



# Best Laid Plans: Community concerns about HIV Molecular Testing

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# Criminalization

HIV is criminalized in Australia

There are various laws across Australia which criminalise HIV in some way

In particular; the criminal laws of the States and Territories have been used to successfully prosecute and imprison people for intentional or reckless HIV transmission (e.g. causing grievous bodily harm)

Generally, the ingredients of such a charge are evidence of intention (or recklessness) + evidence of HIV transmission from one person to another + a willingness to prosecute

‘Intention’ is complex

Involvement of the criminal law (especially in health issues) always makes everything worse for everybody: ‘victim’, ‘perpetrator’, society and everyone with HIV.



# Phylogenetic analysis (as evidence)

Can establish relationships between HIV viruses (and so between people)

Can infer transmission patterns

Large datasets are being created that hold vast amounts of data (samples from people's bodies) at various points over time.

Direction of transmission within clusters can be inferred (Coltart & Hoppe et. al. 2018)

Is STILL used as evidence – even after statements that it is not scientifically definitive

Research centres and governments generally want to share data, match data and find new uses for existing data to maximise knowledge and benefit of HIV research

# Willingness to use data to prosecute

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## ACT police illegally accessed metadata thousands of times more than previously thought

By Jordan Hayne

Updated 26 Jul 2019, 4:09pm

ACT Policing has revealed its officers attempted to access stored metadata without authorisation more than 3,000 times, due to issues dating back to 2015.

Earlier this week it emerged that the Commonwealth Ombudsman had reported on 116 instances from 2015 in which ACT police officers accessed metadata without the authorisation to do so, because the person signing off on the access did not have the authorisation to do so.

But while re-examining the 116 authorisations, police uncovered a further 3,249 instances where data requests had been made, which were subject to the same authorisation problem.



PHOTO: Police did not have proper authorisation to access metadata in 3,249 instances. (ABC Newcastle: Robert Virtue)

RELATED STORY: 'Administrative oversight': ACT top cop defends more than 100 unauthorised accesses of metadata

## Tasmania Police accessed metadata 29,000 times since new data retention laws

Lachlan Bennett

National

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Tasmania Police Deputy Commissioner Scott Tilyard. Picture: Loretta Johnston.

Tasmania Police has accessed metadata more than 29,000 times since the introduction of the controversial data retention laws in 2015.

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## Home affairs unlawfully accessed public's stored metadata, ombudsman reveals

Report by Commonwealth Ombudsman shows that while unlawful access by departments has reduced, errors are still occurring



▲ The Department of Home Affairs has been criticised by the ombudsman for unlawfully accessing private

## 'Lack of awareness': WA Police scooped journalist metadata without warrant, report reveals

By Nathan Hendros  
July 24, 2019 - 5:05pm



WA Police have collected the metadata of at least one journalist without a valid warrant, a Commonwealth Ombudsman report has revealed.

f T A A A



A Commonwealth Ombudsman's report has revealed WA Police had twice obtained the metadata of at least one

# Data Insecurity say



By James Griffiths, CNN

Updated 0326 GMT (1126 HKT) January 29, 2019



A man pins an HIV awareness ribbon to his shirt. The HIV-positive status of thousands of people was leaked from a Singaporean database this month.

**itnews** This is Enterprise, reimagined. *Yes*

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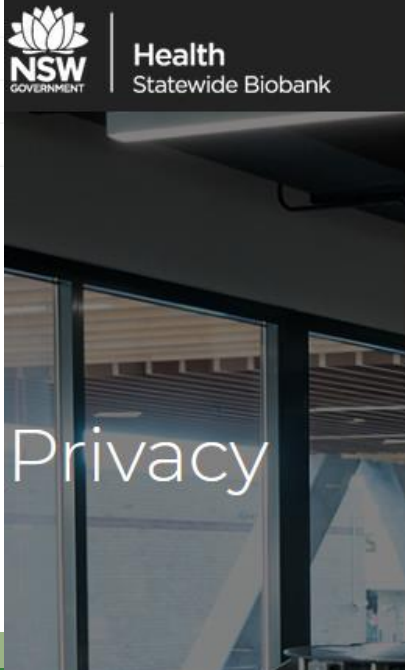
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## Data breaches rise in My Health Record system

