PositiveLifeNSW
the voice of people with HIV since 1988

Nous Group
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Re: Feedback into the Australian Digital Health Agency's Digital Medicines Program Blueprint Project Discussion Paper

To Whom it May Concern,

Positive Life NSW (Positive Life) welcomes the opportunity to provide feedback into the Australian Digital Health Agency's (ADHA) Digital Medicines Program Blueprint Project Discussion Paper.

Positive Life is the 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. Our vision is that all PLHIV are able to live valued and meaningful lives, free from stigma and discrimination with the highest quality and access to health.

We commend the ADHA for their commitment to support improved access to information about medicines, their use and the monitoring and minimisation of risk and harm from medicines. We believe patient centrality is at the core of effectively implementing health strategies and improving health outcomes and systems for consumers. We applaud the ADHA for engaging the community and health consumers to shape the development of this action priority within the Australian National Digital Health Strategy (NDHS).

Rather than focusing on development strategies of the actions within the Medicines Program blueprint, our submission (found at Attachment A), will concentrate our feedback on representing the perspective of the patient journey as PLHIV. It will offer insight into how PLHIV as consumers use medicines and the diverse needs of PLHIV as they interface medicines through clinical and pharmacy environments.

I can be contacted on 0422 509 200 or at craigc@positivelife.org.au if additional information or clarification is required and we look forward to working with you to progress and implement the ADHA Digital Medicines Program.

Yours respectfully,

Craig Cooper
Chief Executive Officer

21 March 2019

ATTACHMENT A

Executive Summary: Positive Life NSW agrees that the NDHS and the associated Framework for Action has the capability to strongly benefit Australian PLHIV and contribute to improved medicine safety, clinical management, adherence and long-term health outcomes. However, the ways in which the NDHS is developed and implemented will determine the degree to which it is able to improve the health and safety of Australian PLHIV and minimise the risk of harm from prescription medications and polypharmacy adverse events.

Positive Life:

- Is not able to comment directly on how the Medicines Safety Program will be developed and implemented. This is outside our areas of expertise. However, we're able to provide the ADHA with information on the experience of PLHIV as they interface with clinicians and pharmacy and manage HIV and a range of other commonly experienced chronic health conditions. These experiences are described below.
- Supports any measures that improve health outcomes for PLHIV. We ask the ADHA to utilize the information provided when developing the Medicines Safety blueprint and ensure that PLHIV can maximise the efficacy of prescription medications safely and minimise the impacts of life-threatening drug interactions and adverse clinical events that often flow from polypharmacy and clinical miscommunication.
- Is prepared to provide further detailed information on any issue that affects the health and safety of PLHIV.

People Living with HIV (PLHIV) in New South Wales and Australia: At the end of 2018 there were approximately 28,000 people living with diagnosed HIV in Australia. Approximately 11,300 (40%) of these PLHIV reside in New South Wales (NSW).[1] A majority (78%) live in Sydney and the remainder live in rural and regional NSW. The population of PLHIV in NSW is increasing by about 300 per year, with a recent drop in new infections to 280 (2018).

HIV disease progression and transmission are effectively controlled by daily adherence to combination antiretroviral therapy (cART). A majority of PLHIV in NSW are prescribed cART and adherence to HIV treatments, achieving viral suppression and preventing onward transmission. As evidence by the 2018 HIV surveillance data where between 91% and 97% of all PLHIV in NSW were taking cART and between 89% and 97% were virologically supressed.[2] PLHIV are therefore reliant on continuous and unbroken access to cART and the relationship between PLHIV, HIV prescriber and pharmacy/pharmacist is central to individual treatment choices, remaining engaged in health, and more broadly contributing to the Australian public health / HIV disease control response.

The NSW population of PLHIV is diverse and includes gay men, bisexual men, heterosexual men and women, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse (CALD) backgrounds, trans and gender diverse people, people who inject drugs, people who are in custodial settings and people who are sex workers. Despite the efficacy of cART in achieving viral suppression and controlling HIV disease progression; HIV infection as a chronic and manageable condition remains a highly stigmatised condition. While gay men living with HIV experience HIV-associated stigma and discrimination, the impact of HIV stigma and discrimination is more pervasive and more acutely felt by PLHIV who are heterosexual, CALD, or of Aboriginal and Torres Strait Islander background, where there is less exposure and understanding of what it means to be living with HIV.

[1] James Jansson, David Wilson and Jo Watson, '*Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia*', 2010, p.19.
[2] Centre for Population Health, *'NSW HIV Surveillance Data Reports: Fourth Quarter and Annual Data Report 2018'*, 2019, p.42.

