

**Submission
No 35**

INQUIRY INTO THE MANAGEMENT OF HEALTH CARE DELIVERY IN NSW

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Legislative Assembly
Public Accounts Committee
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Re: Inquiry into the Management of Health Care Delivery in NSW

Dear Committee Secretariat

Thank you for the opportunity to provide feedback on the Management of Health Care delivery in NSW.

Positive Life NSW (Positive Life) is the state-wide peer based organisation that speaks for and on behalf of people living with and affected by HIV (PLHIV). We provide advocacy and leadership in advancing the human rights and quality of life of PLHIV in NSW.

At Positive Life, we recognise that involving PLHIV and affected communities in line with Australian Safety and Quality Framework for Health Care (ASQFHC) Standard Two makes a powerful contribution to the HIV pandemic. Enabling individuals and communities to draw on their lived experiences, thus aiming to reduce stigma and discrimination and increase the effectiveness and appropriateness of health service delivery for chronic and manageable conditions.

Our vision is that all PLHIV are able to live valued and meaningful lives, free from the impacts of stigma and discrimination, and contributing to the end of HIV transmission. We would like to commend NSW Health for their commitment to continually improve safety and quality outcomes for health consumers. With this focus in mind, our submission (found at Attachment A) will concentrate on health care delivery, and reporting specifically for PLHIV.

If this submission requires additional information and clarification I can be contacted on [REDACTED] or alternately at [REDACTED]

Yours respectfully,

[REDACTED]
Craig Cooper
Chief Executive Officer

31 July 2017

Executive Summary

Positive Life believes the current performance reporting framework for monitoring the effectiveness and efficiency of health care service delivery in NSW could be strengthened. The meaningful involvement of PLHIV will sustain and increase the efficiency and effectiveness of rigorous data collection, monitoring and reporting. Hence supporting and strengthening the aims of the current NSW Health, HIV Strategy 2016-2020 into the future. We respectfully recommend the Committee:

1. Support the formation of a community data research governance framework
2. Implement Patient Reported Measure's for all chronic and complex care services

Background - The population of PLHIV in NSW is increasingly growing older and more diverse. It includes those who were diagnosed in the early 1980s and have been living with HIV for more than 30 years to those who are about to be or who have just been diagnosed. Priority populations are described as gay and bisexual (GBM) and men who have sex with men (MSM), Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds (CALD), people who inject drugs (PWID) and sex workers.

If current rates of diagnosis continue, there will be approximately 11,721 people diagnosed with HIV in NSW by 2020.¹ The current NSW Health, HIV Strategy 2016-2020² details efforts to expand HIV prevention, increase testing frequency as well as increase the number of PLHIV on treatment.

Scope of this submission - In this submission to the Inquiry into the Management of Health Care Delivery in NSW, we will respond to two of the Committee's Terms of Reference:

- a) The current performance reporting framework for monitoring the effectiveness and efficiency of health care service delivery in NSW; and
- b) The extent to which efficiency and effectiveness is sustained through rigorous data collection, monitoring and reporting.

We suggest increased consumer participation and a community data research governance framework will contribute to improved health outcomes from health services delivery in NSW.

Terms of Reference a) the current performance reporting framework for monitoring the effectiveness and efficiency of health care service delivery in NSW

The Hon Jillian Skinner MP launched The NSW HIV Strategy 2016-2020 which kept many aspects of the previous strategy (2012-2015) including the importance of the cornerstones of prevention condom use, testing regularly and early treatment. The NSW HIV Strategy 2016-2020 is reported on a quarterly basis against the framework of 'prevent, test, treat' that outlines the government's goals, and activities funded to achieve the virtual elimination of HIV transmission by 2020. To monitor progress against the strategy goals and targets, a range of data sources are monitored and reported against via a quarterly data report.

¹ Wilson D. Mapping HIV outcomes: geographical and clinical forecasts of numbers of people ;living with HIV in Australia, National Centre in HIV Epidemiology and Clinical Research (Kirby Institute) 2010, key findings, p5

² See: <http://www.health.nsw.gov.au/endinghiv/Publications/nsw-hiv-strategy-2016-2020.PDF>

The Australian Safety and Quality Framework for Health Care (ASQFHC) Standard Two³ describes a vision for safe and high quality care for all Australians, and sets out the actions needed to achieve this vision. The framework specifies three core principles for safe and high quality care. These are that care is consumer centred, driven by information, and organised for safety. Consumer centred care involves the co-design and co-development of all aspects of our healthcare including the management of healthcare delivery.

