BERINO · PROJECTS

CONSULTANCY ON HIV COMPLEX CARE IN NSW

FINAL REPORT

TO POSITIVE LIFE NSW AND THE NSW MINISTRY OF HEALTH

Version 6 – 30 January 2018

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1. PROJECT OVERVIEW

1.1 HIV Complex Care in NSW – Background

In 2016, the NSW Ministry of Health (MoH) engaged Positive Life NSW (PLNSW) to assess the needs of people living with HIV (PLHIV) as they access mainstream and specialist health care in NSW. A discussion paper was developed that described the current and diverse health care needs of PLHIV as they are referred into and access specialist and mainstream health care.

The discussion paper was informed by three major information streams, being:

1. The PLNSW 2015 PLHIV Access to Health Care in NSW Survey
2. Face to face consultation with PLHIV and service providers in Sydney and regional/rural NSW during the period 2012-2015; and
3. A review of relevant research and publications.

The paper aimed to promote a discourse between HIV response partners and work towards resolving access and coordination issues so that, regardless of identity, age, place of residence or health care complexity, the diverse needs of PLHIV could be effectively met. The discussion paper recommended that a roundtable be convened to discuss the issues and agree on next steps. The roundtable was however not convened due to resourcing and capacity factors.

Since the development of the discussion paper, the NSW HIV partnership has moved to address a range of issues affecting people *newly diagnosed* with HIV. This has involved strengthening the HIV Support Program and linking people newly diagnosed with HIV to s100 prescribers, and by removing access barriers to affordable HIV treatments. The needs of PLHIV with *complex care needs* however remain largely unaddressed.

In April 2017, the Bobby Goldsmith Foundation (BGF), in addressing key performance indicators (KPIs) in its funding agreement with the MoH, convened a service planning day in which senior management of partner agencies were invited to address two key issues; being:

1. Determining the case work roles and responsibilities and the referral pathways for case management of PLHIV in NSW who have complex care needs; and
2. Undertaking a gap analysis of PLHIV with complex care issues in NSW to identify access to services barriers and limitation and make recommendations for future service arrangements.

The meeting aimed to stimulate strategic leadership among partners whilst confirming role delineation between services. Agencies involved in the meeting were: ACON, the SESILHD HIV Outreach Team (HOT), SLHD's Positive Central, ADAHPS, BGF, the MoH, SWSLHD HIV Services, and PLNSW. The meeting did not however include most services based outside inner Sydney, or specialist sexual heath or medical services such as the Albion Centre and IBAC.

A key decision of the meeting was to convene an Advisory Group (the HIV Complex Care in NSW Advisory Group – HICCNAG) with the purpose of engaging a consultant to conduct a detailed review of the needs of, and services provided to, PLHIV who have complex care needs.

1.2 The Review

With the agreement of the MoH, PLNSW committed to fund a consultancy on behalf of HICCNAG, and play the role of lead agency in the project. Rick O'Brien of Berino Projects was engaged on 13 September 2017 as the Principal Consultant to the project, with Lance Feeney as Consultant providing further advice and support.

The project involved the following key steps:

- A desk-top review and literature review
- An environmental scan entailing –
  - a needs assessment; and a
  - a service mapping exercise
- Undertaking a gap analysis
- Identify potential options and solutions that merit further investigation; and
- Provide a report of findings and recommendation.

One of the key purposes of the review was to examine options to improve service delivery models within current funding by: highlighting the key elements of the most effective models; addressing service duplication concerns; and identifying gaps in PLHIV knowledge and awareness within other health services that could have a negative effect on the care received.

The review also assessed opportunities and mechanisms to increase partnerships and synergies between NGOs, primary care and public sector service providers, while considering means to manage potential tensions and PLHIV's concerns regarding loss of dignity, independence and autonomy, and fears regarding instability, negotiation and care integration.

As part of that process, 21 meetings and interviews were conducted with senior representatives of key stakeholders. These included NGOs servicing the needs of PLHIV and major publically-funded HIV and Sexual Health Services in Sydney and regional NSW. Only one stakeholder – MNCLHD – was unavailable for consultation. (See consultation list at Appendix A).

NB While the scope of the consultation and review include services provided by both NGO state-wide services and LHD HIV specialist services it is acknowledged that, as funding for LHD HIV specialist services has been devolved to LHDs, there is limited capacity currently to influence LHD programs and/or staffing profiles from within the HIV Program funding.

