PLHIV with multimorbidity requiring treatment**

- In a 2015 Positive Life surveyed 169 PLHIV to assess their health care needs. 21% reported one additional health condition (in addition to HIV), 14% reported two additional health conditions, 11% reported three additional health conditions, 7% four, 2% five, 2% six, 1% eight, and 2% could not be interpreted and included.[10] (I.e. 38% of PLHIV survey respondents had two or more health conditions in addition to HIV).
- In a Dutch study which followed 10, 278 treated PLHIV as they age (ATHENA cohort), it was predicted by 2030 that 84% of PLHIV will have at least one non-communicable disease (NCD), up from 29% in 2010, with 28% of PLHIV having three or more NCDs. And, 54% of PLHIV will be prescribed multiple-medications in 2030 compared with 13% in 2010, with 20% taking three or more medications. Most of this change will be driven by increased prevalence of cardiovascular disease and associated drug treatments. Because of contraindications and drug-drug interactions, in 2030, 40% of PLHIV could have complications with currently recommended HIV regimens.[11]

**Comorbidities and age**

- A 2015 Australian prospective study of 446 HIV positive and HIV negative (228 HIV positive and 218 HIV negative) GBM aged 55 years and over (APPLES), found that HIV positive GBM when compared to HIV negative GBM reported higher rates of thrombosis (10.5% vs 4.2%), diabetes (15% vs 9%), heart disease (20% vs 12%), neuropathy (23% vs 1%), and shingles (32.5% vs 16.9%). When adjusted for smoking and age, a significantly elevated risk of melanoma and prostate cancer were also identified.

  HIV positive men also significantly reported taking medication for osteoporosis and bone disease when compared to HIV negative men. For both HIV positive and HIV negative cohorts, multimorbidity become more prevalent with increasing age and HIV positive GBM reported significantly higher mean numbers of comorbidities compared to HIV negative GBM. For example, 85% of HIV positive GBM reported one or more comorbidities, and just over half (56%) reported two or more comorbidities.

[6] D Wilson, Presentation, South Eastern Sydney LHD HIV and Complex Care & Ageing Forum, 2013
[7] Wilson, D. 2011, Mapping HIV Outcomes: geographical and clinical forecasts of people living with HIV in Australia, Table 5. Number of people living with diagnosed HIV by statistical region and year, pxxi
[8] Ibid,
[9] Wilson, D. 2011, Mapping HIV Outcomes: geographical and clinical forecasts of people living with HIV in Australia, Table 5. Number of people living with diagnosed HIV by statistical region and year,
[10] Positive Life NSW, Report – PLHIV Access to Health Care in NSW – Consumer Survey Report, 2015,
[11] Smit, M. et al. Future challenges for clinical care of an ageing population infected with HIV: a modelling study, Lancet 2015

Of the HIV negative men, 77% reported one or more comorbidities, with 39% reporting two or more comorbidities. Increased prevalence of traditional risk factors among HIV positive people (such as smoking, elevated lipids, hyperglycaemia, altered body composition, alcohol and recreational drug use) significantly contribute to the increased risk of many of these non-communicable diseases.[12]

- Analyses of data from a community survey conducted by Positive Life in 2015 showed that 18% of PLHIV respondents aged 55-64 years had two co-morbid conditions, 20% three, 4% four and 11% five. Of those aged 65-74 years, 8% had two, 50% had four comorbidities, and 17% had five comorbidities.[13]

## 2. Common comorbid conditions in PLHIV

### 2.1 Mental health conditions

- Then Australian 2015 APPLES study identifies self-reported proportions of HIV positive and HIV negative GBM 55 years and over with depression or anxiety to be much higher than the general population. 37.5% of HIV positive GBM and 38.1% of HIV negative GBM reported depression. 19.0% of HIV positive GBM and 23.0% of HIV negative GBM reported anxiety.[14]
- 34.8% of HIV positive respondents to Futures Seven (2013) reported having taken medicines prescribed for depression in the six months prior to completing the survey.[15]
- If depressed, older PLHIV are more likely to experience poverty, to live alone and be socially isolated, lack service knowledge and navigational skills, and have suicidal thoughts as well as experience HIV associated stigma.[16]
- In a 2015 survey conducted by Positive Life into the health care needs of PLHIV in NSW (214 HIV positive respondents), 21% reported a mental health condition, including: depression (13%), anxiety (4%), and psychiatric conditions (4%).[17]
- PLHIV experience higher rates of mental health conditions than the general population. The National Health Survey (Australian Bureau of Statistics, 2009) reports that 5.9% of the Australian population reported having taken antidepressants in the two previous weeks to completing the survey.
- Depression has a significant impact on adherence to ART.[18]

### 2.2 Alcohol and other drugs

- The Flux Study[19] investigated drug use among 2,251 gay and bisexual men in Australia (including HIV positive and HIV negative/unknown). The study found that: 1) 39.6% had smoked tobacco in the previous six months and half did so every day, 2) most (93.3%) drank alcohol with 17.5% drinking at least four days per week, 3) half (50.5%) had used illicit drugs in the last six months, 4) over a quarter (26.9%) had ever used methamphetamine, with 12% having done so recently, 5) one in seven of those who reported use of methamphetamine in the previous six months, used it every week (1.8% of the

[12] Petoumenos, K. et al. Prevalence of self-reported comorbidities in HIV positive and HIV negative men who have sex with men over 55 years – The Australian Positive & Peers Longevity Evaluation Study (APPLES) 2017
[13] Positive Life NSW, Report – PLHIV Access to Health Care in NSW – Consumer Survey Report, 2015
[14] Petoumenos, K. et al. Prevalence of self-reported comorbidities in HIV positive and HIV negative men who have sex with men over 55 years – The Australian Positive & Peers Longevity Evaluation Study (APPLES) 2017, pix
[15] Grierson J et al, HIV Futures Seven, ARCSHS, 2013, pvi
[16] Dr V, Furner, Albion Centre Sydney, Presentation to the South eastern Sydney LHD HIV Complex Care & Ageing Forum 2013
[17] Positive Life NSW, Report – PLHIV Access to Health Care in NSW – Consumer Survey Report, 2015, pxxx
[18] Gonzalez JS et al. Depression and HIV treatment nonadherence. Journal of Acquired Immune Deficiency Syndromes, online edition, 2011
[19] Mohamad A. et al. (2016). Flux: Following Lives Undergoing Change, Gay community life, drug use, and taking care of ourselves and each other, Report 2014-2015. Monograph, The Kirby Institute, UNSW, Sydney Australia Ibid pviii

sample), 6) nearly one in ten (9.2%) men had injected illicit drug in their lifetime, and 4.1% had injected illicit drugs in the previous six months, most commonly methamphetamine.

- The Gay Periodic Survey shows different trends in use of particular drugs over time. Among Sydney based men between 2004 and 2011, use of many drugs increased. For example, cocaine (15.8% to 22.0%), gamma-hydroxybutyrate ('poppers') (9.8% to 13.1%), and erectile dysfunction medications (18.1% to 21.8%). Marijuana use declined (42.1% to 33.1%). About one in twenty men reported recent injecting drug use and 2.1% reported at least monthly injecting drug use.
- Gay and bisexual men constitute about 2% of the adult male Australian population but are overrepresented in studies of drug-using populations. Moreover, high proportions of HIV+ gay/bisexual men use alcohol and other illicit drugs (including methamphetamine) more frequently than the general population. For those who use methamphetamine, they are using greater quantities more frequently to feel the effects of the drug.