The NSW HIV Strategy 2016-2020 and its quarterly reports have proven to be an effective and efficient way to disseminate and interrogate data from a range of government and academic sources to track results and measure successes against the prescribed prevent, test and treat framework. Key performance indicators and activity based funding is formulated based on these results; however there are challenges within these criteria for PLHIV.

From a PLHIV perspective, we believe there is an opportunity to increase transparency and consumer engagement. Such as, data collection at a service delivery level, who accesses the data and patient information, and how the data is used by health services as statutory authorities. At this point in time, consumer involvement in monitoring the effectiveness of data usage is lacking.

It is our take that current healthcare outcomes typically measured for PLHIV are focused on patient retention in care (appointments and activity) and treatments (prescribing and adherence). They monitor and focus on clinical events such as, appointments at clinics and treatment adherence. These measures offer little value to consumers to monitor the effectiveness of the health service or health service provider and the impact it has in assisting people to achieve their health goals or outcomes.

Currently in NSW there is no systematic way to monitor and report on HIV / AIDS deaths. When anti-retroviral therapies (ARVs) became available in 1996, there was a shift from hospital to ambulatory and community care arrangements, as we were living longer. Therefore, there was a need to shift AIDS program resources from hospital beds, to alternate health service delivery models. It is our understanding, over the years that followed, that HIV and AIDS deaths are no longer monitored and reported via the public health units. The consequence of this policy and surveillance decision is that when our friends, family and community members die, there is invisibility and silence about these deaths, as this data is not recorded. Therefore, we'd suggest there be two data reporting processes introduced. Firstly, when a PLHIV dies, this triggers an alert and a peer review of the patient file under a quality improvement or risk management (root-cause analysis) approach to determine if anything else could have been done and the outcomes feed into and value adds to HIV clinical practice. Secondly, that HIV / AIDS deaths are recorded and reported in NSW as a part of a jurisdictional surveillance program, under the following three categories: 1. Deaths related to HIV or an association condition / diagnosis; 2. AIDS Deaths; 3. When a person living with HIV dies.

PLHIV experience multiple chronic health conditions at significantly higher rates than the general population, however the current reporting framework fails to measure and monitor the effectiveness of health service delivery for these non-HIV related conditions or integrated care arrangements (for those engaged with multiple service providers). If patient reported measures (PRMs)⁴ were

³ See: <https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/32296-Australian-SandQ-Framework1.pdf>

⁴ See: <https://www.aci.health.nsw.gov.au/make-it-happen/prms>

introduced within a quality improvement and peer review framework, this would enable the NSW Health Integrate Care strategy⁵ to deliver improved health outcomes for consumers as well as health outcomes that matter to patients. With PRMs, patients would have an equal voice in evaluating and reporting on ease of health system navigation, affordability, patient experience, wait times and their quality of life.

Terms of Reference b) The extent to which efficiency and effectiveness is sustained through rigorous data collection, monitoring and reporting

Currently, Positive Life considers the effectiveness and adequacy of information and communication technology solutions (ICT) such as: eHealth and My Health Record; data linkage research; and communicable disease surveillance and notification databases could be improved by redesigning the structural separation and quarantine via numerous ethics and legislative processes which currently guide monitoring and management. Further, we propose principles to engage the trust and confidence of consumer groups in the collection of patient and laboratory data and monitoring and reporting transparency.

In order to deliver better healthcare management and health outcomes that matter to PLHIV, we need to be meaningfully involved in the development, implementation and review of these benchmarks. Research ethics applications, contract management and health information and privacy legislation operates under connected, yet separate governance frameworks, with little to no consumer input. Maintaining these data collection services in isolation, with separate relationships guiding their governance frameworks raises ethical and ideological concerns about the integrity of the data, interpretation, application, monitoring and reporting.

We believe, to redress these concerns about transparency, consent and consumer engagement a move towards a community co-production and governance model needs to be explored, where PLHIV have a meaningful role from ethics approval to data collection and linkage. This would qualify and strengthen the monitoring and reporting capabilities within the health system, as well as sustain the extent to which efficiency and effectiveness of health service delivery.

Conclusion - We believe that the involvement of consumers in this way will strengthen the effective and rigorous data collection and evidence based management of the NSW health service delivery.

⁵ See: <http://www.health.nsw.gov.au/integratedcare/pages/default.aspx>