The consultancy project was originally intended to conclude in late November 2017 with a report back to HICCNAG. The process proved however to be somewhat more complex and drawn out than originally envisaged, and the draft report has been delayed by about a month due to delays in arranging consultation meetings and the complexity of information requests. This draft report is the outcome of that consultancy.

The process involved drafting a detailed definition of HIV complex care needs (Appendix B) and undertaking the literature review and desktop analysis (see Appendix C). The environmental scan built on the literature review – a needs assessment and service mapping

exercise involved setting a range of questions to be raised in each stakeholder interview (see Appendix D), and requesting a range of additional information from key interviewees.

The project background also involved clarifying the latest population distribution data for PLHIV in NSW.

This was met through the provision of 2011 ABS data updated in 2016 by the Kirby Institute to estimate figures by ABS region across NSW for June 2017 (see Appendix E).

A summaries and analyses of services provided to populations across NSW are set out in Appendix F (Summary comparison of PLHIV with complex care needs receiving care by Region), and a more detailed analysis of Numbers of PLHIV with complex care needs being serviced by NSW publically-funded HIV specialist services & NGOs by Region (Appendix G).

Finally, Appendix H sets out comparative case support activity (but not case management) of PLHIV clients by region for two NGOs: BGF's Casework and Community Support (Health & Wellbeing, Comprehensive, Complex level programs); and ACON's Care Co-ordination program. While noting that the services are not identical, it was considered useful for a comparative case study to assess the relative levels of access to relevant NGO services.

This Draft Report has been prepared to advise and seek comment and feedback from members of the HICCNAG prior to preparation of the Final Report.

1.3 Summary of Findings

a. The demographic and epidemiological pattern of PLHIV in NSW has changed dramatically in the last 20 years. People are now living much longer than expected in the 1990s and fewer people than previously predicted are becoming infected with HIV. People living longer with HIV are thus a growing proportion of the total.
b. By 2020, there will be nearly 45% of PLHIV aged 55 and older. PLHIV with issues of ageing are at increased risk of a range of serious chronic and life threatening health conditions. This is particularly so for those who were diagnosed in the 1980s and 1990s.
c. There has also been a measurable change in the backgrounds of people newly infected or presenting for the first time to HIV services. The starkest differences from the experience of last century are the growth in the number of people from non-English speaking backgrounds, of women, and of men who do not identify as gay or bisexual (GBM).
d. The younger cohort of PLHIV with complex care needs, whether GBM or otherwise, tend to come from a diverse array of backgrounds, live across greater Sydney and often lead chaotic lives, experiencing significant mental health problems and drug & alcohol issues.
e. These developments present new and changing patterns of demand from PLHIV for chronic health care services. Those have been reflected in the definition of HIV and Complex Healthcare Needs drafted as Appendix B to this report.
f. Overall, 14.0% of PLHIV with complex care needs in NSW receive case support/care coordination services of medium to high intensity, and 4.8% of PLHIV in NSW are currently case managed. This amounts to approximately 1,360 PLHIV in NSW who receive

case support/care coordination services and approximately 465 PLHIV being case managed. The percentages however vary considerably across NSW (see Appendix F), due in part to initiatives taken in the past in response to specific population demands.

g. The residential distribution of PLHIV in NSW has changed significantly in the 21st century. Only 15.9% of PLHIV live in SESLHD, and 28.5% live in Sydney LHD. Therefore, the area bounded by the coast from Bondi to Cronulla, Loftus, Georges River, Lakemba, Homebush, Parramatta River and Sydney Harbour accounts for less than 45% of the total population of PLHIV in NSW.
h. GBM remain the predominant group of PLHIV, both overall and of new infections. However the proportion of GBM is dropping to about 60-70% and as little as 50% for the increasing number of PLHIV who live outside inner Sydney and the North Coast of NSW. Increasing percentages of heterosexual and CALD PLHIV now reside in Western, South Western and Northern Sydney, the Hunter and in Southern and Western NSW.
i. HIV services are however largely distributed like its 1999 – there is a significant pattern of relative over- and under-servicing across NSW, with resources still overly focused on the legacy areas of inner Sydney and to an extent the NSW North Coast – these inequities are also largely compounded rather than counterbalanced by NGO service distribution.
j. The legacy of service arrangements built by the sector for PLHIV over the last 20 years have led some PLHIV, particularly GBM living in inner Sydney, to become accustomed to high levels of support and a continuity of services not available to PLHIV elsewhere in NSW.
k. Some PLHIV residing long-term in the inner Sydney area have over many years, had the opportunity to choose between public and NGO service providers, while others have limited services or go without. While the first casualty of scarcity is choice, these client expectations, accepted by some services, will be challenging to overcome.
l. Those LHDs with relatively fewer resources tend to focus on less-demanding care support, rather than on case management – under-servicing appears to be greater for the more resource-intensive case management needs, and the depth and intensity of case management varies considerably based on demand and resources available.
m. Some services experience considerable stress and difficulty in dealing with the needs of often chaotic, resource-intensive clients. Others did not identify similar pressures or unmet demand. These differences may reflect differing socio-economic factors across regions.
n. There are challenges to deal with in a world of fixed resources where most allocation decisions are made by geographically-based LHDs. Nevertheless, the changing demand pattern means that all available funding tools should be deployed to address unmet needs.
o. Flexibility of statewide resource allocation decisions thus needs to focus mainly on services for PLHIV funded directly by the MoH and provided by NGOs with statewide roles.
p. Tensions will be inevitable if services are altered or moved. Addressing inertia in services and staffing attitudes generally will need to figure in any change strategy.

