19 February 2019

PositiveLifeNSW
the voice of people with HIV since 1988

Blood Borne Viruses and Sexually Transmissible Infections Standing Committee (BBVSS)
BBVSTITSH@health.gov.au

Re: Submission into Developing the Implementation Plans for the National Blood Borne Viruses and Sexually Transmissible Infections Strategies 2018-2022

To Whom it May Concern,

Positive Life NSW (Positive Life) welcomes the opportunity to provide a submission into Developing the Implementation Plans for the National Blood Borne Viruses and Sexually Transmissible Infections Strategies 2018-2022.

Positive Life is the peak state-wide peer-based non-profit organisation that speaks for and on behalf of people living with and affected by HIV (PLHIV) in NSW. We provide leadership and advocacy in advancing the human rights and quality of life of all PLHIV, and to change systems and practices that discriminate against PLHIV, our friends, family and carers in NSW.

At Positive Life, we support the guiding principles of the Eighth National HIV strategy in which the voices and meaningful participation of PLHIV 'is essential to the development, implementation, monitoring and evaluation of effective programs and policies.' [1] As PLHIV and peers we are the experts in educating and upskilling our peoples and populations, including those from key affected communities about HIV and related issues. Our peer navigation and peer education models, promote and raise the awareness with all at risk peoples about the importance of HIV testing, the range of HIV prevention tools of PrEP, PEP, TasP and reducing barriers to access to HIV treatments.

Positive Life has a mandate to challenge and eliminate stigma and discrimination throughout NSW including raising the awareness of clinical health professionals. We advocate for co-payment wavier and fair and equitable access to HIV treatments for PLHIV who are ineligible for Medicare. Further, we recognise access and service navigation barriers that obstruct priority populations from achieving health outcomes and remaining engaged in health.

Our vision is that all PLHIV are able to live valued and meaningful lives with equitable access to health services, free from the impacts of stigma and discrimination and contributing to the end of HIV transmission. We would like to commend the Blood Borne Viruses and Sexually Transmissible Infections Standing Committee (BBVSS) for their commitment to include stakeholders input to shape the development of this implementation plan. Our submission (please see attachment) will concentrate on the proactive and pivotal role Positive Life can play in achieving outcomes against the Eighth National HIV strategy.

I can be contacted on 0422 509 200 or at craigc@positivelife.org.au if this submission requires additional information or clarification.

Yours sincerely,

Craig Cooper
Chief Executive Officer

[1] Commonwealth of Australia Department of Health. (2018). 'Eighth National HIV Strategy 2018-2022.' Accessed 7 January 2019 at: http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-1/$File/HIV-Eight-Nat-Strategy-2018-22.pdf.