## 2.3 Cardiovascular disease

- The risk of cardiovascular risk is increased for PLHIV. A range of interrelated factors including chronic inflammation from HIV infection, altered lipids, insulin resistance and smoking, increase the risk of cardiovascular disease in PLHIV.[20]
- The proportion of PLHIV with hypertension and ischaemic heart disease increases with age. The proportion of PLHIV with hypertension increases from 5% of those aged 40-49 years to approximately 30% of those aged 60-69 years, and 50% of those aged 70-79 years. The rate of ischaemic heart disease increases from 4% of those aged 50-59 years to 13% of those aged 60-69 year and 19% of those aged 70-79 years.[21]
- The Australian APPLES study found that 43.5% of HIV positive gay men aged 55 years and over reported hypertension and 19.5% reported heart disease. In contrast, 12.2% of HIV negative gay men reported heart disease.[22]
- In a 2015 survey conducted by Positive Life into the health care needs of PLHIV in NSW (214 HIV positive respondents), 20% of all respondents reported cardiovascular disease, including: hypertension (8%), hyperlipidaemia (5%) and hear conditions and stroke (7%).[23]

## 2.4 Cancers

- Despite effective HIV antiretroviral therapy, infection with HIV is associated with increased risk of Non-Hodgkin lymphoma, anal cancer, and Hodgkin lymphoma, vagina, penis, oral, throat and skin cancers.[24]
- The most common cancers in HIV positive men are (in order): lymphomas, Kaposi sarcoma, anal cancer, lung cancer, non-melanoma skin cancers, Hodgkin disease, liver cancer, head and neck cancers, urothelial cancers prostate cancer colorectal cancer and melanoma. In HIV positive women the most common cancers are (in order): lymphoma, breast cancer, Kaposi sarcoma, lung cancer, Hodgkin disease, cervix cancer, anal cancer, non-melanoma skin cancers, liver cancer, head and neck cancer, colorectal cancer melanoma.[25]

[20] Dr D Baker, East Sydney Doctors, Presentation to the South eastern Sydney LHD HIV Complex Care & Ageing Forum 2013
[21] Ibid
[22] Petoumenos, K. et al. Prevalence of self-reported comorbidities in HIV positive and HIV negative men who have sex with men over 55 years – The Australian Positive & Peers Longevity Evaluation Study (APPLES) 2017, pix
[23] Positive Life NSW, Report – PLHIV Access to Health Care in NSW – Consumer Survey Report, 2015,
[24] Grulich, A. et al. Lancet 2007
[25] Lanoy E. et al. The spectrum of malignancies in HIV-infected patients in 2006 in France: The ONCOVIH Study, International Journal of Cancer, 2011

- The incidence of non-AIDS defining cancers in PLHIV is: anal cancer in PLHIV is 70-130/100,000py, 54/100,000 for Hodgkin's lymphoma, 43/100,000 for oral/pharyngeal cancer and 48/100,000 for melanoma.[26]
- The treatment of many cancers involves chemo/radiotherapy and radical surgery. Treatment procedures leave PLHIV fatigued and debilitated from months to years.
- The five year prognosis after a cancer diagnosis is variable. However, the five year prognosis after diagnosis and treatment for anal cancer is 50-60%.[27]

### 2.5 HIV associated neurocognitive disorders

- Despite the impact of ART on plasma HIV viral suppression, some PLHIV experience HIV associated neurological disorders (HAND). HAND is a common disease in PLHIV with varying reporting prevalence of 20-69%. Of those with HAND, most will experience asymptomatic neurocognitive impairment (ANI) (33-60% of all HAND), some will experience mild neurocognitive dementia (MND), and some will develop HIV-associated dementia (HAD),(1% in 2000).[28]
- MND and HAD significantly affect an individual's ability to perform activities of daily living, self-care, employment, and medication adherence etc.

### 2.6 Frailty

- The combination of HIV infection, multi-morbidity and age can lead to frailty. PLHIV after diagnosis and treatment of cancer, heart attack, stroke and fractures are prone to increasing symptoms of frailty. Symptoms include: low endurance and reduced energy reserves, poor strength, reduced exercise tolerance and loss of muscle mass, loss of balance, dysregulation of physiological systems including immunity, neurologic, inflammatory and endocrine systems, increased susceptibility to falls, fractures, disability, loss of independence and death.[29]
- Frailty increases with age and time of HIV infection for PLHIV. PLHIV infected for 8-12 years at age 55 years, exhibit a 9 fold higher risk of frailty than aged match controls.[30]
- Frailty leads to reduced functional independence, and increased accommodation and care needs.

## 3. Complexity and HIV

Complexity has a profound effect on healthcare outcomes of PLHIV. It is characterised by multiple interrelating dimensions, including co-occurring and multifaceted medical conditions, situational complexity such as age, frailty, socio-economic factors, and culture, environment, behaviour, and systems factors such as health care service access, delivery and coordination.[31] Complexity can thus be conceptualised into three interrelating and compounding domains: 1) medical complexity, 2) situational complexity, and 3) systems complexity.

### 3.1 Medical Complexity

- Multi-morbidity (multiple co-occurring medical conditions) in PLHIV include conditions such as: non-AIDS related cancers, neurocognitive disorders, mental health conditions, cardiovascular disease, osteoporosis and osteopenia, diabetes and frailty. PLHIV diagnosed with HIV prior to the

[26] Dr V, Furner, Albion Centre Sydney, Presentation to the South eastern Sydney LHD HIV Complex Care & Ageing Forum 2013, Source – Silverberg, M. et al. CROI 2010. Abstract 28
[27] Dr Richard Hillman, St Vincent's Hospital Sydney, 2017
[28] Carroll, A. Brew, B. HIV-associated neurocognitive disorders: recent advances in pathogenesis, biomarkers, and treatment, F1000Research, 2017
[29] Sandy Beveridge, Director of Geriatric Medicine and Ambulatory Medicine St Vincent's Hospital Sydney, Presentation to the South eastern Sydney LHD HIV Complex Care & Ageing Forum 2013
[30] Ibid, Source – Desquilbet, et al. J Gerontal Med Sci 2007; 62A:1279-86
[31] Complexity and health care, health practitioner workforce services, roles, skills and training, to respond to patients with complex needs, Queensland Government, Griffith University, 2011

advent of ART and older PLHIV who experienced side-effect prone early ART regimens are particularly prone to multi-morbidity and complexity. Multi-morbidity is often associated with decreased quality of life and increased psychological distress and multi-morbidity creates unique challenges due to 1) the need for complex PLHIV self-care regimens, 2) the use of multiple (and sometimes counteracting) medicines (polypharmacy), 3) the need for care coordination with multiple specialists and allied health care workers, 4) demands on the time available in a consultation, and 5) difficulty for the clinician applying standardised guidelines in complex and multifaceted presentation.[32]

- Diagnostic and treatment complexity – challenge practitioners' capacity to recognise signs and symptoms and to differentiate between multiple co-occurring health conditions. Treatment is also complicated because a treatment indicated for one health condition may potentially have an antagonistic effect on the treatment for a coexisting condition.[33]
- Severity of illness (from multiple health conditions) is a key component in complexity, however, complex medical conditions need not necessarily be serious and complex for all PLHIV at all times. Indeed, some complex conditions may be serious and complex at some points during the course of illness and be less so at other times. This fluctuating capacity over time can result in an increased or decreased degree of functional impairment and capacity to be involved in their health care and to maintain independent living.[34]
- The level of need for comprehensive care management reflects not just the medical or biological complexity, but the characteristics of the management of the condition, the context of the condition, and the interactions and communications between the person and the provider or service. This process can involve shared care provision between primary and specialist health care providers and multiple services both public and private.[35]

## 3.2 Situational or contextual complexity

- Situational complexity has been acknowledged by the Ottawa Charter as an important focus for health promotion. Even relatively simple medical conditions may become complex as a result of the contextual realities in which people live, work and play.
- Environmental factors include the physical and social environments in which people live and conduct their lives. They factors are external to the person and can influence a PLHIVs health condition, functioning and interaction with the health system either positively or negatively.
- Environmental factors that can negatively influence a PLHIV's ability to self-care and interact with the health system include: unsatisfactory housing, lack of social support, relationship status and being without spousal or family or supports from friends, low socioeconomic status, place of residence, access to transport, access to technology, and the impacts of HIV associated stigma and discrimination etc.[36] Variations in environmental factors unequally expose PLHIV to influences that damage health, and opportunities for health, in different ways. For example, PLHIV who live alone in poverty in rural areas are more likely to experience reduced access to specialised treatment and care and incur less favourable health outcomes. [37]
- The health care service environment also impacts on complexity. Factor influencing complexity include: 1) the degree of access that PLHIV have to services, 2) The nature of responses to a patient's needs by a particular health care provider, and the quality of interaction between the PLHIV and the

[32] Fortin, et al., 2007; Stack, Elliott, Noyce, and Bundy, 2008
[33] Jowsey et al., 2009; Safford,et al., 2007; Soubhi et al., 2010; Gask. Et al., 2008;
[34] Complexity and health care, health practitioner workforce services, roles, skills and training, to respond to patients with complex needs, Queensland Government, Griffith University, 2011, pxiv
[35] WHO, 2002
[36] International Classification of Functioning, Disability and Health, 2001
[37] Marmot, 2007

health care provider.[38] Further, cultural background, family environment, language and income status may further influence and impact on a PLHIV's capacity to adhere to health care recommendations.

