

People living with HIV (PLHIV) and Digital Health

Digital Health and PLHIV = A New Frontier

Saturday 21 April 2018

PositiveLifeNSW
the voice of people with HIV since 1988

What's Ahead?

Setting the Scene:

- what is My Health Record?
- primary use of the My Health Record
- secondary use of the My Health Record
- risks and possible impacts for PLHIV

Positive Life concerns:

- explicit, informed consent and your health data
- ownership and control of your health data
- highly sensitive health information when shared
- commercialised, offshore and private entities

Summary

Recommendations

Discussion

A photograph of a young man with short dark hair, wearing a light blue t-shirt and dark jeans, sitting on a wooden bench outdoors. He is smiling and looking towards the camera. The background consists of green foliage and a grey wall. A semi-transparent blue box is overlaid on the image, containing the text "What is My Health Record?".

What is My Health Record?

What is My Health Record?

My Health Record is a national electronic record system that centralises all the health information for all Australians, including PLHIV in the one place.

- By the end of 2018 the Australian Digital Health Agency (the Agency) will create a My Health Record for everyone.
- For **some PLHIV** this might be useful. It will improve health outcomes and reduce waiting times and inefficiency (pathology, polypharmacy etc.).
- Your My Health Record can include your prescriptions, your medical conditions, allergies, test results (like pathology results, blood tests or x-ray reports), information from MBS or PBS items and Medicare (like the last time you went to see your doctor). It can also hold documents uploaded by your GP (like referral letters to specialists) and hospitals can upload discharge summaries and follow-up care information.
- This is what is known as **‘primary use’** of your My Health Record.

‘Primary Uses’ of your My Health Record

- The ‘primary use’ of the My Health Record will be critical for some PLHIV
- It will reduce waiting times for test results and prevent duplicated tests and treatments
- It will improve the coordination of healthcare to PLHIV and it will improve the quality and availability of your healthcare
- Your My Health Record will have records from Medicare (PBS and MBS) from the previous **two years** migrated into the record, as the record is set up
- It is likely to reduce the incidence of adverse medical events and ensure everyone has the information they need to treat you in a responsive and timely way

PLHIV who could benefit from My Health Record

People:

- living with three or more diagnosis, seeing more than two doctors and that need to manage their own care coordination across generalise and specialist care providers
- who are ageing (55 years and older) and/or people who have multiple hospitalisations
- who do not have current or previous drug and alcohol use, illicit substance use, iatrogenic dependency
- who are not sexually active or are in a monogamous relationship and able to maintain viral suppression
- living with mental health concerns and diagnosis (HAND, memory and comprehension problems)
- who are highly mobile for example fly in/fly out workers
- who take reasonable precautions (use condoms, disclosure and negotiation)

‘Secondary Uses’ of the My Health Record

The primary benefits of the My Health Record is likely to be undermined by the use of personal health data for any secondary purposes.

Some examples of the ‘any secondary purposes’, with or without the consent of the individual record holder include:

- benign or active surveillance of individuals or populations
- linking health data across systems and passing information to law enforcement authorities
- accessing your health data by insurers in the case of vehicle accident claims
- accessing your health data to set insurance premiums
- accessing your health data in the preparation of legal proceedings before any court or tribunal
- marketing for clinical trials and research

Risks and Impacts for PLHIV

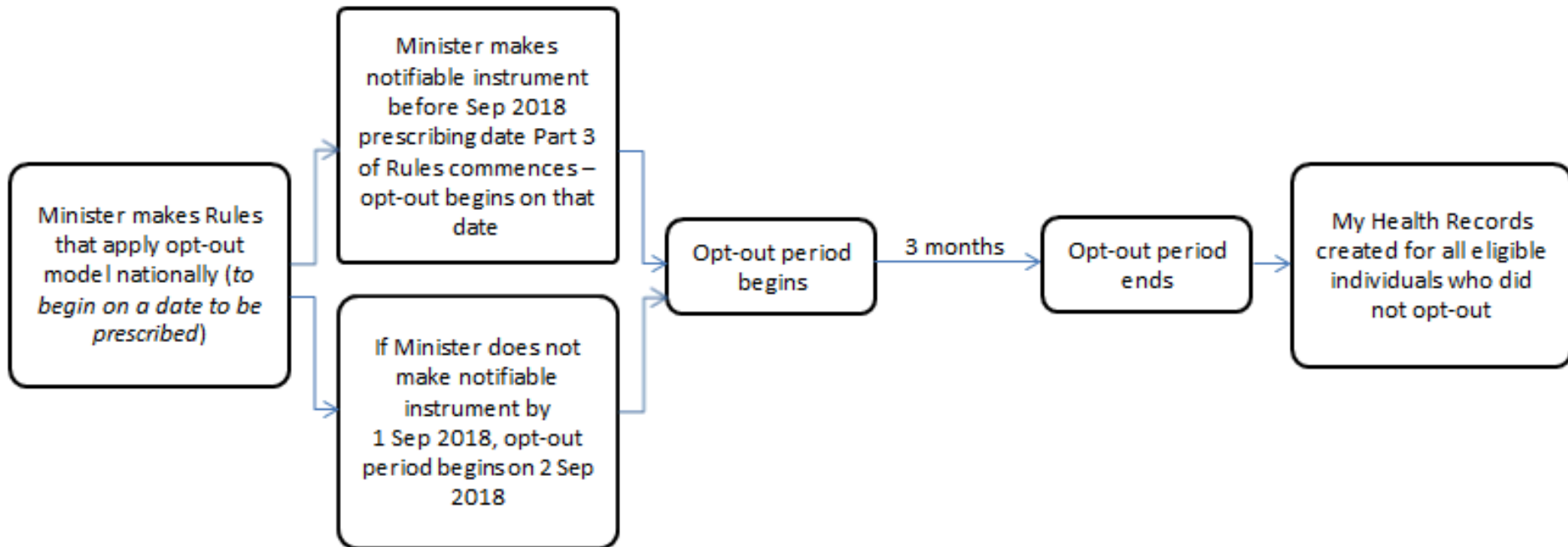
- My Health Record can pose significant risk to PLHIV such as people who are sex workers, people who use drugs (licit and illicit), women living with HIV, immigrants and refugees living with HIV
- For these PLHIV, personal and sensitive health data will become available for 'secondary uses' at any stage
- Positive Life has concerns about the impacts of stigma, privacy, and potential legal impacts or criminalisation of PLHIV with any 'secondary use' of the My Health Record