Implementation Plan: Eighth National HIV Strategy

Name/organisation: Positive Life NSW

Email contact: craigc@positivelife.org.au

Higher-level Priority Areas		Key area for action	PRIORITY FOR ACTION: H = highest priority for 2019/20 L = lower priority - to commence 2021/22	CURRENT ACTIVITIES: What current main activities are supporting this key area for action?	NEXT STEPS: What additional activity is needed to progress this key area for action?	Who is the lead for initiating / implementing this additional action?
Education and prevention Maintain focus on health promotion, prevention and peer education to improve knowledge and awareness of HIV in priority populations and reduce risk behaviours associated with HIV transmission Ensure priority populations have access to the means of prevention Increase knowledge of, and access to, treatment as prevention for individuals with HIV Increase knowledge of treatment as prevention for those individual at risk of HIV	1	Maintain and implement targeted programs, including community-led and peer-based approaches, which improve HIV-related knowledge, reinforce prevention and promote safe behaviours in priority populations	**H**	**Will this include a definition of what safe behaviours are or some examples?** **What is HIV related knowledge? (health literacy, shared decision making, prevention, condoms, TasP, PrEP, PEP etc.)** **Programs such as peer navigation, treatments officers, Genesis and Peer 2 Peer support groups.** **Partnerships with service providers such as Multicultural HIV and Hepatitis Service and Positive Life's "7 reasons to treat" and "7 reasons to test" campaigns.**	**Promote Genesis and peer to peer for recently diagnosed and progress peer navigation across all jurisdictions. Provide support groups for Aboriginal and Torres Strait Islander and specific Culturally and Linguistically Diverse (CALD) People Living with HIV (PLHIV). Employ education officer positions within peer based PLHIV organisations. Resource communities with culturally and information correct factsheets and forums. Increase health literacy and self-agency for PLHIV.**	**Peak bodies representing people living with HIV and those at risk of HIV.**
	2	Promote the availability and effectiveness of PEP and PrEP and facilitate rapid, widespread and equitable access to PEP and PrEP across the country	**H**	**Modelling from the Kirby Institute suggests for a reduction in HIV transmission to be achieved, rapid scale-up of PrEP for those at high risk of HIV acquisition is needed. GP prescribing and support for PrEP needs to be consistent and equitable. Likewise, the GCPS provides evidence of the lack of awareness and accessibility for PEP. Investment in community education and increasing awareness of PEP needs to occur while PrEP campaigns rollout**	**Upskilling of knowledge of PEP and PrEP to wider public audiences beyond Australian gay bisexual men to other people at risk of HIV using culturally appropriate education for including but not limited to MSM overseas born men, women, Aboriginal and Torres Strait Islander people and, Trans and gender diverse people. Training for GP's and sexual health nurses and sexual health service providers is also necessary in promoting PEP and PrEP. Factsheets written in culturally appropriate community/ peer-based language outlining the use of PrEP and PEP what this means for PLHIV who can't reach an Undetectable Viral Load (UVL)**	**ASHM, Peak bodies, jurisdictional sexual health services.**
	3	Ensure clinical prevention approaches are delivered in combination with education on STI prevention and regular STI testing.	**H**	**Not occurring equitably across populations, regions or systems. A systematic way for this to occur needs to be devised and this needs to be a data item, so outcomes can be monitored**	**Funding and investigation into systematic process to increase the levels of education through promotional strategies and training to maintain and enhance current levels of testing.**	**Jurisdictional sexual health services, peak bodies**
	4	Increase the knowledge and awareness of HIV among general practitioners /primary care professionals in relation to the suite of available prevention methods, including TasP, PEP and PrEP; how to support priority populations; and the availability and effectiveness of HIV treatment, with a particular focus in areas of high need	**H**	**Workforce development and training is needed, which covers shared care, primary care and integrated care across service provision models for PLHIV with multi-morbidities (such as, S100 prescribers GPs), for people that are Medicare ineligible, CALD people, people that use alcohol and other drugs, people with mental health concerns and complex care needs. Positive Life NSW (PLNSW) have worked in this space within several ways including:** • **Review of Stigma guidelines** • **Contracting tracing 'peer led partner notification'**	**While there have been many collaborations with Gp's and primary care professionals there remains significant barriers to awareness and education that need to be identified to avoid aspects of power imbalance and PLHIV feel less empowered by their doctors.** **Promotion of harm reduction such as NSPs, continuation of access to free condoms, legalise exemption for people who inject drugs (PWID) to distribute and carry sterilised equipment among other PWID.** **Standardised training modules.** **Broader understanding of zero transmission effectiveness of TasP.**	**Health Departments, ASHM, peak bodies, RSGCP**