- Personal factors including: gender, race, age, culture circumstances, lifestyle, upbringing, life events, educational background, impact on the way PLHIV experience HIV infection and other health conditions.[39] These elements impact on the way PLHIV interact with health practitioners and with the health system in general, but also with the way health information is understood and by the way PLHIV engage or don't engage with their own health care.
- Thus, personal factors are deeply embedded within health care complexity.[40] They are associated with the way in which PLHIV and health care practitioners interact, and the way in which health care information is understood, responded to and acted upon. As with environmental factors, health care practitioners must be able to identify and work with PLHIV in ways that recognises the important personal factors that interact with their medical condition/s. Carefully identifying and working with these factors, influences the activates/treatment and ways in which PLHIV participate in their own health care.
- A PLHIV's ability to participate in their own heath care and activities such as learning, applying knowledge, communication and self-care, can be significantly impacted by the severity of multiple co-occurring medical conditions and situational factors.[41]

### 3.3 Health care system complexity

- HIV management is conducted by accredited specialist prescribers (s100 prescribers). S100 prescriber are located both within private practice and publically funded sexual health clinics in NSW. Some PLHIV choose to separate their HIV care and their health care for other non-HIV conditions. They therefore access an s100 prescriber for their HIV monitoring and prescribing and a GP for the health care of other conditions. In some cases, the GP is also an s100 provider and this mean that PLHIV can access HIV and non-HIV care from the one health care provider. GPs and GP/S100 providers are the main gateway into specialist services and hospital services.
- Complexity is increased when there are a large number of health care practitioners involved in the delivery of health care, particularly when these providers come from different disciplines and backgrounds.[42] As PLHIV move between different part of the health system (public and private, primary and tertiary) they encounter different health system structures, roles and responsibilities among health care providers, as well as different terminologies and clinical approaches.[43] As a result, PLHIV may experience this fragmented heath care system as cumbersome, unwieldly and difficult to navigate and understand.
- The inherent complexity of the healthcare system is magnified for those with complex needs who must navigate generalist and a range of specialist health service providers. As well as creating consumer confusion with an array of public and private health service providers, systemic complexity can contribute to inadequate or uncoordinated health care responses, miscommunication, perceived barriers and disengagement of PLHIV from health care.
- Moreover, systemic complexity increases the risk of service duplication, increasing service gaps and inadequate coordination and personalisation of care. In a complex system involving generalist and various specialist health care professionals, clinicians may also struggle to diagnose and manage the various conditions PLHIV with complex healthcare needs experience.

[38] Eppic-Jordan, Puitt, Bengoa, & Wagner, 2004; Wagner et al., 2001
[39] Threats, 2007
[40] Ueda & Okawa, 2003
[41] Schneidert, Hust, Miller & Ustun, 2003
[42] Stiefel, et al., 2006
[43] Kodner & Spreeuwenberg, 2002

### 3.4 Social considerations of PLHIV

- **Accommodation** – 12.8% of Australian PLHIV report public rental accommodation (government owned), 4.8% live in rent-free accommodation, provided by friends/family, 3.8% live in community housing and 3.1% report 'other' accommodation. [44]
- **Employment** – 38.5% of PLHIV are working full-time, 14.7% are working part-time, 19.7% are retired/not working, 10.6% are unemployed, 4.6% are studying, and 11.8% reported 'other'.[45] 40.7% reported moderate stress at work, 20.4% reported high stress and 9% reported very high stress.[46]

  While 53.9% reported that HIV had no impact on work capacity, 46.1% reported an impact from HIV than ranged from increased tiredness to having to negotiate different duties.[47]
- **Income and Poverty** – 47.1% reported receiving a salary, 38.1% Benefits/social security/pension, 5.7% superannuation or savings, 3.5% partner/family/friends support me, 5.7% 'other'.[48]

  More than two fifths of those people not in employment (44.4%) are living below the poverty line.[49]
- **Discrimination** – despite discrimination on the basis of HIV status being unlawful, PLHIV continue to experience less favourable treatment in many domains of their lives (such as accommodation, health services and the workplace.[50]

## 4. HIV Case Management and Referral Project

- In May 2011, Susan Johnston Consultancy Services delivered a report on the HIV Case Management and Referral Project for the AIDS and Infectious Diseases Branch, NSW Department of Health and for Adahps. The purpose of the project was to identify a case management and referral model to strengthen outcomes for PLHIV and the systems and infrastructure required to support the model into practice. After an extensive consultation with 47 agencies associated with the care of PLHIV, the consultants proposed the HIV Complex Needs Case Management Model and an implementation over a period of 12 months followed be evaluation/.
- The proposed HIV Complex Needs Case Management Model was a state-wide model of care that provided expertise and support from high HIV prevalence areas to lower HIV prevalence areas in NSW. The model reflected the changing nature of HIV and the impacts of ageing on PLHIV in NSW. It also reflected the need to support regional sexual health centre staff as they supported PLHIV with complex care needs in their local area. Adahps, SESLHD HIV Community Outreach Team and Positive Central were to extend their roles and to work beyond their geographic area. Adahps was also to extend its role by providing services to PLHIV with a broader range of complex needs. The proposed model proposed that the SESLHD HIV Community Outreach Team would cover the Southern and Murrumbidgee LHDs, Positive Central would cover Western and Far Western NSW LHDs and Adahps would cover the Northern, North Eastern and Hunter New England LHDs.
- A project evaluation was conducted by Brenda Currie Consulting and Hecate Consulting in 2013. The program was subsequently discontinued. The evaluation found that client numbers were less than had been expected. Reasons for the low client numbers were:
  i. A lack of clarity about what the program offered
  ii. A reluctance to promote the program in case it was unable to meet need or it were not to continue past the initial 12 months

[44] Grierson, J. et al. HIV Futures Seven, The Health and Wellbeing of HIV Positive People in Australia, ARCSHS, 2013, pxxiii
[45] Ibid, pxxiii
[46] Ibid pxxiv
[47] Ibid pxxiv
[48] Ibid pxxv
[49] Ibid pxxvi
[50] Ibid pxxix

iii. An absence of local case managers available to optimise take up and follow through for clients; and

iv. Its roles and expectation were not sufficiently clarified at the outset of the program pilot.