PLHIV, multimorbidity and prescription medicines: The association between ageing and increased rates of age-related chronic health conditions is a crucial factor impacting on the prescribing and dispensing of non-HIV medicines, and the health of PLHIV. The population of PLHIV is ageing and is estimated that by 2020, 44.3% of Australian PLHIV will be aged 55 years and 17% will be aged 65 years and older. Older PLHIV - particularly those diagnosed in the pre-cART era (prior to 1996) - experience high rates of multimorbidity, polypharmacy and a greater burden of disease than their non-HIV infected counterparts. Chronic health conditions associated with PLHIV include heart disease (arteriosclerosis, heat attack and stroke), metabolic disorders including diabetes, non-AIDs related cancers (particularly anal, vaginal, throat and neck cancers), liver and kidney disease, respiratory disease, mental health conditions and neurocognitive disorders.[3] These conditions require lifelong clinical monitoring and management with prescription medicines. For example, it would not be unusual for a 60-year-old male PLHIV to be prescribed multiple antiretroviral medications as well as medications for depression/anxiety, hypertension, dyslipidaemia, herpes zoster and peripheral neuropathy. We believe the digital medicines program will enable PLHIV with multimorbidities to have greater control of the medications they're taking, enhance safety and reduce the risk of polypharmacy and associated adverse events. The Digital Medicines Program Blueprint as a priority action will empower PLHIV to partner in their health with prescribers and dispenser of medicines.

PLHIV, polypharmacy, and limiting drug/drug interactions and adverse events: The association between PLHIV, clinicians and pharmacy are important factors in determining both short-term and long-term health outcomes. PLHIV frequently access multiple clinicians and multiple pharmacies. For example, the clinical management of HIV and prescribing of cART is restricted to specialist clinicians (s100 prescribers). PLHIV attend these specialist prescribers to monitor the effectiveness of cART and to renew cART prescriptions. They also attend GPs to monitor non-HIV health conditions and to renew prescriptions. In some cases, the GP is also an s100 prescriber and this permits monitoring and prescribing for both HIV and non-HIV conditions. This is not always possible however, due to the limited availability of a GP/s100 prescribers. If there are no GP/s100 prescribers, PLHIV will need to attend an s100 prescriber for HIV clinical management and a GP for the management of other chronic health conditions. This creates a communication gap and the potential for drug interactions and adverse events due to multiple prescribers not being aware of the patient's pharmaceutical history.

The separation of GP and s100 prescriber is also used by some PLHIV (heterosexual, CALD, Aboriginal and Torres Strait Islander) specifically to limit HIV disclosure and the possibility that an HIV diagnosis may become known within their community. This is particularly the case for PLHIV who live in rural and regional communities where PLHIV are isolated and stigmatised. For example, we know PLHIV in regional and rural NSW who have needed to locate to another area of NSW because disclosure of their HIV status by non-clinical staff in medical centres or in a pharmacy has resulted in them being discriminated against and rejected by their community.

The prescribing of new medications by different clinicians therefore substantially increases the risk of drug to drug interactions and adverse events. The introduction of electronic prescribing would enable all prescribers involved in the health care of PLHIV to have access and knowledge of the PLHIV's list of current medications. This would result in a minimisation of risk and potential harm from contraindicated medications. Real-time prescription monitoring would additionally enable prescribers to monitor adherence to cART and other non-ART medications and be aware when PLHIV were no longer adherent. In addition, hospital staff would also have access to the list of prescribed medications during hospital admissions. This would prevent further adverse medical events.

Dispensing of cART and non-ART medicines in different pharmacies (hospital, community etc.) further adds to a potential risk for drug interactions and adverse events. Were electronic dispensing

[3] Lance Feeney, *'People living with HIV and access to health care in NSW – a community survey',* 2015, P 3.

and real-time prescription monitoring available, pharmacists would be better able to identify potential drug to drug interactions at the point of supply and reduce the potential risk of adverse events.

While these benefits are uncontested, it must be acknowledged that some PLHIV will be fearful of non-clinical staff (particularly pharmacy sales staff and administration staff in medical clinics) having access to PBS dispensing history and by association, diagnosed medical conditions. The fear of disclosure may result in some PLHIV disengaging from treatment and healthcare and would have serious and life-threatening consequences.

Conclusion: Positive Life's position is that we support the implementation of Digital Medicines Blueprint project and actions outlined in NDHS and the associated Framework for Action and its capability to strongly benefit health outcomes for all Australians. We believe these advancements will contribute to improved medicine safety for health consumers, a higher standard of clinical management, increase adherence, minimise risk of harm and result in better long-term health outcomes. For PLHIV, this will result in more efficient medication safety that minimises the impacts of life-threatening drug interactions as well as less adverse clinical events from polypharmacy and clinical miscommunication. Positive Life believes that patient centrality must be incorporated in the foundation of the development and implementation of the NDHS to successfully meet these outcomes. To ensure we remain engaged with our healthcare, PLHIV also need to continue to have patient control over privacy and security of their health information in respectful partnership with prescribers and dispensers. We urge the ADHA to apply the information provided when developing the Digital Medicines Safety blueprint and ensure that the needs PLHIV in NSW are met.