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				• Positive Speaker Bureau presentations for clinicians, • Review of health pathways data base • Implementation of Positive Life accredited community pharmacy • Representation on ASHM National Curriculum committee	Oppose mandatory spitting laws that would undermine scientific evidence of TasP. Development of culturally appropriate peer education for CALD and Aboriginal and Torres Strait Islanders.	
	5	Support and prioritise TasP by increasing awareness of HIV treatment; promoting the benefits of having an undetectable viral load; and by supporting access, uptake and adherence to antiretroviral treatment immediately after diagnosis	H	Co-payment waiver nationally. Immediate treatment commencement across populations and jurisdictions, as standard prescribing practice. Treatment forums through 'In the know', Social media campaigns and web-based information. Medicare ineligible factsheets, community outreach, '7 reasons to test' / '7 reasons to treat'	Strength and expand the implementation of peer navigator programs to assist PLHIV awareness of TasP, UVL and treatment adherence. Peer education. CALD and Aboriginal and Torres peer reviewed resources / employ peer workers. Oppose mandatory testing that would undermine scientific evidence of TasP.	Jurisdictional State representative organisations those representing marginalised communities.
	6	Ensure the wide distribution and availability of sterile injecting equipment and safer-injecting education among people who inject drugs, including a focus on priority populations and people living in regional, rural and remote areas	H	Increased access to sterile injecting equipment (including within correctional facilities), via peer distribution models. Vein care, people who inject others, people who are considering other ways to administer drugs and move away from injecting	Address the barriers of access to sterile injecting equipment in correctional facilities. Promote harm reduction methods. Change legislation to grant legal exemption to allow members of the community to exchange sterile injecting equipment resulting in reduction rates of HIV and other BBVs including Hepatitis C.	Peak bodies representing people who use drugs, AOD services and BBV and STI prevention (health promotion) programs.
	7	Improve surveillance and research on priority populations, including through improved data collections and greater granularity of epidemiological data, and use these data to inform approaches	H	Consistent quarterly real time data collection nationally (across jurisdictions). Actual data, rather than estimates or linked data sets. The monitoring of transmitted drug resistance. HIV hospitalisations and deaths via the national surveillance program. Definition of risk among priority populations (key affected peoples/communities), Cascades of care for priority populations to assess health outcomes	Maintain timely quarterly reporting and increase the detail, comprehensiveness and timely of the quarterly surveillance to make it more meaningful. Increased development of data collection, online survey of at-risk populations to evaluate the needs of priority populations. Improve research on priority populations with better identification of those from CALD and Aboriginal and Torres Strait Islander backgrounds as well as Trans and gender diverse people.	Health departments and peak bodies.
Testing, treatment and management Improve the frequency, regularity and targeting of testing for priority populations, and decrease rates of late diagnosis Improve early uptake of sustained treatment to improve quality of life for people with HIV and prevent transmission	8	Expand the use and accessibility of a range of HIV and STI testing technologies and options, and tailor testing approaches to the needs of priority populations and sub-populations, particularly where there is a need to improve early diagnosis	H	DBS, home testing, diversifying testing options for at risk populations and people living with undiagnosed HIV.	Address stigma and discrimination by health care providers. Promote inclusive testing strategies particularly to CALD and Aboriginal and Torres Strait islanders particularly in rural, remote and isolated areas. Diversifying testing by using peer-based testing models.	ASHM, RSCGP, respective services for CALD and Aboriginal and Torres Strait Islander people.
	9	Improve the knowledge and awareness of health professionals and community-based health workers of indications for HIV testing, including for health professionals, the investigation of non-specific symptoms without identifiable risk factors	H	Identify late presenters. ASHM clinical indicators, specialist services inform, non-specific clinical presentation. Training for medical students.	Late diagnoses are still happening. Need to increase awareness and uptake of HIV testing including a systematic review of guidelines or practice notes for specialist services to avoid missing the diagnosis late presenters. Debunking healthcare perceptions of who is at risk of HIV. Implement standardised practice for everyone to be access for STI and be offered a HIV test annually.	ASHM, RSCGP, universities and education of undergraduate health care workers.
	10	Ensure that people diagnosed with HIV are promptly linked to treatment, ongoing care and peer support using approaches that address the specific barriers experienced by priority populations and sub-populations across priority settings	H	Increase knowledge of options to doctors and PLHIV/ peer-support options as standard of care and referral practice at the point of diagnosis.	Access to peer navigators as a formal part of the testing, diagnoses and treatment pathway. Need for changing the guidelines and practice within diagnosing clinician care. Removal of structural barriers to	Embedded within policy and procedures within all jurisdictions, peak bodies.