PLHIV who we suggest 'Opt-Out' from My Health Record

People:

- living with two or fewer diagnosis, only seeing one or two doctors and who can manage their own care coordination across generalise and specialist care providers
- who currently or have previously used drugs and alcohol (licit and illicit substance use), iatrogenic dependency
- involved in sex work
- living with a criminal history or involved with the criminal justice system
- who are sexually active and that are non-monogamous, polyamorous and single
- who receive a sexually transmitted infection diagnosis and treatment every six to twelve months

'Opt-out' Sequence and Timing



Explicit, Informed Consent and My Health Record

Positive Life takes the position that all health data, whether identified or unidentified must have explicit and informed consent.

At the present time:

- there is **no explicit consent** for use and disclosure of health data in the My Health Record framework
- the starting default setting of each record **is set to 'open'**
- your healthcare providers will upload health information about you **UNLESS** you have specifically asked your provider NOT to upload a particular document
- the range of providers who have access to your information is **extremely broad** (includes physiotherapists, counsellors, dentists), and includes contractors who provide services to your doctors and the Australian Digital Health Agency, like IT companies for example

Ownership and Control of My Health Record

Positive Life takes the position that your health data remains permanently owned by you and under your authority or control (your data sovereignty).

At the present time:

- there are a number of situations where your health information can be disclosed **without your knowledge or control**
- research and commercial priorities take precedence **over the interests of health consumers**
- there is **no ‘oversight’ or independent accountability framework** protecting the interests of health consumers
- there is **no public register detailing organisations or individual requests** including purpose, nature and status of data for ‘secondary use’

Highly sensitive health information and My Health Record

Positive Life believes the access to and sharing of highly sensitive PLHIV health information by government and private entities is of great concern.

At the present time:

- information can be passed to authorities to aid an investigation even with **no evidence** of a crime
- information can be passed to authorities if it **is suspected** a crime has been committed
- ‘secondary use’ of your health data is **very broad** and includes direct marketing by commercial entities
- if you share information with your doctor in a confidential setting to get treatment (e.g., for drug use) even if your doctor has no intention to report your use, **authorities will have access to this information**
- computer programs can make decisions with the full authorisation **as if they were decisions made by a human being** e.g., Robocalls and Centrelink debts

PLHIV and the My Health Record

Positive Life takes the positions:

- each individual health record should start with the **highest restrictive privacy setting** level. Even at the highest level of restriction that has been set previously, every document that is uploaded is automatically set to 'open'
- all PLHIV must be **fully informed** what personal health information could become available to researchers and other third parties
- people must be able to **completely delete sections** of our own record if we wish. The "effective delete" removes files from view but is forever on the system linked to your account. Questions remain as to the retrievable/viewable nature of the file depending on who logs in and views the account
- people be **notified every time any part of our health data** is passed on or linked for research or commercial interests

Recommendations

If you share any of these concerns, Positive Life is suggesting PLHIV opt-out of My Health Record until your concerns are allayed.

- By **June 2018** Positive Life will provide a step-by-step resource on **how to opt-out**
- For people living in the Nepean Blue Mountains area who have already been signed up to the My Health Record and cannot opt-out, Positive Life will be offering step-by-step resource on **how you can 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**



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

The government is yet to prioritise HIV criminalisation, therefore ‘Opting-Out’ of My Health Record is crucial for some PLHIV so HIV criminalisation doesn’t become a reality.



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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