q. Especially across greater Sydney, services overall have not always demonstrated consistent enthusiasm for cooperation and collaboration to maximise efficiencies and effectiveness for their clients' benefit (with the exceptions of the Hunter and NSW North Coast).

r. Different and divergent models of case support/care coordination and case management are practiced throughout NSW, and the service structure and reporting lines vary from service to service. This means that service quality varies from area to area and no consistent service models currently exist.

s. There is an estimated gap of up to 2,000 PLHIV who at some time in the future may be likely to need care coordination or case management to remain stable and prevent disease progression and admissions to tertiary health care.

1.4 Key Recommendations

The following are the key recommendations of the review:

i. The MoH should examine the resources it provides to NGOs that could be better directed to reflect overall contemporary demand by evaluating funding recipients, the nature of the funded services and staffing profiles, and the needs and residential locations of PLHIV

ii. In so doing, the MoH should review funding agreements with NGOs so they better reflect contemporary consumer and service needs, and include measurable and substantive KPIs

iii. Funding should be provided on the principle of maximising equitable service provision across NSW – NGOs should as a result make best endeavours to eliminate duplication by ensuring complex care clients are advised that they may not have a choice of service provider funded through the NSW HIV Program

iv. Service funding provided by the MoH to NGOs should be focused on greatest need – that is, on complex care support and case management of PLHIV – and should encourage service models that embrace multi-disciplinary care and focus on engaging allied health staff in care support and case management roles

v. Where there is flexibility through service agreements, funding for complex care services need to shift out of inner Sydney – This should focus on re-directing NGO-based complex care and case management services to complement relatively underserviced areas, notably the western part of SLHD, SWSLHD (based in Liverpool) and NBMLHD (based in Penrith)

vi. There would also be merit in services provided by NSLHD and/or an NGO being encouraged to expand the coverage of the Central Coast, and of SESLHD and/or and NGO expanding the coverage of the Illawarra region

vii. In the case of western and southern NSW, the relatively small number of widely dispersed clients and thinly distributed resources requires a re-examination of service co-ordination options, using eg Telehealth and regular visits, with an increase in resources provided by BGF and ACON to support the LHD-based staff

viii. Options to consider in delivering these outcomes include:

1. The MOH consult and agree with recipient NGOs that they provide services in geographic areas less well-served by public HIV services as part of their funding agreement
2. The MoH, in consultation with NGOs, review which are best placed to provide targeted services in collaboration with and to complement LHD-delivered services
3. Focusing care and services on clients with the greatest need by concentrating resources on case management and complex care coordination; and
4. The MoH working with an NGO/s to refocus and/or relocate services to an area of greater need (for example in the wider Western Sydney area)

ix. The MoH and PLNSW, in consultation with the HICCNAG, should convene a small working group to develop and refine a set of principles and outcome measures for PLHIV and complex care needs that can inform various models of care and service structures – that is, be applicable from moderate care support and co-ordination through to complex case management, whatever the clinical/governance models of individual services

x. The MoH and PLNSW should also facilitate regular service coordination and collaboration meetings to address the services required by PLHIV with complex health care needs across regions, and encourage LHDs and NGOs to improve communication and collaborate at a regional level on caseloads and support, thus:

1. Inner Sydney - SESLHD, SLHD, BGF, ACON, Adahps, Albion Centre, IBAC
2. Outer Western Sydney – SWSLHD, WSLHD, NBMLHD, BGF, ACON, Adahps, Pozhets, MHAHS
3. Central Coast –NSLHD, CCLHD, BGF, ACON, Adahps, Pozhets, MHAHS
4. Illawarra – SESLHD, ISLHD, BGF, ACON, Adahps, Pozhets, MHAHS
5. Northern NSW – HNELHD, MNCLHD, NNSWLHD, BGF, ACON, Adahps
6. Western NSW – WNSWLHD, FWLHD, BGF, ACON, Adahps, Pozhets
7. Southern NSW – SNSWLHD, MLHD, ISLHD, BGF, ACON, Adahps, Pozhets

xi. There would be merit in LHDs providing services to PLHIV with complex care needs also being encouraged to review their service profiles and staffing structures with the aim of maximizing service effectiveness, efficiency and program reach, and improving client access, engagement and retention in care.

2. METHODOLOGY AND DELIVERABLES

2.1 Scope of the Review & Consultation

The review and consultation focussed on:

i. A desk-top review including:
   - Analysis of source documents (including those identified by the advisory group) that describe the current population profile of PLHIV with HIV comorbidity and complex care needs in NSW, and a brief literature review to identify any other relevant source documents for analysis; and
   - Developing a working definition for HIV complex care for PLHIV involving three inter-related domains: medical complexity; situational complexity; and health care system complexity (see discussion below)

ii. A service mapping exercise and needs assessment (through both face-to face meetings and teleconferences) with publically funded sexual health clinics, and HIV specialist LHD and NGO services in NSW to identify:
   - the number and population profile of PLHIV with complex care needs attending HIV specialist services in NSW
   - the range and nature of complex health needs of the cohort
   - the types of services provided (including case support and case management, referral and follow-up)
   - partnering agencies and the extent and nature of the relationships
   - client access and retention in care issues
   - the capacity to meet current and future needs of PLHIV with HIV complex care needs
   - any gaps, limitations or duplications in the current service system; and
   - potential solutions to resolve outstanding issues.

iii. A gap analysis based on the findings from the needs assessment, service mapping exercise/consultation to assess whether the range of HIV specialists and mainstream services in metropolitan and regional/rural NSW effectively meet the current and future care and support requirements of PLHIV with multimorbidity and complex care needs.

   The gap analysis also assessed the impact of service duplications, the consequential impact of inefficiencies for service provision and the potential realignment of services structures to address gaps and access inequity for PLHIV with complex care needs. The analysis involved follow-up consultations with stakeholders to clarify and obtain further information for analysis post interview.

iv. A draft report was provided for comment to stakeholders on 20 December 2017, and it and related were considered at the HICCNAG meeting held on 24 January 2018. This Final Draft Report has been revised to reflect those views.

3. KEY ISSUES

3.1 Summary of literature review and desk-top analysis

The literature review and desk-top analysis found that:

- The demographic and epidemiological pattern of PLHIV in NSW has changed dramatically in the last 20 years. Since the advent of highly active antiretroviral therapy, people are now living much longer than expected in the 1990s and fewer people than previously predicted are becoming infected with HIV. People living longer with HIV are thus a growing proportion of the total.
- 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 movements.
- The PLHIV population in NSW is ageing – 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.
- A sizable proportion of the PLHIV population now live outside the inner Sydney metro areas and this proportion is likely to increase as PLHIV relocate due to financial pressures and general demographic changes –
  - 28% of the PLHIV population live in Sydney LHD – inner Sydney, inner Western Sydney (east of Homebush) and in the Canterbury area
  - 17.5% of PLHIV in NSW live in Western Sydney, South Western Sydney and the Nepean Blue Mountains LHDs, with a further 17% living in Northern Sydney and Central Coast LHDs (34.5% in total); and
  - Only 15.9% live in SESLHD – Eastern Suburbs and St George-Sutherland areas
- There are measurable changes in the backgrounds of people newly infected or presenting for the first time to HIV services. The starkest differences from the experience of last century are the growth in the number of people from non-English speaking backgrounds with HIV, in the number of women generally, and in the number of men who do not identify as gay or bisexual men.
- This is not to say that GBM are not the predominant group of PLHIV in NSW, both overall and of new infections. They remain so. It does however mean that the proportion of GBM is dropping overall from around 80-90% of the total to more like 60-70%, depending on the area in which those PLHIV reside. This is especially so for the increasing number of PLHIV who live outside inner Sydney and the North Coast of NSW. In some cases non-GBM comprise 50% of the total area population.
- PLHIV are at increased risk of a range of serious chronic and life threatening health conditions and particularly as they age. This is particularly so for those PLHIV who were diagnosed in the 1980s and 1990s. Many studies have found relatively high rates of multi-morbidity in PLHIV.