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					immediate treatment and strengthening referral pathways and building clinician confidence of peer navigation.	
	11	Promote the use of evidence-based clinical guidelines and resources	**L**	**Needs to be ongoing, reinforce and profile existing resources. Positive Life have written articles raising awareness of poly pharmacy, treatment reviews and on-going maintenance.**	**Promote the evidence for Immediate START to treatment, zero risk of transmission. ASHM to generate a HIV monitoring resource for all S100 doctors.**	**Peak bodies, relevant jurisdictional state organisations.**
	12	Investigate a sustainable model for access to treatment for people with HIV who are ineligible for Medicare	**H**	**People who are ineligible for Medicare need to be included in existing regulations and frameworks within clinical services.**	**Affordability access schemes for PLHIV who are eligible for Medicare. Ensure dispensing fees are waved to promote medication access and adherence fulfilling goals in ending HIV.**	**Relevant health departments. Lobbying by peak organisations representing PLHIV and at-risk populations.**
<u>Equitable access to and coordination of care</u> Ensure healthcare and support services are accessible, coordinated and skilled to meet the range of needs of people with HIV, particularly as they age Ensure people with HIV are engaged in the development, delivery and evaluation of the services they use	13	Improve the integration of care provided to people with HIV, including by general practitioners, sexual health physicians, psychosocial support services, community pharmacies, community-based nursing, other health services and specialists, and aged care services, particularly in rural and remote locations	**L**	**Improved shared care and integrated care options for PLHIV and monitor via PozQoL, PROMs and HIV Hospitalisations and deaths, rather than viral load monitoring, dispensing data and attendance at medical appointments**	**Promote the benefits of relevant models of care to service users. Enhance discharge and linkage to care pathways.**	**STIPU, ASHM, RSCGP, sexual health services.**
	14	Identify, implement and evaluate models of care that meet the needs of people with HIV who are ageing and ensure quality of care across services	**H**	**Pilot peer support and HIV aged care programs, that can support aged care service access and navigation HIV research advice into APPLES 2 to access functional impairment correlated to age demographics of PLHIV. Contribution into end of life Palliative care partnership with clinical services and HIV and complex care in NSW. Review of service delivery model in collaboration with LHDs in NSW. Feedback surrounding ageing demographics with PozQoL.**	**Enhance education of Aged Care services. Integrated peer navigator models. Submission into the royal commission into aged care, health and safety**	**Peak bodies and relevant state organisations.**
	15	Increase capacity for HIV treatment and care in those health services providing culturally appropriate care to Aboriginal and Torres Strait Islander people and culturally and linguistically diverse populations	**H**	**Cultural sensitivity, priority access for CALD and Aboriginal peoples to address health inequities**	**Audit of resources available rework to include culturally appropriate language with peer review process to effectively CALD and Aboriginal and Torres Strait Islander populations. Peer workers. Identifying barriers to access and improving access barriers for Aboriginal and CALD PLHIV with complex care needs.**	**Relevant organisations representing and proving services to PLHIV, CALD and Aboriginal and Torres Strait Islander populations.**
	16	Increase HIV awareness, capability and collaboration of service providers to support people with HIV, including in settings such as drug and alcohol, mental health, aged care, disability, housing, employment, child and family, and justice and corrective services	**H**	**Through care, care coordination and discharge planning need to be improved and showcased. Communications and health promotions with community through Talkabout and Pozlite.**	**Development of resources targeted for service providers within these settings. HIV education training modules for service providers including peer presenters.**	**Relevant peak bodies representing PLHIV and substance use.**
<u>Workforce</u> Facilitate a highly skilled multidisciplinary workforce that is respectful of and responsive to the needs of people with HIV and other priority populations	17	Continue to regularly update, maintain, and make accessible evidence-based clinical guidelines, tools and support for prevention, testing and management of HIV and related comorbidities	**H**	**HIV related conditions and co (multi)morbidities is not adequately reported, documented and monitored. How clinicians, patients and the health system does this, needs to be prioritised. HIV and STI committee and expert data group and its role in generating an opportunity for researches, clinicians and community to come together to engage**	**Enhance surveillance and epidemiological data collection. Enhanced linking of communications and referral pathways using technology between providers. Continue dialogues between different sectors on the HIV response and maintain an enabling environment that allows input within HIV research. Increase committee meetings to a biannual basis.**	**Relevant jurisdictional health departments.**

