

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*

Concerns:

- *explicit, informed consent and your health data*
- *ownership and control of your health data*
- *highly sensitive health information when shared*
- *risks and possible impacts for PLHIV*
- *secondary use of the My Health Record*

Summary

Recommendations

Discussion

A young man with short dark hair, wearing a light blue t-shirt and dark jeans, is 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 with a white border 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 health information for Australians, including PLHIV in the one system

- *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.), particularly those with multi-morbidities, complex care needs and shared care arrangements*
- *Your My Health Record can include your prescriptions, your medical conditions, allergies, test results (pathology results, blood tests or x-ray reports), information from MBS or PBS items and Medicare (the last time you went to see your doctor). It can also hold documents uploaded by your GP (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 (multimorbidity and polypharmacy) and it will improve the quality 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, when considering comprehensive and integrated care arrangements*

PLHIV who could benefit from My Health Record

People:

- *living with three or more diagnoses, seeing more than two doctors and who need to manage their own care coordination across generalist and specialist care providers*
- *who are ageing or who have had multiple hospitalisations*
- *who do not have current or previous drug and alcohol use, illicit substance use*
- *who are not sexually active or are in a monogamous relationship and able to maintain viral suppression and take reasonable precautions (use condoms, disclosure, PrEP, TasP)*
- *living with mental health concerns and diagnosis (HAND, memory and comprehension problems)*
- *residing, working and receiving health care in a number of states and territories (mobile people and populations)*
- *undiagnosed with HIV*

Risks and Impacts for PLHIV

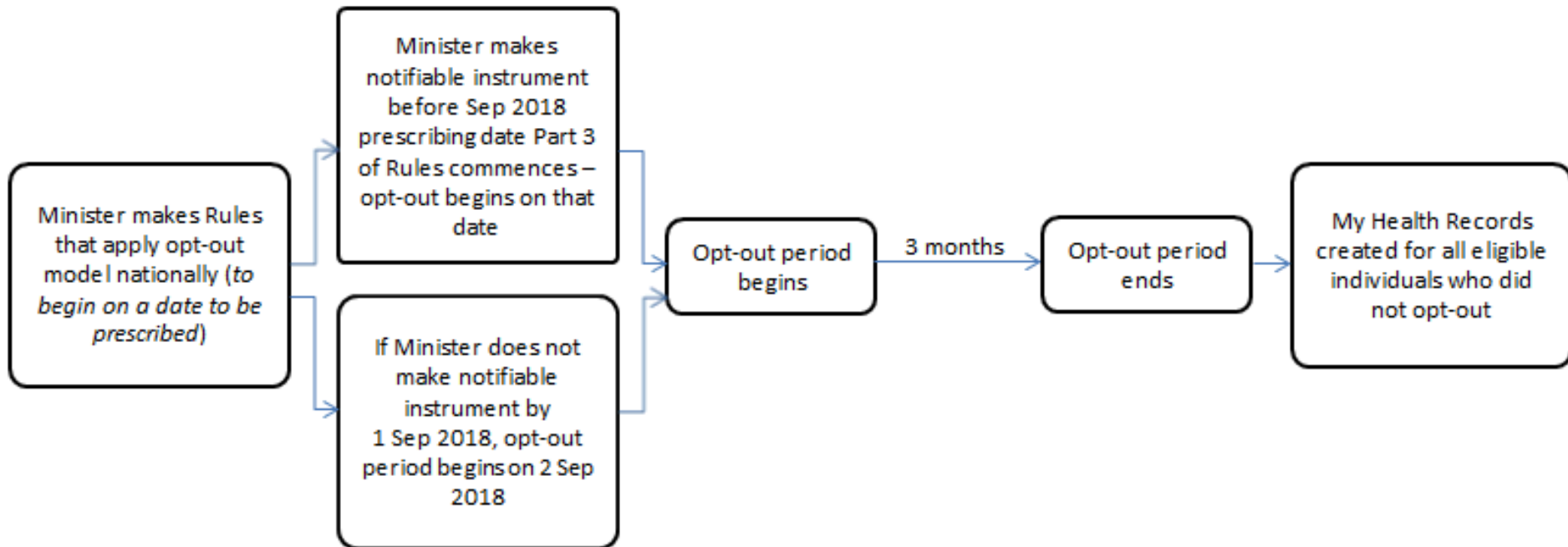
- *Are the impacts of stigma, privacy and potential criminalisation of PLHIV worth remaining in My Health Record?*
- *My Health Record can pose significant risk to PLHIV such as people who are sex workers, people who use drugs (licit and illicit), women living with HIV, immigrants and refugees living with HIV*
- *For these PLHIV, personal and sensitive health data could be available to healthcare workers other than their clinicians (clinic reception staff, administration etc.), such as small rural communities*