The 2015 Australian APPLES Study found that 85% of HIV positive gay and bisexual men (GBM) aged 55 years and over reported one or more comorbidities and 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 prevalence of elevated lipids, hyperglycaemia, and altered body composition, as well as alcohol and stimulant use and smoking in PLHIV, significantly contribute to increased risks of many serious and debilitating chronic health conditions.
- Analyses of data from a community survey conducted by PLNSW in 2015 of 214 PLHIV showed that 59% of respondents answered yes to having other diagnosed health conditions in addition to HIV. 21% identified 1 additional health condition, 14% two other health conditions, 11% three other health conditions, 7% four other health conditions, and 5% five or more other health conditions.
- Although the percentages need to be treated with some caution, it would mean that in NSW there are: 2,033 PLHIV with one health condition other than HIV; 1,355 PLHIV with two other health conditions; 1,065 with three other health conditions; 677 with four other health conditions; and 485 with five or more other health conditions.
- The degree of impairment and health complexity experienced by individual PLHIV will vary according to the severity of these other health conditions and their compounding impacts. For example, a PLHIV with a diagnosed CVD, HAND and anal cancer, will be significantly more complex than a PLHIV with well controlled depression, diabetes and hypertension.
- Complexity has 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 a non-western country, and having language and adjustment issues, as well as dealing with cultural and socioeconomic impacts, all affect health service access, delivery, care coordination and overall service inequity.
- Healthcare system complexity 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 for consumers, the health system can contribute to inadequate or uncoordinated health care as well as miscommunication and potential disengagement from care. PLHIV with mental health conditions and stimulant abuse issues are particularly at risk of disengagement.
- Shortage of public housing in the Sydney metro and some regional NSW centres continues to be a problem 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.

Being homeless or couch-surfing results in inconsistent medical monitoring and medication non-compliance, a worsening of physical and mental health conditions and the potential for self-medication/abuse of alcohol and stimulants as a coping mechanism.

- While a significant proportion of PLHIV are employed, Futures Seven reports about 45% rely on government income support (Aged Pension, DSP, Newstart, study allowance). These individuals are mainly older, have multi-morbidities and have been living long-term with HIV and in relative poverty for decades. They are unlikely to return to the workforce. As they continue to age and their health deteriorates, self-care and lost to follow up will become an increasing challenge for service responding to PLHIV with complex care needs.
- The idea of expanding case coordination and case management of PLHIV with complex care needs is not new. The HIV Complex Needs Case Management Model, proposed in 2011, was a NSW model of care designed to provide expertise and support from high prevalence areas to low prevalence areas of NSW.

  Adahps, the SESLHD HOT and Positive Central were invited to extend their roles and work beyond their areas. An evaluation of the pilot project found that number of clients engaged was less than had been expected, in part due to: a lack of clarity about the program; reluctance to promote the program across NSW, a lack of local case managers to follow up with clients; and lack of clarity about the roles and expectations of the pilot project.

3.2 HIV, medical, situational and health care system complexity

An important first step in the consultancy was to establish a working definition of HIV and complex care and to identify the many factors that contribute to the classification. It was found from the literature that complexity can be defined by three board domains, and these domains have been reflected in the definition of HIV Complex Healthcare Needs drafted as Appendix B to this report. In short, complex health care of PLHIV can be defined by:

- *Medical complexity*, involving multiple co-occurring medical conditions including non-AIDS related cancers, neurocognitive disorders, mental health conditions, cardiovascular disease, osteoporosis and osteopenia, diabetes and frailty, including the effects of years living with an immune-compromised system;
- *Situational complexity*, involving such factors as gender, race, culture and language, age, sexual identity, education, self-agency, poverty, and place of residence, as well as lifestyle and behavioural factors, such as excessive alcohol consumption, drug misuse and smoking, among others; and
- *Health care system complexity,* involving the need to navigate generalist and specialist health services provided by the public and private health care sectors. Health care system complexity can contribute to inadequate or uncoordinated health care responses and disengagement of PLHIV, and increasing the risk of service gaps, duplication and inadequate care coordination.