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				together made aware and reviews evidence and update guidelines within jurisdictions.		
	18	Ensure that access to PrEP, TasP and other prevention methods are supported by consistent and targeted information and messaging for health professionals	**L**	**Ongoing delivery of in-services, training sessions, conference presentations and practices guidance documents**	**Debunking myths and perceptions of healthcare workers and providers as to who is at risk of HIV. Research into barriers Aboriginal and Torres Strait Islanders face with engaging with PrEP, TasP and other prevention methods. Enhance culturally appropriate services to address these barriers and the stigma and discrimination often experienced within these communities. Universal and free access of HIV medications with all co-payments (dispensing fees) waived. Removal of barriers to enable treatment targets to be reached. Promotion of "doctor shopping" for second opinions and medication reviews (as doctors are not willing to consider treatment side-effects and polypharmacy concerns for PLHIV).**	**Relevant bodies representing marginalised populations at risk.**
	19	Continue to explore and share experiences of innovative multidisciplinary models of care for HIV prevention and management, particularly models for rural and remote areas and areas of workforce shortage	**H**	**PLHIV in regional and rural NSW and Australia typically have longer waiting times, distance to travel and fewer treatment options**	**Enhance access to IPTAS. Enhance knowledge and capacity of local health care providers within these respective judications. Meaningful involvement and utilisation of people living in rural areas as consumers involved in the development and implementation of care models (co-design).**	**Health departments, RSGCP, ASHM, peak bodies**
	20	Develop knowledge and awareness of HIV across the multidisciplinary workforce to facilitate the delivery of appropriate services and address the ongoing care and support needs of people with HIV	**L**	**Conferences, training, updates and webinars, newsletters**	**Continue to support research and funding to HIV services. Identify clinical education points relevant for health care workers in respective jurisdictions. Implement stronger HIV programs within educational settings.**	**Educational facilities and workforce development programs**
	21	Support the capacity and role of community organisations to provide education, prevention, support and advocacy services to priority populations	**H**	**State-wide and national peer-based organisations need to be sufficiently resourced, so they can support PLHIV and address health inequities**	**Increased funding and resources and to upskill PLHIV enhancing access to employment and housing and healthcare.**	**Funding bodies**
<u>Addressing stigma and creating an enabling environment</u> Implement a range of initiatives to address stigma and discrimination and minimise the impact on people's health-seeking behaviour and health outcomes Continue to work towards addressing the legal, regulatory and policy barriers which affect priority populations and influence their health-seeking behaviours Strengthen and enhance partnerships and connections to priority populations, including the meaningful engagement and participation of people with HIV	22	Implement initiatives to reduce stigma and discrimination across priority settings, including education which incorporates messaging to counteract stigma	**H**	**Regular and ongoing education and training needs to be delivered to combat and address HIV stigma and discrimination. Stigma and discrimination forums run by PLNSW.**	**Oppose mandatory spitting laws, replace section 79 of Public Health Act 2010 on STI criminalisation more accessible and reprimandable process involved with complaints processes. Process where reports of experiences of stigma and discrimination are collected and implemented into a portfolio report.**	**Peak bodies and agencies representing PLHIV**
	23	Implement initiatives that assist people with, and at risk of, HIV to challenge stigma and build resilience	**H**	**Complaints processes within a peer support and patient advocacy framework Individual and group capacity building and training sessions on how to education, confront and address HIV stigma (along with racism, sexism, homo-phobia etc.)**	**Identity and focus on the qualities that contribute to building of resilience and improved links to peer support and peer navigation.**	**Organisations representing PLHIV**
	24	Maintain and develop peer support models appropriate for priority populations and maintain support for people with HIV as peer navigators in diagnosis, treatment and care	**H**	**Peer navigation programs across the jurisdictions, when suitably resources will be able to address system navigation and**	**Pathways to peer support embedded within current policies and procedures.**	**Policy and procedural design within each jurisdiction.**

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				service access barrier and retention in care and adherence problems for PLHIV		
	25	Monitor laws, policies, stigma and discrimination which impact on health-seeking behaviour among priority populations and their access to testing and services; and work to ameliorate legal, regulatory and policy barriers to an appropriate and evidence-based response	**H**	**In NSW – it's the NSW HIV and STI strategies implementation committee that investigate and monitor policy barriers**	**Under MACBVVS, convene a working group, with the Commonwealth AGs, to assess legislation and policies that stigmatise and criminalise PLHIV. A monitoring framework logically follow the implementation plan**	**Commonwealth (MACBVVS), relevant health departments**
	26	Review and address institutional, regulatory and system policies which create barriers to equality of prevention, testing, treatment and care and support for people with HIV and affected communities	**H**	**Dispensing and prescribe (universal access), co-payment waiver.**	**Increasing awareness and uptake of HIV testing by debunking healthcare perceptions of who is at risk of HIV. Incorporate within standardised practice for everyone who access STI testing to be offered a HIV test annually regardless of "risk profiles".**	**Relevant jurisdictional health departments, ASHM**
	27	Engage in dialogue with other government sectors to promote the use of up-to-date HIV-related science to improve policies affecting people with HIV and to discuss the impacts of wider public policy decisions on the health of priority populations	**L**	**Return on investment reports and cost for government when PLHIV are not receiving equitable standards of care**	**Using ACCESS, phylogenetic study, etc. Oppose mandatory spitting laws that would undermine scientific evidence of TasP.**	**National and international research institutions + strategy implementation committees**
<u>Data, surveillance, research and evaluation</u> Continue to build a strong evidence base for responding to HIV in Australia that is informed by high-quality, timely data and surveillance systems	28	Identify gaps in surveillance data for measuring and monitoring the implementation of this strategy and prioritise these for action	**H**	**Transmitted drug resistance, care and discharge data, PLHIV deaths and hospitalisations.**		
	29	Identify opportunities to improve the timeliness and consistency of data collection				
	30	Improve surveillance of issues impacting on people with HIV, including morbidity and mortality, stigma and discrimination, quality of life measures, the availability of new biomedical interventions and HIV drug resistance				
	31	Build on the existing strong evidence base to effectively inform the implementation of the priority actions of this strategy				
	32	Ensure current and future programs and activities are evaluated to ensure linkage and alignment to the priority areas of this strategy				
	33	Explore opportunities for assessing the impact of legislation and regulation on barriers to equal access to health care				
Would you like to provide any other comments? (Free text)						