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 manage their own care coordination across generalist and specialist care providers*
- *who currently or have previously used drugs and alcohol (licit and illicit substance use)*
- *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 or single and are not practicing reasonable precautions (condom use, PrEP, cART etc.)*
- *who receive a sexually transmitted infection diagnosis and treatment every six to twelve months and remain sexually active*

'Opt-out' Sequence and Timing



Explicit, Informed Consent and My Health Record

All health data, whether identified or de-identified must have explicit and informed consent

At the present time:

- *If people do not opt-out it is assumed that consent to be registered is given for a health record and that they have given consent to have their health data gathered and made available to health professionals involved in their treatment and care*
- *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 **broad** (includes physiotherapists, counsellors, dentists), and includes contractors who provide services to your doctors and the Australian Digital Health Agency, for example IT companies*

Ownership and Control of My Health Record

Your health data needs to be 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***
- *The release of information and data for the public good and research takes precedence **over the interests and rights of health consumers***
- *The **oversight, accountability and governance** within the secondary Framework to guide the secondary use of My Health Record system is devolved to 'The Board', rather than data protection legislation*

Sensitive health information and My Health Record

Access to and the sharing of highly sensitive PLHIV health information by government and private entities is of 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*
- *opting out of the ‘secondary use’ of My Health Record data is insufficient and fails to address the requirement of informed consent for health consumers and ensure **patient ownership and control** of system data is central (**trust**)*
- *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***

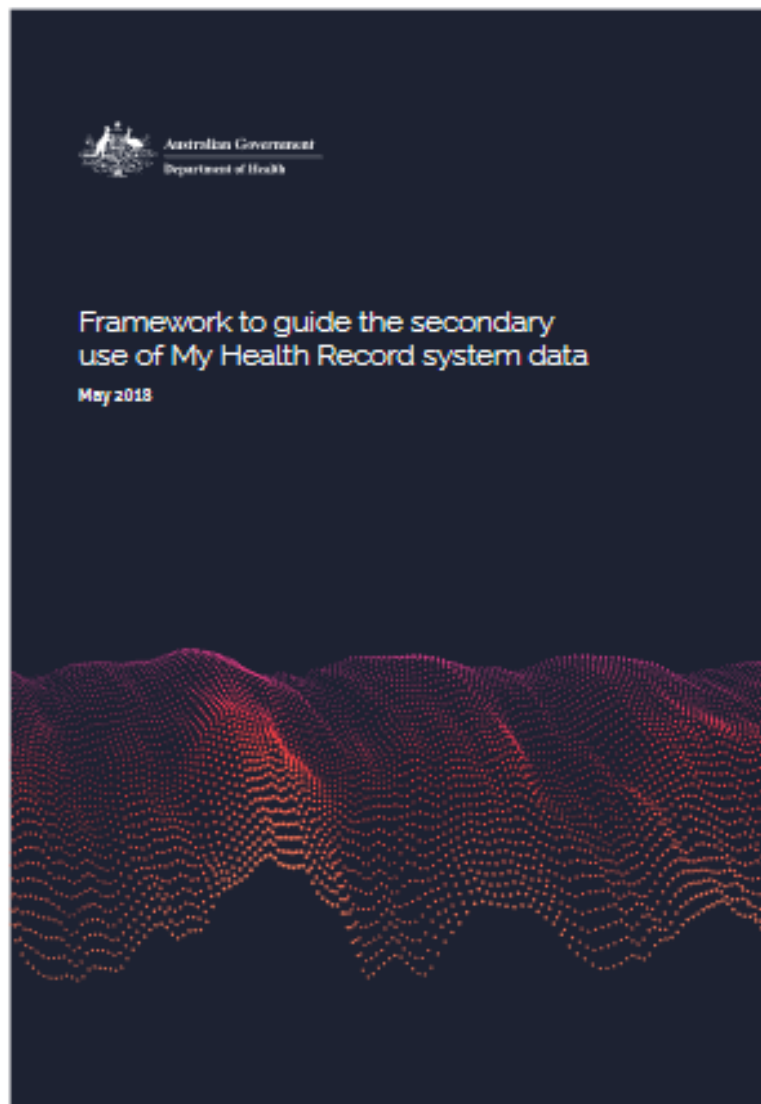
‘Secondary Uses’ of the My Health Record

There’s a risk that the primary benefit of the My Health Record will be undermined by the use of system data for secondary purposes

Some examples of the ‘any secondary purposes’ include:

- *surveillance of individuals or populations*
- *linking health data across systems and passing information to law enforcement authorities such as in preparation of legal proceedings before any court or tribunal*
- *benign or active surveillance of individuals or populations, with or without the consent of the individual record holder*
- *clinical trials and research*