3.3 Strategic Observations

- During the consultation, PLHIV who have complex healthcare needs were found to divide into the following four broad categories:
  1. *PLHIV diagnosed between 1984 and 1998* who lived for many years with untreated HIV and low CD4 T-cell counts. Most were diagnosed at some time with an AIDS defining illness, and many have complex healthcare needs due to living with untreated HIV for some years, the diseases associated with long term HIV infection, and ageing
  2. *People who were diagnosed with HIV after 1998* but are now ageing. The burden of disease differs from the group in 1 above. They are however at risk of a range of conditions including anal carcinoma, CVD, HAND, stroke, other HIV related conditions and age-related comorbidities
  3. *PLHIV with late diagnosis*. This group includes MSM and heterosexual men and women, including people born overseas, and may present to health services with advanced disease and spend some time in hospital before HIV was diagnosed. They tend to gradually improve after 2 to 3 years but experience a range of health and social complications
  4. *Those people who experience life crises* associated with substance abuse, mental illness, and chaotic lifestyles including transience and/or homelessness and have HIV (and often also HCV). These issues rather than HIV are the principal concerns for this group
- All HIV related services are stretched, but there is no prospect of growth in HIV resources – this suggests that services need to look at the most cost-effective and efficient staffing structures to deliver care support and case management services, including the option of increasing the allied health mix to address care and support coordination needs
- Budgets and resourcing decisions regarding government-provided HIV services have been devolved to the LHDs managing and operating those services
- Flexibility of statewide resource allocation decisions thus focuses mainly on HIV services funded directly by the Ministry of Health and provided by NGOs with statewide roles
- Meeting new needs or addressing relative over-or under-servicing or potential duplication of services can effectively occur only through the re-allocation of existing resources
- While the NDIS may provide some benefit and free up resources for services such as Adahps, it is not clear whether and to what extent the great majority of PLHIV with complex care needs would benefit from the NDIS due to eligibility and/or age restrictions
- The location and business focuses of specialist HIV services dealing with PLHIV with complex healthcare needs do not reflect the current and future geographic distribution of PLHIV. Legacy arrangements and the concentration on services for GBM mean that the great majority of services are based in, and deal with clients from, the inner Sydney area
- The Albion Centre, IBAC, the HOT, ADAHPS, ACON, PLNSW, BGF and Poz Central are all situated within two kilometres of Central Station. Sydney Sexual Health, PozHet,

MHAHS and the RPA HIV service are within four kilometres of Central. Moreover, three of the major private and NGO HIV medical services fall within the same catchment area.

- The residential distribution of PLHIV in NSW has changed significantly in the 21st century, with 15.9% of PLHIV living in SESLHD, and 28.5% living in Sydney LHD. These LHDs comprise the area bounded by the coast from Bondi to Cronulla, Loftus, Georges River, Lakemba, Homebush, Parramatta River and Sydney Harbour and account for less than 45% of all PLHIV in NSW.
- There are also some specialist public and NGO services located in Parramatta, Liverpool, Nepean/Blue Mountains, North Shore, Hunter and the North Coast.

  However, analysis of the size and capacity of all services with the role and/or capacity to deal with PLHIV who have complex healthcare needs reveal significant inequities in resource distribution.
- The factors of limited resources with an expanding profile of PLHIV who have complex healthcare needs also indicates the importance of assessing the scope and level of services provided to PLHIV and targeting those with the greatest unmet needs. This should also acknowledge that the most effective services are often in the form of social support, case management and coordination, rather than direct clinical services available elsewhere.
- In the case of services for PLHIV and complex health care needs, this involves a careful examination of the resources provided by the Ministry of Health to NGOs that could be directed to reflect the overall contemporary demand – for analysis of relevant existing NGO services other than for case management, see Appendix H)
- It also should look at potentially more effective consumer access and engagement strategies and efficient staffing profiles for HIV services, both public and NGO-based – this however needs to acknowledge the limited capacity of generalist health services to meet the complex health care needs of PLHIV without collaborative specialist services
- Any service model and resource deployment changes mooted and proposed will of course need to be considered in the light of existing client expectations and relationships,
- Tensions will be inevitable if services are altered or moved, and those who are likely to lose something tend to fight harder than those who would benefit. Inertia in services and staffing attitudes will likewise figure in any change strategy.

3.4 Gaps, Duplication and Service Inequity

Where do key imbalances in service access lie? The tables set out on Appendices F and G show the variations in complex care service access across NSW. The one-page table in Appendix F shows the number of PLHIV receiving case management and care support service (including comprehensive and complex support from BGF and Care Coordination from ACON).

Overall, 14.0% of PLHIV with complex care needs in NSW receive care support services (not including BGF's lower level Health and Wellbeing support) and 4.8% of PLHIV in NSW are currently case managed. This amounts to *1,820* people out of a total of *9,682* PLHIV in NSW.