## 5. Conclusion

The literature review found that:

- The estimated population of people living with diagnosed HIV (9,683) in NSW at 30 June 2017 is slowly increasing by approximately 300 people per year, minus deaths and interstate movement
- PLHIV in NSW are ageing and increasingly at risk of a range of serious and protracted chronic health conditions, both physical and psychological. By 2020, nearly half the Australian population of PLHIV will be 55 and over and the proportion of those aged 55-64, 65-74 and 75 years and older are all increasing. The risk of acquiring cardiovascular, neurological, metabolic, oncological, osteopathic exponentially increase with age. Rates of mental health conditions are much higher in PLHIV
- 28% of the PLHIV population live in Inner Sydney, Inner Western Sydney (east of Concord) and Canterbury. Only 16% live in the Eastern Suburbs and St George-Sutherland areas. There are however, 17.5% of PLHIV living in Western Sydney, South Western Sydney and the Blue Mountains areas, and a further 17% living in Northern Sydney, the Northern Beaches and the Gosford-Wyong areas (34.5% in total). Therefore, there is a sizable PLHIV population now living in the Outer Sydney Metro areas
- Many studies of PLHIV have found increased rates of multimorbidity in PLHIV. For example, The 2015 Australian APPLES Study found that 85% of HIV positive GBM 55 years and over reported one or more comorbidities and just over half (56%) reported two or more comorbidities. HIV-positive GBM reported higher rates of mental health conditions (compared to the general population) and higher rates of thrombosis, diabetes, heart disease, neurological disease, cancers and bone disorders than their HIV-negative counterparts. The increase prevalence of elevated lipids, hyperglycaemia, altered body composition, alcohol, stimulant use and smoking in PLHIV, significantly contribute to increased risk of many serious and debilitating chronic health conditions
- Complexity was found to have a profound effect on healthcare outcomes for PLHIV. The combination of multiple co-occurring and multifaceted medical conditions compounded by age, gender, sexual orientation, being newly arrived from another non-western country, and having language and adjustment issues, as well as dealing with cultural and socioeconomic realities, all contribute to health service access, delivery, care coordination and service equity.
- The inherent complexity of the healthcare system is magnified for those with complex health care needs who must navigate a range of HIV specialist and generalist public and private service providers. As well as creating confusion, health system complexity can contribute to inadequate or uncoordinated health care; miscommunication and potential disengage of PLHIV from health care. This is particularly relevant for older PLHIV with high rates of chronic physical and mental health conditions, for PLHIV whose lives are in chaos due to stimulant abuse and for people with severe mental health and neurological disorders.
- The shortage of public housing properties in the Sydney metro and regional NSW continues to be an issue for PLHIV on low incomes. Waiting times for public housing can be two to four years and often results in PLHIV being inappropriately housed or becoming homeless in the interim. Being homeless or couch surfing results in inconsistent medical monitoring and medication non-compliance, a worsening of physical and mental health conditions and frequent self-medication/abuse of alcohol and stimulants as a coping mechanism
- While a significant proportion of PLHIV are employed, a substantial proportion (~45%) rely on government income support (Aged Pension, DSP, Newstart, study allowance). These individuals are mainly older, with multimorbidity and long-term HIV infection and have been living in poverty for decades. They are unlikely to return to the workforce.

- The idea of expanding case coordination and case management of PLHIV with complex care needs is not new. For example, the HIV Complex Needs Case Management Model (proposed in 2011) was NSW model of care that provided expertise and support from high prevalence areas to low prevalence areas of NSW. Adahps, SESILHD HIV Outreach Team and Positive Central were asked to extend their roles and to work beyond their geographic areas.
- An evaluation of the pilot project found that client numbers were less than had been expected and this was in part due to lack of clarity about the program, reluctance to promote the program in outer metro and rural and regional NSW, lack of local case managers to follow through with clients, and lack of clarity about the roles and expectations of the pilot project.

Appendix D

## HIV and Complex Care Needs – Consultation Questions

| | |
|---|---|
| **Needs of PLHIV & CCN** | • What is the profile of your clients with HIV&CCN – age, gender, ethnicity/language, sexual orientation?<br>• How many of these clients do you have at any one time, and what is the range in rates of occasions of service?<br>• Where do the consumers come from (location) and reside?<br>• What is the range of their current health care needs? In particular, what are the three or four most significant needs?<br>• How will their needs likely change (over the next 5 to 10 years)?<br>• Are their individual service consumers who can assist us with the investigation? |
| **Service mapping exercise** | • What services do you provide directly for consumers? Clinical, social and systemic/liaison<br>• What are your service delivery modes, intake processes and client follow up procedures?<br>• Does your organisation take a case management role for these consumers? If not, who if anyone does?<br>• What referral pathways do you use?<br>• Who do you partner/cooperate with to deliver services?<br>• What is the level of client service retention and turnover?<br>• What is your capacity to meet current and future need and to what extent could you now expand services to consumers? |
| **Gaps and limitations in the current service system** | Specifically:<br>• How well is your service meeting its funded/mandated role?<br>• Are there service and system gaps and limitations – for current consumers and for consumers you could be servicing?<br>• Are there service duplications or related issues of concern?<br>• How good is access for outer metro rural and regional clients?<br>• How effective for consumers is cooperation with and communication /feedback between primary health care, hospital and NGO HIV specialist services?<br>• Does integration and coordination of care for consumers vary between generalist and HIV and other specialist health services? How?<br>• How are/will the NDIS and aged care affect your consumers?<br>• What are the key limitations to service expansion/evolution – funding, staffing, training, integration, others? |
| **Potential solutions** | We'd like your views on service solutions, in particular to address the following:<br>• Improve health outcomes<br>• Improve service access, navigation and integration<br>• Improve care coordination and communication<br>• Improve engagement and retention in care<br>• Improve service partnerships and synergies; and<br>• Improve efficiency and effectiveness<br>Finally, if you were given the opportunity to make two or three key strategic changes overnight to address the current and future needs of PLHIV & CCN, what would they be? Why those? |

Appendix E

## PLHIV numbers by ABS statistical region in NSW

Table 1 and Table 2 provide estimates of the number and percentage of diagnosed PLHIV in NSW by Australian Bureau of Statistics (ABS) statistical region as at 30 June 2017.

The tables are based on modelled estimates conducted by David Wilson and published by the Kirby Institute and NAPWHA in 2011. The forecasts estimated the number of diagnosed PLHIV by ABS statistical region for the years 2010 and 2020.[51] The figures for 2015 represent the midpoint between the published estimated population numbers for 2010 and 2020.

Since that modelling was published, the total number of people living with diagnosed HIV has been revised down by the Kirby Institute – in June 2015 to 9,890[52] and again in October 2016 to 9,222.[53] From October 2016 to 30 June 2017 a further 461 NSW residents were diagnosed with HIV[54]. Thus at 30 June 2017, there were approximately 9,682 NSW residents with diagnosed HIV.

**NB** The 2015 figures have therefore been reduced by about 10.5% to produce the 2017 estimates.

**Table 1**

| Region | 2015 (est) | 2017 | % of NSW |
|---|---|---|---|
| **NSW** | **10,816** | **9,682** | **100%** |
| **Inner Sydney Metro Areas** | | | |
| Inner Sydney [Sydney LHD] | 2370 | 2,121 | 21.8% |
| Eastern Suburbs [South Eastern Sydney LHD] | 1068 | 956 | 9.8% |
| Inner Western Sydney [ Sydney LHD] | 448 | 401 | 4.1% |
| Canterbury | 233 | 209 | 2.6% |
| **Total Inner Sydney** | **4,119** | **3,687** | **38.4%** |
| **Outer Sydney Metro Areas** | | | |
| St-George-Sutherland | 671 | 601 | 6.1% |
| Bankstown | 232 | 208 | 2.6% |
| Fairfield Liverpool | 353 | 316 | 3.2% |
| Outer South Western Sydney | 191 | 171 | 1.8% |
| Central Western Sydney | 445 | 398 | 4.2% |
| North Western Sydney | 618 | 553 | 5.7% |
| Lower North Shore | 624 | 558 | 5.7% |
| Central Northern Sydney | 531 | 475 | 4.9% |
| Northern Beaches | 336 | 301 | 3.1% |
| Gosford-Wyong | 338 | 303 | 3.1% |
| **Total Outer Sydney** | **4,339** | **3,884** | **40.4%** |
| **Total Sydney Metro** | **8,458** | **7,571** | **78.8%** |

[51] D Wilson, 2011, Mapping HIV Outcomes: geographical and clinical forecasts of people living with HIV in Australia, pxxi
[52] NSW HIV Strategy 2016-2020, NSW Ministry of Health, 2016, pviim
[53] The NSW 2015 HIV Cascade, R Gray, Kirby Institute UNSW, October 2016
[54] NSW HIV Strategy 2016-2020, Quarter 4 & Annual 2016 Data Report, pvi &

