

A high-angle, blurred photograph of a crowd of people walking on a paved surface, overlaid with a semi-transparent blue filter. The motion blur suggests a busy, active environment.

# People living with HIV (PLHIV) and Digital Health

*A New Era*

*Craig Cooper CEO*

*28 November 2018*

**PositiveLifeNSW**  
the voice of people with HIV since 1988

# Acknowledgement

- *Traditional Custodians of the Land*
- *PLHIV, Community and Health Consumer Elders and Leaders*
- *Australian Digital Health Agency and Health Consumers NSW*





# Positive Life NSW

*Who we are:*

- *Positive Life NSW (Positive Life) is the public face and voice of all people living with HIV (PLHIV) in NSW*
- *We're a peer-based organisation that works to promote a positive image of PLHIV, with the aim of eliminating prejudice, isolation, stigma and discrimination*
- *We collaborate with HIV specialist and NSW Health services to improve the health and quality of life of PLHIV, and facilitate greater involvement of PLHIV in the NSW HIV response*



# Positive Life NSW

*What we do:*

- **Peer support**, such as, HIV treatments advice and patient advocacy, housing support, return to employment, community events (social inclusion programs)
- **Health promotion** and social media, such as, regional and rural outreach, resources/factsheets
- **HIV health policy**, including **representation** with health service partners and researchers, **systemic advocacy**, Poz Action
- **Positive Speakers Bureau** (HIV public awareness aimed at combating stigma and discrimination)
- **Capacity building**, including education and training, community engagement forums, conference presentations





# Agenda

- *The My Health Record (MyHR) Partnership*
- *What has Evolved for PLHIV, Health Consumers and the NSW Health System*
- *MyHR Enablement and Adoption for PLHIV and other Health Consumers in NSW*

## **Concerns addressed through engagement:**

- *explicit, informed consent and your health data*
- *ownership and control of your health data, secondary use of data framework*
- *highly sensitive health information when shared*

A photograph of a young man with dark hair, wearing a light blue V-neck t-shirt and dark jeans, sitting on a wooden bench. He is smiling and looking towards the camera. The background consists of green foliage and a grey wall. A semi-transparent blue overlay covers the entire image, and a white text box with a thin blue border is centered over the man's torso.

# The My Health Record Partnership





## Positive Life NSW

- *Submissions and participation in community forums concerning PCEHR, MyHR and the Secondary Use of MyHR Data*
- *Ran a Community Consultation and Engagement Forum in March 2018 for PLHIV to listen to what people thought about MyHR, the management of health information (data sovereignty and ownership) and digital health in NSW*
- *The Forum feedback from PLHIV resulted in: a blueprint for agency submissions and communications program; and our stakeholder relations approach with Health Consumers NSW, the Australian Digital Health Agency, Commonwealth Department of Health, NAPWHA and the Australian Institute of Health and Welfare*

# What PLHIV Said

*MyHR is critical for some PLHIV as it will:*

- *Reduce waiting times for test results and prevent duplicate tests and treatments*
- *Improve PLHIV ownership of and access to their health information and enable people to fully participate in their healthcare coordination*
- *Reduce the risk of adverse events and ensure health service providers have the information they need so people are treated in a responsive and timely way. E.G. admissions to Emergency Departments, advanced care directives etc.*







# What has Evolved for PLHIV

- *Two Community Information Forums (Sydney and Parramatta)*
- *Digital and Print Communications to PLHIV and other Health Consumers (Facebook, electronic communications, letters sent to consumers, Factsheets, MyHR Briefing Paper etc.)*
- *Australasian HIV Conference in Sydney Panel Discussion*
- *Numerous presentations to health service providers and health consumers (NSW and ACT)*
- *Facilitated contact and increased networks between ADHA and other sector partners*

# MyHR Enablement and Adoption

*Continued communication and engagement with PLHIV about:*

- *the MyHR Opt-Out period*
- *changes to the legislation and the implications for health consumers*
- *the implementation of the MyHR Secondary Data framework by the AIHW*

*Deliver a series of MyHR access and navigation workshops, aim at improving PLHIV digital health literacy and confidence in managing their MyHR*

*Explore the feasibility of MyHR (health information) health consumer data governance and sovereignty (ownership)*





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*Trust in the health system and government is critical for PLHIV to remain engaged in health.*

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Positive Life NSW works to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination.

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