

# PLHIV & MY HEALTH RECORD

*'If in doubt, OPT OUT!'*



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

*The contract we have with our doctors is confidential and non-judgemental. The MHR places this sacred relationship at risk.”*

*- Craig Cooper*

## WHAT IS MY HEALTH RECORD?

- My Health Record (MHR) is a national electronic record system that centralises all health information for all Australians, including people living with HIV (PLHIV). By 2019 everyone will be automatically signed up to a MHR.
- Your MHR can include your prescriptions, your medical conditions, allergies, blood test results, x-ray reports, information from the Medicare Benefits Scheme (MBS) or Pharmaceutical Benefits Scheme (PBS) items. It can also hold documents uploaded by your healthcare providers like specialists' referral letters and hospitals discharge summaries.

## WHAT DOES THIS MEAN FOR PLHIV?

- The **'primary use'** of the MHR will be beneficial for some PLHIV. It will improve the coordination and accessibility of your healthcare and ensure everyone has the information they need to treat you.
- It is the **'secondary use'** of the MHR that is of significant concern to Positive Life. The information you allow on your MHR will be accessible to agencies such as law enforcement, clinical trials, insurance companies and even commercial entities such as app developers **without your explicit consent**. This poses considerable risks to all PLHIV.
- Some examples of 'Secondary use' of MHR with or without your explicit consent include linking your health data across systems and passing information to law enforcement even when there is no evidence of a crime ('fishing expeditions'); accessing your health data by insurers in the case of vehicle accident claims and to set insurance premiums; in the preparation of legal proceedings before any court or tribunal; benign or active surveillance of individuals or populations; and marketing for clinical trials and research.
- Positive Life has concerns about the impacts of stigma, privacy and potential legal impacts or criminalisation of PLHIV with any secondary use of the MHR.



**Keep your private health data, safe and secure.**

**If you have any concerns, opt-out of the MHR until your concerns are allayed. If in doubt, opt out!**

### **WE SUGGEST THESE PLHIV OPT-OUT OF MHR**

- PLHIV who are sex workers
- PLHIV who currently or have used drugs and alcohol (licit and illicit)
- PLHIV with less than two diagnoses and see only one or two doctors
- PLHIV who live with a criminal history or are involved with the criminal justice system
- PLHIV who are sexually active and non-monogamous, polyamorous or single
- PLHIV who receive a sexually transmitted infection (STI) diagnosis and treatment every six to twelve months and are not taking reasonable precautions.

### **RISKS AND IMPACTS**

The risks to PLHIV with a MHR includes

- access and use of your private data by law enforcement even without evidence of a crime
- decrease in confidentiality between PLHIV and their doctors
- secondary use of your MHR by researchers and commercialisation of your health data
- breach of privacy without explicit and informed consent

### **NEXT STEPS**

- You will be able to Opt-Out of the MHR between **16 July 2018 to 31 January 2019**. Positive Life offers a step-by-step factsheet on how to opt-out or [click here to visit this website to Opt-Out online](#).
- For PLHIV living in the Nepean Blue Mountains area who have already been signed up to the MHR and cannot opt-out, Positive Life offers a step-by-step factsheet on how to cancel, restrict or modify your record.
- For people living with HAND or with limited access to a computer, Positive Life staff will be available to assist you in this process to opt-out.
- If you need further support or have more questions about the secondary use of MHR data **you can contact Positive Life on (02) 9206-2177**.
- If you decide to stay in the MHR system, know how to control access to your information.

### **PLHIV WHO COULD BENEFIT**

- those who live with three or more diagnoses and/or see more than two doctors
- who self-manage their own care across generalist and specialist health care providers
- who are 55 years and older and/or have multiple hospitalisations
- who do not have a current or previous drug or alcohol history
- who are not sexually active or are in a monogamous relationship and able to maintain viral suppression (UVL)
- who are living with mental health concerns and diagnoses such as HAND, memory and comprehension problems
- are highly mobile (eg fly-in/ fly-out workers)
- who take reasonable precautions consistently (condoms, disclosure and negotiation)
- those who have an enduring guardianship or advanced care directives

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### **MORE INFORMATION**

[www.positivelife.org.au](http://www.positivelife.org.au)

free call 1800 245 677



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

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