**Table 2**

| Regional NSW | 2015 (est) | 2017 | % of NSW |
|---|---|---|---|
| **Northern NSW** | | | |
| Hunter | 612 | 548 | 5.6% |
| Mid-North Coast | 319 | 285 | 2.9% |
| Richmond-Tweed | 334 | 299 | 3.1% |
| Northern | 128 | 115 | 1.2% |
| **Northern NSW Total** | **1,393** | **1,247** | **12.8%** |
| **Western NSW** | | | |
| Central West | 147 | 132 | 1.4% |
| Far Western | 75 | 67 | 0.7% |
| **Western NSW Total** | **222** | **199** | **2.1%** |
| **Southern NSW** | | | |
| Illawarra | 383 | 343 | 3.5% |
| South Eastern | 178 | 159 | 1.6% |
| Murray-Murrumbidgee | 182 | 163 | 1.7% |
| **Southern NSW Total** | **743** | **665** | **6.8%** |
| **Total Regional NSW** | **2,358** | **2,111** | **21.2%** |

**Methodology**

- In June 2015, it was estimated by the Kirby Institute that there were approximately 11,500 people living with HIV (PLHIV) in NSW. Of these, 86% (9,890) had been diagnosed. 92% of those diagnosed with HIV were on treatment and 92% had a suppressed viral load.[55]
- In October 2016, The Kirby Institute recalculated and revised the number of people living with diagnosed HIV (PLDHIV) as part of a 2015 NSW HIV Care Cascade. The number of PLDHIV equalled the estimated number of PLDHIV, minus (-) the number of deaths, +/- overseas migration, +/- interstate migration. At that time (2015), it was estimated that the number of PLHIV equalled 9,947 (range 8,834 – 11,085), the number of PLDHIV in NSW equalled 9,222 (range 8,338-10,121), the number of PLDHIV in care equalled 8,761 (range 7,632 – 10,000), the number receiving ART 7,882 (range 7,497 – 8,647), and the number with supressed HIV viral load equalled 7,089 (range 6,659 – 7,874).[56]
- There were 317 NSW residents diagnosed with HIV between January and December 2016,[57] and 144 NSW residents diagnosed with HIV between January and June 2017.[58]
- Therefore, there are approximately 9,683 PLDHIV in NSW as at June 2017.

[55] NSW HIV Strategy 2016-2020, NSW Ministry of Health, 2016, pviim
[56] The NSW 2015 HIV Cascade, R Gray, Kirby Institute UNSW, October 2016
[57] NSW HIV Strategy 2016-2020, Quarter 4 & Annual 2016 Data Report, pvi
[58] NSW HIV Strategy 2016-2020, April – June 2017 Data Report, pvi

# Summary comparison of PLHIV with complex care needs receiving care by region

The table below compares the numbers and percentages of PLHIV with complex care needs receiving case support/care coordination and/or case management by area. The table shows: 1) the number and percentage of PLHIV by region, 2) the number and percentage of PLHIV with complex care needs receiving case support/coordination services by region, and 3) the number and percentage receiving case management by region. Percentages shown in red indicate significantly higher than average access to case support/care coordination and/or case management services.

| **Region** | **LHDs** | **Number (and % of total NSW PLHIV population) by area** | **Number (and % of population by area) receiving complex care support services** | **Number and (% of population by area) receiving case management** |
|---|---|---|---|---|
| Inner Sydney Metro | South Eastern Sydney LHD | 1557 (15.9%) | 285 (18.3%) | 127 (8.2%) |
| | Northern part of Illawarra-Shoalhaven LHD | 343 (3.5%) | 17 (5.0%) | 10 (2.9%) |
| | Sydney LHD | 2731 (28.5%) | 259 (9.4%) | 68 (2.5%) |
| Outer Sydney Metro | South Western Sydney LHD | 695 (7.6%) | 106 (15.2%) | 25 (3.6%) |
| | Western Sydney LHD | 951 (9.9%) | 146 (25.9%)* | 129 (14.5%) |
| | Nepean Blue Mountains LHD# | | 100 (25.9%)* | 9 (0.8%) |
| Northern Sydney & Central Coast | Northern Sydney LHD | 1334 (13.7%) | 70 (5.2%) | 21 (1.6%) |
| | Central Coast LHD | 303 (3.1%) | 6 (1.9%) | 1 (0.3%) |
| **Greater Sydney average receiving case support or case management** | | | Average 11.4% | Average 4.8% |
| Northern NSW | Hunter New England LHD | 548 (5.6%) | 125 (22.8%) | 46 (8.4%) |
| | Mid-North Coast LHD | 285 (2.9%) | Data not provided | Data not provided |
| | Northern NSW LHD | 414 (4.3%) | 174 (42%) | 13 (3.1%) |
| Western NSW | Western NSW LHD & Far Western NSW LHD | 199 (2.1%) | 48 (24.1%) | Nil |
| Southern NSW | Southern NSW LHD/southern end of Illawarra/Shoalhaven LHD | 159 (1.6%) | 30 (18.9%)# | |
| **Regional NSW average receiving case support or case management** | | | Average = 26.9% | Average = 17.0% |
| **NSW average receiving case support or case management** | | | **Average = 14.0%** | **Average = 4.8%** |

* The percentage of Case Support Services clients for WSLHD and NBMLHD are combined, as disaggregated population data are not available

# The level of services people receive in Southern NSW flexes based on (limited) available resources and is thus combined

# Numbers of PLHIV with complex care needs being serviced by NSW publically-funded HIV specialist services & NGOs by Region

The tables below describe the number and percentage of people living with diagnosed HIV by region (LHDs and ABS statistical regions)

The regions include:

- Inner Sydney Metro (includes: SESLHD, SLHD and the Illawarra part of Illawarra-Shoalhaven LHD)
- Outer Sydney Metro (includes: SWSLHD, WSLHD, NBMLHD)
- North Sydney and the Central Coast ( includes: NSLHD, CCLHD)
- Northern NSW (includes: HNELHD, MNCLHD, NNSWLHD)
- Western NSW (includes: WNSWLHD and FWNSWLHD
- Southern NSW (includes: SNSWLHD, MLHD and the southern part of the Illawarra/Shoalhaven LHD)

HIV specialist and NGO services providing case support and case management to PLHIV with complex care needs are included for each area. Information includes:

- the total PLHIV caseload for the service (where available)
- the number and percentage of PLHIV receiving service who are considered to be complex by the service (as a percentage of the PLHIV population by area), and
- the number and percentage of PLHIV who are case managed by the service (as a percentage PLHIV population by area.

**Adahps** - It should be noted that Adahps clients have not been included in the tables. This is to prevent double counting. Adahps co-case manages clients with other services such as SESLHD HIV Outreach Team, Positive Central, BGF, and Sydney metro and regional sexual health centres. Adahps a state-wide service supporting approximately 77 PLHIV with HIV cognitive impairment, HIV and non-HIV related comorbidities and psychosocial issues (representing 0.8% of the NSW PLHIV population). These PLHIV are some of the most complex clients in NSW. While most Adahps clients live in the SLHD or SESLHD, some live in regional NSW, including clusters in the Northern Rivers and Hunter regions. 11 Adahps clients reside in specialist residential facility at Yaralla (Concord) and 2 clients are living in nursing homes.

**NB** ACON advised on 29 January 2018 that there are additional PLHIV with complex care needs currently receiving services from its Care Coordination Program in Sydney and regional NSW. Client numbers are therefore provisional.