NB Data on care support and case management vary considerably within catchment areas LHDs, suggesting that resources are deployed differently based on capacity as well as demand, with those LHDs with relatively fewer resources focusing on less demanding care support rather than case management. It should also be noted that the depth of case management also varies considerably based on demand and resources (see below).

Implications of the Key Findings are assessed above, but can be summarised for both case management and complex care support thus, noting that under-servicing appears to be greater for the more resource-intensive case management:

- A broad pattern emerged among services providing care support to PLHIV who have complex needs – overall the services have not always demonstrated a consistent enthusiasm for cooperation and collaboration to maximise efficiencies and effectiveness to the clients' benefit (except in the Hunter New England and Northern NSW Areas). Some services (NGO and LHD) however have demonstrated a willingness to reorient their service structures to more effectively meet changing need.
- In particular, the effectiveness of co-case management with Adahps was cited as a concern on more than one occasion. Three issues were raised: acceptance by Adahps of clients was too restrictive; the level of participation by Adahps was too little or too infrequent as it is often not the lead agency; and the impact will increase as more clients suffer cognitive impairment with ageing of the cohort.
- Adahps has recently advised that it revised it co-case management model in 2016 to a collaborative case management model. Adahps has become the primary case manager in rural and regional areas (where no other HIV outreach services existed to take on a primary case management role). Relevant de-identified data provided by Adahps is attached at Appendix I.
- Overall case management for PLHIV varies from nil in Western and Far Western NSW up to about 14.5% of the catchment population of Western Sydney LHD. Other relative under-servicing occurs in Central Coast, Nepean Blue Mountains, Sydney LHD, the Illawarra region, South Western Sydney and Northern NSW (Tweed and Richmond). Relative over-servicing is also found in SE Sydney LHD and Hunter New England LHD.
- Complex care support services for PLHIV vary from 1.9% of the population in Central Coast LHD up to 42% of the catchment population in Northern NSW. Significant relative under-servicing is also noted for the Illawarra region and Sydney LHD. Significant relative over-servicing is also shown in Western Sydney, Nepean Blue Mountains, Western and Far Western NSW, Hunter New England and SE Sydney LHD.
- In assessing overall resources and current unmet service demand, it would appear that case management services should be built up in Sydney LHD, South Western Sydney LHD, Central Coast LHD and the Illawarra region. In two cases – Nepean Blue Mountains LHD and Northern NSW LHD – it may also be appropriate to consider diverting some care support to more case management services.

- In three areas – SE Sydney LHD, Western Sydney LHD and Hunter New England LHD – there appears to be relative over-servicing of both case management and care support services. It should be noted though that this observation does not take into account the relative intensity of services and the numbers of case managed clients.
- Care coordination and case management practices vary significantly between services:
  - For instance, three to four social workers at WSLHD's Sexual Health Service provide case management to 125 PLHIV from a total caseload of 380 individuals
  - The SESLHD HOT in Darlinghurst provides case management to 130 individuals with two social workers, three clinical nurse specialists and two clinical nurse consultants
  - In contrast, BGF (with two case managers) provides case management to 16 PLHIV in the Sydney metropolitan area and 13 PLHIV in Northern NSW
- Clearly, the levels of case management service vary considerably when client numbers range from 13 to 40 per case worker (within an overall caseload of 100 clients per case worker in the case of WSLHD).
- The tables in Appendix G show in more detail the numbers of PLHIV across the various regions of NSW, the range of services they receive and the relevant service providers, both public and NGOs. What is obvious is the diverse mix of services reflecting ad hoc responses to historical demands and needs.

3.5 Assessing the numbers of PLHIV with unmet complex care needs

- The factors contributing to complex care needs are multifactorial. They include combinations of co-occurring medical conditions of varying severity and treatment complexity. A combination of some health conditions, such as cancer, stroke, heart attack, HIV associated neurocognitive impairment, will likely have a greater impact on health and well-being than well-managed depression, anxiety, hypertension and diabetes.
- In the case of PLHIV, the tipping point from coping relatively well to managing a serious, life-threatening array of conditions can emerge suddenly, due to the onset of a life changing health event such as anal cancer, a heart attack/stroke, frailty, or dementia.
- Many HIV clinicians in Australia regard the threshold for HIV medical complexity to be *two or* more diagnosed chronic health conditions. Data from a 2015 PLNSW survey into PLHIV health care needs reported 37% as having two or more diagnosed health conditions in addition to HIV. This equates to 3,580 PLHIV in NSW – about double the number of the clients captured in this review.
- Assessing unmet needs also requires the consideration of compounding social factors, such as stigma associated with being a heterosexual or Aboriginal PLHIV, being recently arrived from a non-western country, and dealing with the potential chaos resulting from the loss of employment or relationship breakdowns. These are often also associated with increased mental health problems and drug use, and PLHIV who experience these precipitating events are much more likely to require complex care services for the first time in their lives.