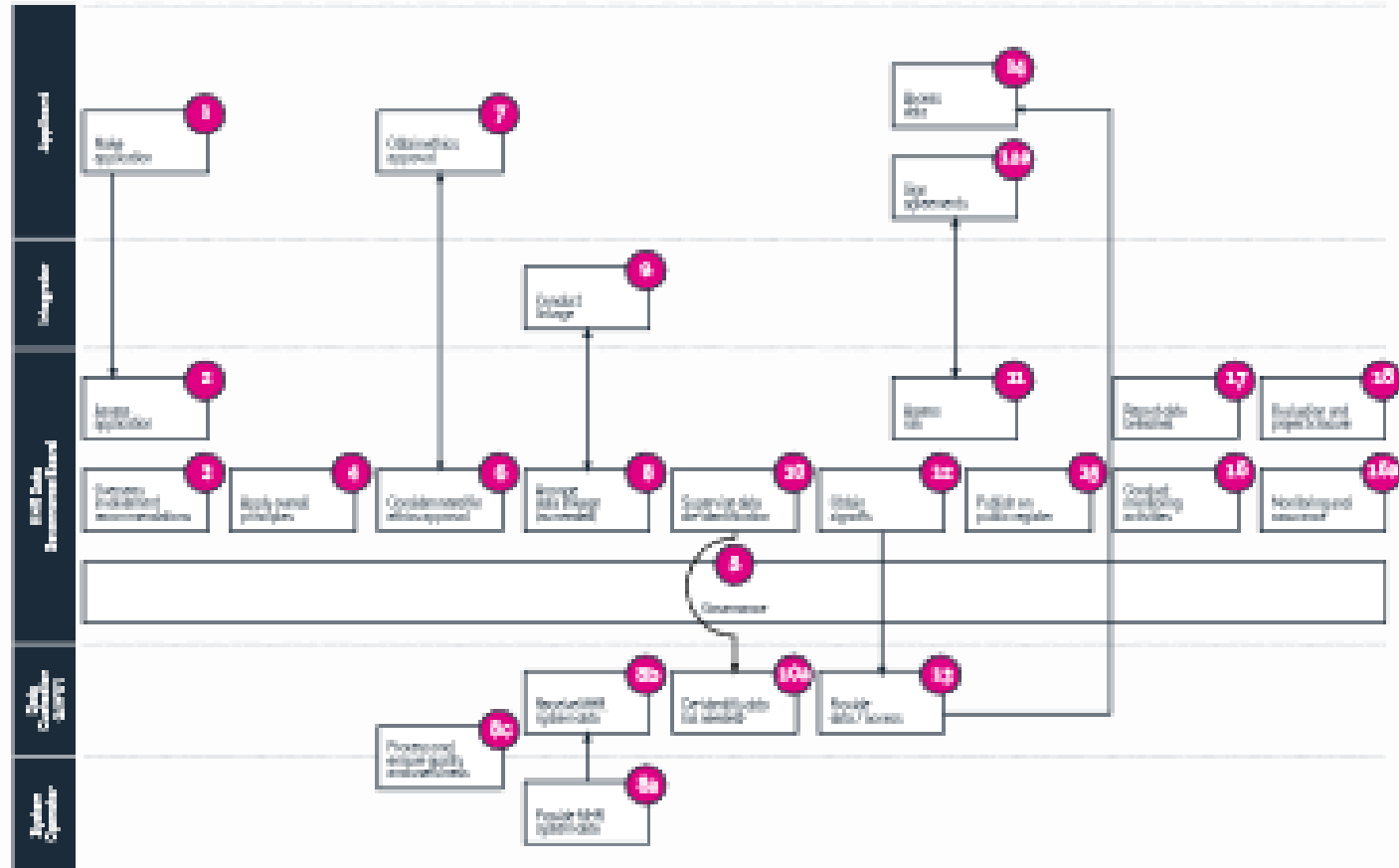
Secondary Use of My Health Record Data Framework



Secondary Use Processes and Responsible Parties

Research to guide the secondary use of HIV research data | May 2024

Figure 1: Processes and responsible organisations/parties



PLHIV and My Health Record

- *each individual health record needs to 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 and consent gained** before personal health information is made available in the interest of public health and to researchers and other parties*
- *people must be able to **completely delete sections** of their our own record if they 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, such as, police, courts or tribunals*
- *people be **notified every time any part of our health data** is passed on or linked for research*

Recommendations and Support

If PLHIV have concerns about My Health Record risks, we recommend they opt-out until doubts are allayed or changes made to the legislation and system

- *The Australian Digital Health Agency (the Agency) has announced the My Health Record (MHR) three month opt-out period is from the **16 July 2018 to 15 October 2018***
- *Positive Life is producing resources 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 or those already signed up, resources are in development on **how you can cancel, restrict or modify your record***
- *For people living with HAND or with limited access to a computer, peer support staff are available to **assist you in the 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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