**Inner Sydney Metro**

| | LHDs, including ABS Statistical Regions | # of PLHIV | % of NSW Total | SESLHD HIV Outreach Team | | Positive Central & HIV Community Team | | BGF Casework and Case Management (not incl Health and Wellbeing) | | ACON - Care Coordination Program – PLHIV with complex needs | | Positive Life NSW - Housing Support Program | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Total Service PLHIV Caseload** | | | | 150 | | 160 | | 923[#] | | 70 | | 27 | |
| | | | | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed |
| **Inner Sydney Metro** Includes: SESLHD, Sydney LHD (and Illawarra part of Illawarra-Shoalhaven LHD) | **South Eastern LHD** (including Eastern Suburbs and St George- Sutherland) | 1557 | 15.9 | 120 (7.7%) | 120 (7.7%) | | | 129 (8.3%) | 7 (0.5%) | 25 (1.6%) estimate | | 11 (0.7%) | |
| | **Illawarra region** of Illawarra-Shoalhaven LHD | 343 | 3.5 | 10 (2.9%) | 10 (2.9%) | | | 5 (1.6%) | Nil | | | 2 (0.6%) | |
| | **Sydney LHD**, (Including Inner Sydney, Inner Western Sydney and Canterbury) | 2,731 | 28.5 | | | 140 (5.1%) | 65 (2.4%) | 103 (3.8%) | 3 (0.1%) | 9 (0.3%) estimate | | 7 (0.2%) | |
| **Total** | | **4,631** | **47.9** | **130** | **130** | **140** | **65** | **237** | **10** | **34** | **Nil** | **20** | **Nil** |

*Albion Centre refers to SESILHD HIV Outreach Team, Positive Central, and Adahps for case management

# Total BGF nos of 923 includes about 550 low acuity Health and Wellbeing clients not counted in this table analysis

**Notes**

- There are approximately 561 PLHIV with complex care needs receiving case support services from SESLHD HIV Outreach Team, Positive Central, BGF, ACON Care Coordination Team and Positive Life NSW Housing Support Program. This represents 12% of the Inner Sydney PLHIV population
- There are 205 PLHIV with complex care needs being cased managed in the inner Sydney metro. This represents 4.4% of the inner Sydney metro PLHIV population

- In addition there are 25 (mainly itinerant PLHIV being supported by St Vincent's Hospital IBAC. This represents 1.6% of the South Eastern Sydney PLHIV population
- A further breakdown by area of the 34 PLHIV with complex care needs being supported by the ACON Care Coordination Program in the Inner Sydney Metro was not available and the numbers in the table for SELHD and SLHD are estimates.
- SESLHD HOT have advised that 10-15 of the 120 clients (~10%) are not case managed and receive care only from a dietician

**Outer Sydney Metro**

| Radial Categories | LHDs, including ABS Statistical Regions | # of PLHIV diagnosed | % of NSW Total | Parramatta Sexual Health & Mt Druitt Clinics | | Liverpool Hospital HIV Clinic & HIV Outreach Team | | Nepean & Katoomba Clinic | | BGF Case Work & Case Management | | ACON - Care Coordination Program – PLHIV with complex needs | | Positive Life NSW - Housing Support Program | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Total Service PLHIV Caseload** | | | | 200/400 (active) clinical<br>375 (social workers) | | 250 | | 135 (Nepean 85 & Katoomba 50) | | 923 (Includes about 550 Health and Wellbeing clients) | | 70 | | | |
| | | | | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed |
| **Outer Sydney Metro** Includes: SWSLHD, WSLHD, NBMLHD | **South Western Sydney LHD**, including Bankstown, Fairfield- Liverpool and Outer South Western Sydney | 695 | 7.6 | | | 75 (10.8%) | 25 (3.6%) | | | 20 (2.9%) | Nil | 8 (1.1%) | | 3 (0.4%) | |
| | **Western Sydney LHD** and **Nepean Blue Mountains LHD**, including Central Western Sydney and North Western Sydney | 951 | 9.9 | 125 (13%) | 125 (13%) | | | 90 (9.46%) | 9 (0.9%) | 29 (3.0%) | 4 (0.4%) | | | 2 (0.2%) | |
| **Total** | | **1,646** | **17.5** | **125** | **125** | **75** | **25** | **90** | **9** | **49** | **4** | **8** | **Nil** | **5** | **Nil** |

**Notes**

- There are approximately 585 PLHIV (represents approximately 35% of PLHIV in the Outer Sydney metro area) receiving clinical care from Parramatta, Mt Druitt, Liverpool Hospital Immunology Clinic, and Nepean, Katoomba Sexual Health Clinics. PLHIV with complex care needs who attend Liverpool Sexual Health Clinic are referred to Liverpool Hospital HIV Immunology Clinic.
- There are approximately 345 PLHIV with complex care needs (21% of PLHIV population in Outer Sydney Metro) receiving support services from Parramatta Sexual Health Social Workers, Liverpool Hospital HIV Outreach Team (social workers), Nepean and Katoomba Sexual Health Clinics nursing staff, BGF case support workers, ACON Care Coordination Program and Positive Life Housing Support Program
- There are approximately 163 PLHIV with complex care needs (9.9% of the PLHIV population of Outer Sydney metro) receiving case management from Parramatta Sexual Health Social Workers, Liverpool Hospital HIV Outreach Team social workers, Nepean and Katoomba Sexual Health Clinic staffs, BGF case managers and Positive Life Housing Support Program

**Northern Sydney and Central Coast**

| **Radial Categories** | **LHDs, including ABS Statistical Regions** | **# of PLHIV** (diagnosed) | **% of NSW Total** | **Clinic 16** | | **BGF Case Work & Case Management** | | **Positive Life NSW - Housing Support Program** | |
|---|---|---|---|---|---|---|---|---|---|
| **PLHIV Caseload** | | | | 225 | | 923 | | 27 | |
| | | | | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed |
| **Northern Sydney & Central Coast** Includes: NSLHD,CCLHD | **Northern Sydney LHD** including Lower North Shore, Central Northern Sydney and Northern Beaches | 1,334 | 13.7 | 60 (4.5%) | 20 (1.5%) | 10 (0.7%) | 1 (0.1%) | | |
| | **Central Coast LHD**, including Gosford-Wyong | 303 | 3.1 | | | 5 (1.6%) | 1 (0.3%) | 1 (0.3%) | |
| **Total** | | **1,637** | **16.8** | **60** | **20** | **15** | **2** | **1** | **Nil** |

**Notes**

- There are approximately 76 PLHIV with complex care needs (4.6% of the Northern Sydney and Central Coast PLHIV population) receiving social support services from Clinic 16 social work team, BGF Case Support workers and Positive Life NSW Housing Support Program

- There are approximately 22 PLHIV (represents 1.3% of PLHIV in the Northern Sydney and Central Coast area) with complex care needs who are case managed by Clinic 16 social workers and BGF case managers.

# Regional NSW

**Northern NSW**

| **Radial Categories** | **LHDs, including ABS Statistical Regions** | **# PLHIV (Diagnosed)** | **% of NSW Total** | **Lismore Sexual Health** | | **John Hunter Hospital + Pacific Tamworth & Taree Clinics** | | **BGF Case Work & Case Management** | | **ACON - Care Coordination Program – PLHIV with complex needs** | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Total PLHIV Service Caseload** | | | | 336 | | 200, 112, 50, 10, Total=372 | | 923 | | 70 | |
| **Northern NSW** Includes: HNELHD, MNCLHD, NNSWLHD | | | | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed |
| | **Hunter NE LHD** | 548 | 5.6 | | | 95 (17%) | 46 (8.4%) | 16 (2.9%) | Nil | 14 (2.5%) | |
| | **Mid-North Coast LHD** | 285 | 2.9 | | | | | 6 (2.1%) | Nil | | |
| | **Northern NSW LHD**, Including Northern NSW and Richmond-Tweed | 414 | 4.3 | 120 (29%) | Nil | | | 40 (9.7%) | 13 (3.1%) | 14 (3.4%) | |
| **Total** | | **1,247** | **12.8** | **120** | **Nil** | **95** | 46 | **62** | **13** | **28** | **Nil** |

**Notes**

- It should be noted that data was not provided by the Mid-North Coast LHD
- There are 336 PLHIV (81% of PLHIV in the Northern NSW LHD) receiving clinical care from Lismore Sexual Health
- There are 372 PLHIV ( representing 68%) of PLHIV in the Hunter New England LHD receiving clinical care from John Hunter Hospital, and the Pacific, Tamworth and Taree Sexual Health Clinics

- There are 305 PLHIV (representing 24.5% of PLHIV in Northern NSW) with complex care needs who are receiving support services from Lismore Sexual Health social worker, the John Hunter Hospital Social Worker, BGF case workers and the ACON Care Coordination Program
- There are 59 PLHIV (represents 4.7%) with complex car needs in Hunter New England and the Northern Rivers being case managed by BGF case managers and the John Hunter Social Worker as well as staff at ACON Hunter
- A further breakdown of the proportion of clients from Hunter and Northern Rivers receiving support from the ACON Care Coordination Program was unavailable. Therefore, a 50/50 split between Hunter and Northern Rivers is estimated