- It is reasonable therefore to estimate a gap of around 2,000 PLHIV who at some time in the future are likely to need care coordination or case management to prevent disease progression and admissions to tertiary health care. While it is impossible to predict who will deteriorate and difficult to forecast when these PLHIV will need support, it is likely that this unmet need will grow with the aging of the overall PLHIV population.
- There is also a small population of PLHIV with perinatal acquired HIV (16-25 year olds) who are transitioning to adult services. These individuals often struggle to effectively transition between services and require substantial levels of support to improve service access, navigation and retention in care.
- Whatever the proportion of people now being well-managed in the private sector, HIV NGO and specialist services will need the capacity to respond to this future need.

3.6 Case Management and Care Coordination needs

PLHIV with complex care needs have differing experiences of services across NSW, based on the history of the epidemic and the legacy of service arrangements built by the sector for PLHIV that are in most cases unavailable to other disease groups. These HIV service models have led some PLHIV, particularly GBM living in inner Sydney, to become accustomed to high levels of support and expect continuity of services unavailable to PLHIV in other parts of NSW.

Client expectations have in some instances been reinforced by services keen to retain existing clients and otherwise demonstrate their value in order to maintain a case for funding in a competitive environment. As a result, patterns of care delivery vary markedly across NSW. Some PLHIV who have complex care needs are receiving high levels of care support, while others are going without support, or receiving much less support than they should receive.

Moreover, some NGO and LHD-based services (eg SWSLHD HIV Team) demonstrated considerable stress and difficulty in dealing with the needs of often chaotic, resource-intensive clients. Others with comparatively little in the way of additional supports (eg NSLHD HIV Team) did not identify similar pressures or unmet demand. These differences may reflect socio-economic factors and the varying capacity of PLHIV to have their needs met elsewhere.

Nevertheless, NGO service models require review where relative over-servicing has become the norm and overall resourcing of HIV specialist services has become increasingly constrained. Given the current, devolved, funding arrangements to LHDs, the only practicable means of freeing up resources and improving equity of care and support to PLHIV with complex care needs across NSW is to re-direct resources provided to NGOs to areas of greatest need.

3.7 Options

Addressing these challenges could be achieved in a number of ways:

- *First*, by the MOH consulting NGOs and agreeing that recipient NGOs provide services in geographic areas less well-served by public HIV services as part of their funding agreement

- *Second,* by focusing care and services on clients with the greatest need by concentrating resources on case management and complex care coordination
- *Third,* by the MoH in consultation with NGOs reviewing which are best placed to provide targeted services in collaboration with and to complement LHD-delivered services; and
- *Fourth,* by the MoH working with an NGO/s to refocus and/or relocate their services to an area of greater need (for example in the wider Western Sydney area)

None of this is however as straightforward as it might seem, as NSW Health is not the only source of funding to either eg BGF or ACON, and the funds provided cover a range of functions beyond case management and complex care coordination.

It does however suggest an opportunity to review the NSW Health HIV Program funding so that it is focused more equitably on services to PLHIV who require case management or complex care coordination.

NB Limitations in consultation

PLHIV in NSW with complex care needs access a broad range of services, from primary health care provided by GPs (, s100 GPs) from Sexual Health Clinics, Hospital Outpatient facilities or private specialists, or a combination of these services. Due to project timelines and budget constraints, the consultants focused however on PLHIV with complex care needs who access publically funded sexual health, hospital outpatient, LHD allied health and HIV NGO services.

Thus, PLHIV with complex care needs who access primary health care from private s100/GPs and/or private specialists, and otherwise have no contact with publically funded services, are not included in these analyses. NB This may in part explain the very low rate of PLHIV residing in NSLHD being provided with publicly-funded services noted above.

While the consultants consider this may potentially impact on the thoroughness of the consultation and analyses, we also believe that when appropriate, many PLHIV accessing private S100/GPs and non-s100/GPs are referred onto specialist HIV services for care support, and therefore may be receiving adequate services from the eg private sector.

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