**Western NSW**

| **Radial Categories** | **LHDs, including ABS Statistical Regions** | **# PLHIV (Diagnosed)** | **% of NSW Total** | **Dubbo (& Bourke), Orange, Lightning Ridge Clinics** | | **BGF Case Work & Case Management** | | **Positive Life NSW - Housing Support Program** | |
|---|---|---|---|---|---|---|---|---|---|
| **PLHIV Caseload** | | | | 41, 14, 3, Total=58 | | 923 | | 27 | |
| | | | | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed |
| **Western NSW** | **WNSWLHD and FWLHD,** including Central West and Far West | 199 | 2.1 | 44 (22%) | 0.0 | 3 (1.5%) | Nil | 1 | Nil |
| **Total** | | **199** | **2.1** | **44** | **Nil** | **3** | **Nil** | **1** | **Nil** |

NB - There are no private s100 prescribers west of Orange

**Southern NSW**

| **Radial Categories** | **LHDs, including ABS Statistical Regions** | **Number of diagnosed PLHIV** | **% of NSW Total** | **Bega, Batemans Bay, Queanbeyan and Goulbourn Clinics** | | **Albury, Wagga Wagga, Griffith Clinics** | | **BGF Case Work & Case Management** | |
|---|---|---|---|---|---|---|---|---|---|
| **PLHIV Caseload** | | | | | | | | 923 | |
| | | | | Complex | Case Managed | Complex | Case Managed | Complex | Case Managed |
| **Southern NSW** | **SNSWLHD and Shoalhaven** part of Illawarra-Shoalhaven LHD | 159 | 1.6 | 30 (18.9%) | 0-30* 0-18%) | | | 2 (1.2%) | Nil |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | **MLHD**, including Murray-Murrumbidgee | 163 | 1.7 | | | 5 (3%) | 5 (3%) | 2 (1.2%) | Nil |
| **Total** | | **322** | **3.3** | **30** | **0-30*** | **5** | **5** | **4** | |

- ***** There are between 5-35 PLHIV (1.5-11% of PLHIV) being case managed in SNSWLHD and MLHD, dependent on staff capacity

Notes

- There are approximately 39 PLHIV with complex care needs (12% of PLHIV in Southern NSW) receiving services from Sexual Health Clinics at (Bega, Batemans Bay, Queanbeyan, Goulbourn, Albury, Wagga Wagga, Griffith and BGF

# Comparative case support activity – BGF (Health & Wellbeing, Comprehensive, Complex) and ACON (Care Co-ordination) – PLHIV client population distribution

The table below describes and compares the numbers of NSW people with diagnosed HIV as at 30 June (by clustered LHDs and ABS statistical regions), with the proportions of PLHIV accessing BGF services: 1) Health and Wellbeing, 2) Comprehensive, and 3) Complex casework programs. LHDs (which include 2017 population projections for ABS statistical regions) are grouped into: a) Sydney Metro [Inner Sydney Metro, Outer Sydney Metro, Northern Sydney and Central Coast], and b) regional NSW [Northern NSW, Western NSW and Southern NSW] to align with Sydney metropolitan and regional NSW LHDs.

| Radial Categories | LHDs, including ABS Statistical Regions | Number of diagnosed PLHIV | % by area | BGF Health & Wellbeing Clients – % by LHD | BGF Comprehensive Clients – % by LHD | BGF Complex Clients - % by LHD | ACON Care Coordination - % by LHD |
|---|---|---|---|---|---|---|---|
| **Inner Sydney Metro** Includes: SESLHD, Sydney LHD (and Illawarra part of Illawarra-Shoalhaven LHD) | South Eastern LHD, including Eastern Suburbs and St George-Sutherland | 1,557 | 15.9 | **31.5** | **33.8** | **35.5** | **35.7** |
| | Sydney LHD, Including Inner Sydney, Inner Western Sydney and Canterbury[i] | 2,731 | 28.5 | 29.9 | 26.1 | 29.0 | **12.9** |
| | Illawarra region[ii] of Illawarra-Shoalhaven LHD | 343 | 3.5 | 1.8 | 1.9 | 0.9 | **Nil** |
| **Total – Inner Sydney** | | **4,631** | **47.9** | **63.2** | **61.8** | **65.4** | **48.6** |
| **Outer Sydney Metro** Includes: SWSLHD, WSLHD, NBMLHD | South Western Sydney LHD, including Bankstown, Fairfield-Liverpool and Outer South Western Sydney | 695 | 7.6 | **2.9** | 4.5 | **2.8** | 11.4 |
| | Sydney Western LHD and Nepean Blue Mountains LHD, including Central Western Sydney and North Western Sydney | 951 | 9.9 | 9.1 | 10.2 | 6.1 | **Nil** |
| **Total – Outer Western Sydney** | | **1,646** | **17.5** | **12.0** | 14.7 | **8.9** | 11.4 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Northern Sydney & Central Coast** Includes: NSLHD,CCLHD | Northern Sydney LHD including Lower North Shore, Central Northern Sydney and Northern Beaches | 1,334 | 13.7 | **3.8** | **1.9** | **3.3** | **Nil** |
| | Central Coast LHD, including Gosford-Wyong | 303 | 3.1 | **1.8** | **1.3** | **1.4** | **Nil** |
| **Total – Northern Sydney and Central Coast** | | **1,637** | **16.8** | **5.6** | **3.2** | **4.7** | **Nil** |
| **Total Sydney Metro & Central Coast** | | **7,914** | **82.2** | **80.8** | **79.7** | **79.0** | **60** |
| **Northern NSW** Includes: HNELHD, MNCLHD, NNSWLHD | Hunter NE LHD | 548 | 5.6 | 4.0 | 3.8 | 4.7 | **20** |
| | Mid-North Coast LHD | 285 | 2.9 | 1.6 | 1.9 | 1.4 | Nil |
| | Northern NSW LHD, Including Northern NSW and Richmond-Tweed | 414 | 4.3 | 7.7 | **11.5** | **10.3** | **20** |
| **Total Northern NSW** | | **1,247** | **12.8** | **13.3** | 17.2 | 16.4 | **40** |
| Western NSW | WNSWLHD and FWNSWLHD, incl Central West and Far West | 199 | 2.1 | 2.0 | 0.6 | 0.9 | Nil |
| **Total Western NSW** | | **199** | **2.1** | **2.0** | 0.6 | 0.9 | Nil |
| Southern NSW | SNSWLHD and Shoalhaven part of Illawarra-Shoalhaven LHD, includes South East NSW | 159 | 1.6 | 1.1 | 1.2 | 0.0 | Nil |
| | MLHD, including Murray-Murrumbidgee | 163 | 1.7 | 2.7 | 0.0 | 0.9 | Nil |
| **Total Southern NSW** | | **322** | **3.3** | **3.8** | **1.2** | **0.9** | **Nil** |
| **Total Regional NSW** | | **1,768** | **18.2** | **19.1** | **19.0** | **18.2** | **40** |
| BGF clients-no fixed address | | | | 0.1 | 1.3 | 2.8 | NA |
| **Total NSW** | | **9,682** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

**NB** Highlighted data: Blue = relative over-servicing Red = relative under-servicing Black = neutral servicing **Bold =** more extreme cases

[i] Population of Canterbury-Bankstown divided - 50% Canterbury, 50% Bankstown. The Illawarra region has been included in the Inner Sydney metro. This is because the SESLHD HIV Outreach Team services PLHIV in the Illawarra region

# Adahps

Adahps was established to provide addition support to local services in the management of complex clients with HIV associated neurocognitive impairment. In 2016 we adjusted our model due to a lack of available services in regional and rural NSW. The new service model is based upon a collaborative approach involving cooperation and collaboration with other services to maximise our capacity to deliver state-wide services. Ideally Adahps strives to use a collaborative case management model in areas where other services are available mainly metropolitan Sydney (SESLHD and SLHD) and a primary case management model in areas where there are no other services available. (Table 1)

Adahps is the sole case manager for 9 clients in  SESLHD and 9 clients in SLHD this is due to a number of factors including differing assessment of client need, short staffing of HIV teams and a lack of understanding of the statewide Adahps role. Additionally Adahps takes a lead role in the case management of 16 shared clients.

Table 1

| LHD | Number of clients case managed by Adahps with no other case manager | Number of clients collaboratively case managed by Adahps with another service | Number of collaboratively case managed client where Adahps is the lead service provider |
|---|---|---|---|
| SESLHD | 9 | 16 | 6 |
| SLHD | 9 | 16 | 5 |
| WSLHD | 2 | 2 | 2 |
| NBMLHD | 1 | 1 | 1 |
| HNELHD | 1 | | |
| NSLHD | 1 | 3 | 1 |
| MNCLHD | | 1 | 1 |

| | | | |
|---|---|---|---|
| SWSLHD | | 1 | |
| NNSWLHD | 1 | 2 | |
| WNSWLHD | 4 | | |
| MLHD | 1 | | |
| **TOTAL** | **29** | **42** | **16** |

**Adahps Case Managed Clients**
**NB. Yaralla clients no included**

| **Name of Client** | **Case Manager** | **HIV Clinic** | **Other services Involved** | **Engagement Level** | **Level of Need** |
|---|---|---|---|---|---|
| AA | Adahps<br>Positive Central | Waratah Clinic | Positive Life: John Carr<br>BGF | Very Low | High |
| BN | Adahps | Parramatta Sexual Health | Positive Life: John Carr<br>Ankali<br>NDIS<br>BGF | Very Low | High |
| CF | Adahps | Dubbo Sexual Health | Positive Life: John Carr<br>BGF | High | Medium |
| CW | Adahps | Clinic 16 | Positive Life: John Carr<br>Acon Home Base Service<br>Ankali<br>BGF (Financial and community Support) | Medium | High |
| ES | Adahps | | Ankali<br>Acon Home Base Service | Low | Low |

| | | | | | |
|---|---|---|---|---|---|
| FC | Adahps | | Acon Home Base Service<br>NDIS | High | Low |
| GS | Adahps | Newcastle Sexual Health | Positive Life: John Carr<br>Acon Home Base Service<br>BGF (Financial)<br>NDIS | Medium | High |
| LU | Adahps<br>Positive Central<br>Sydney District Nursing | RPA HIV Clinic | Acon Home Base Service<br>BGF (Financial)<br>NDIS | Medium | High |
| JN | Adahps<br>Positive Central | Albion Centre | NDIS<br>BFG (Financial) | Low | Low |
| MM | Adahps | Blue Mountains Sexual Health | NDIS | Medium | Low |
| MW | Adahps<br>Positive Central | RPA HIV Clinic | BGF (Financial) | Low | High |
| MF | Adahps | Dubbo Sexual Health | | Low | Low |
| MO | Adahps<br>Positive Central | | Acon Home Base Service<br>NDIS | | |
| PB | Adahps:<br>Sydney District Nursing | Albion Centre | Acon Home Base Service<br>BGF (Financial)<br>NDIS | Medium | High |
| PS | Adahps<br>Sydney District Nursing | RPA HIV Clinic | Acon Home Base Service<br>NDIS | High | High |
| RH | Adahps | RPA HIV Clinic | Acon Home Base Service<br>NDIS | High | Low |
| RM | Adahps<br>Positive Central | IBAC | Acon Home Base Service | Medium | Low |

| | | | | | |
|---|---|---|---|---|---|
| SC | Adahps | IBAC | BGF(Financial)<br>NDIS | Low | Low |
| VL | Adahps<br>HOT | IBAC | NDIS | Low | Low |
| PX | Adahps | Prof Brew SVH | IBAC<br>NDIS | High | High |
| BF | Adahps<br>Maroubra mental health | IBAC Prof Brew | IBAC<br>BGF | Medium | Mediu m |
| JP | Adahps<br>HOT | IBAC Prof Carr | IBAC<br>BGF brokerage | Medium | Low |
| MK | Adahps<br>Positive Central | Prince of Wales Clinic<br>Dr Clezy | Annie Green Court | High | High |
| RO | Adahps: Dee Holland<br>Marrickville community mental health: | RPA clinic<br>Prof Brew | BGF brokerage | Medium | Mediu m |
| AT | Adahps: | Prof Brew | BGF floating care | Low | Low |
| JS | Adahps:<br>Port Macquarie Sexual Health:<br>Lynelle Woods | Dr Emanuel Vlahakas<br>Port Macquarie /<br>Kempsey Sexual health clinic | | Low | Low |
| DL | Adahps:<br>HOT | Prof Brew SVH | Haymarket Centre, HIV/AOD Integrated Care Project | Medium | High |
| ND | Adahps:<br>Mercy Centre Albury | Albury | Mercy Centre Albury | Low | High |
| JA | Adahps:<br>Pos Central: Karen Pearson | Prof Brew<br>Albion Street Centre | BGF<br>Quality Health Care - brokerage | High | Low |

| | | | | | |
|---|---|---|---|---|---|
| GT | Adahps: | Prof Brew | BGF | High | Medium |
| LK | Adahps:<br>Allison Suttor CNC (Westmead) | Westmead Clinic | | Low | High |
| PN | Adahps:<br>Rebecca Moran: Positive Central | RPA clinic | BGF - brokerage | Low | High |
| CH | Adahps:<br>Andrew Everingham: Parramatta Sexual Health | Parramatta Sexual Health | | Medium | Medium |
| SM | Adahps<br>Althea Barry: HOT | Dr Bloch / Prof. Brew | | High | Medium |
| SB | Adahps<br>Ann Morris | Prof. Brew | Wendy's homecare - brokerage | High | Low |
| ST | Adahps<br>Kate Mason at Clinic 16 | Clinic 16 | BGF | Low | High |
| PV | Adahps<br>Vicki Gibb: clinic 16 | Clinic 16 | JBC- Northern Suburbs | High | Medium |
| JK | Adahps<br>HOT: Matt O'Rourke | IBAC | | High | Medium |
| AE | Adahps: Heidi Giewald<br>HOT: Ian McLaughlin | IBAC | BGF - brokerage | High | Medium |
| MF | Adahps<br>HOT: Mike Smith | IBAC | | Low | High |

| | | | | | |
|---|---|---|---|---|---|
| DW | Adahps<br>HOT: Mike Smith | IBAC | | Medium | Low |
| EA | Adahps<br>Lara Goulding: Parramatta Sexual Health | Parramatta Sexual Health | Wendy's Home Care - brokerage<br>Lauren BGF | High | Mediu m/high |
| DR | Adahps<br>Trish (Australian Unity) | Lismore Sexual Health Clinic | | Low | Low |

| **Name of Client** | **Case Manager** | **HIV Clinic** | **Other services Involved** | **Engage ment Level** | **Level of Need** |
|---|---|---|---|---|---|
| DG | Adahps | Albion Street Centre | HOT | High | High |
| BO | Adahps | Albion Street Centre | BGF<br>Haymarket Centre | High | High |
| LM | Adahps | RPA clinic | NDIS services JBC | High | High |
| SS | Adahps | IBAC | | Low | High |
| CM | Adahps | Holdsworth House Medical Centre | HOT | High | High |
| CH | Adahps | Prof Brew | HOT + BGF | Low | High |
| AC | Adahps | Taylor Square Private Clinic | | Medium | Mediu m |
| SM | Adahps | Westmead hospital<br>Dr Gilroy | | High | High |
| DM | Adahps | East Sydney Doctors | HOT + BGF | Low | Mediu m |

| | | | | | |
|---|---|---|---|---|---|
| TM | Adahps | RPA clinic | Poz Central | Medium | Medium |
| JR | Adahps | RPA clinic | | High | Medium |
| AM | Adahps | Lismore Sexual Health | BGF | High | Medium |
| SV | Adahps | RPA clinic | Multicultural HIV Services + Poz Central | High | High |
| LS | Adahps | Lismore Sexual Health | BGF | Medium | Medium |
| JW | Adahps | Holdsworth House Medical Centre | Poz Central | High | Medium |
| DF | Adahps | Wagga Wagga Sexual Health | | Low | High |