By Staff Writers

Numbers up year-on-year.



ing the My Health  
the past financial year,

y (ADHA) said in its  
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office of the Australian



## Australians' Medicare details illegally sold on darknet - two years after breach exposed

Medicare Madness listing suggests details 'of any living Australian citizen' have been available since September 2018



The vendor Medicare Machine is offering Medicare details illegally on the darknet for \$US21. Photograph: AAP

## Singapore HIV data leak shakes a vulnerable community

By Sharanjit Leyl  
BBC News, Singapore

22 February 2019

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# De-identification, stigma & small cohorts

Next-Generation Sequencing makes “true anonymisation difficult” (Coltart & Hoppe et. al. 2018)

“A virus sequenced from an individual could be used in principle to relink that individual to an earlier study with high reliability” (Coltart & Hoppe et. al. 2018)

Storage of phylogenetic information should be de-identified so as to prevent misuses of data

Re-identification of test subjects for contact tracing purposes isn't something that should happen until HIV has been decriminalised.

Stigmatisation of particular marginalised groups is a risk. Mitigation plans to address these risks should be in place.

# Informed Consent

Concerns that informed consent is not always present or current

Basic ethical responsibility that on the collectors of information to:

- inform people about what they are collecting and how they are storing it,
- what they are using the data for,
- to give people the opportunity to make an informed decision to participate or not
- and to provide the ability to withdraw and delete information

We need to re-consider re-consenting people as new threats arise or things change

Traditional epidemiological studies allow people to filter what information to give. Molecular testing means that, after you consent to the initial test all your secrets, written into the evolutionary history of your virus, can be revealed for ever more.

Information is not benign

# Surveillance (& perceptions of)

## ATO Wants To Access Your Metadata For Investigations

Sarah Basford  
Sep 13, 2019, 12:45pm - Filed to: ato

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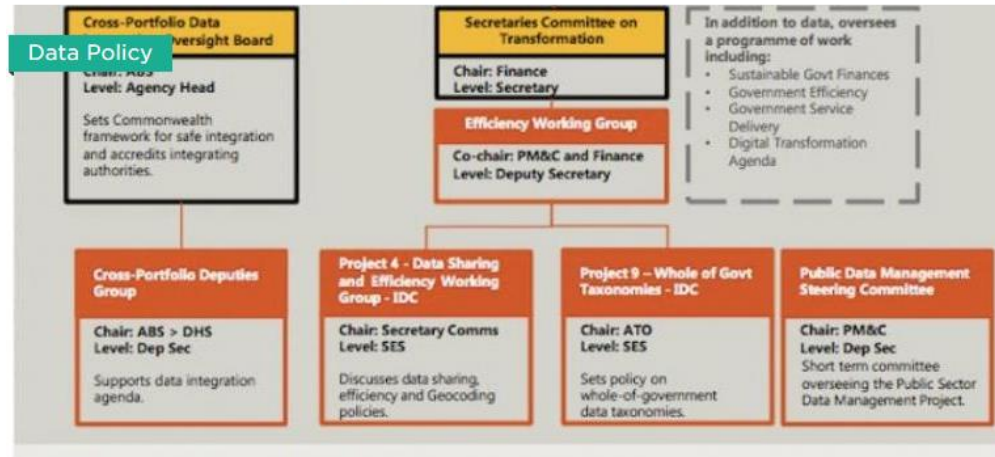


Image: Getty Images

The Australian Tax Office (ATO) has made no secret its after access to Australian's metadata in order to investigate tax evasion in the country. It comes after the tax agency was excluded from warrant-free access with the 2015 metadata retention laws.

ROSIE WILLIAMS | SEPTEMBER 4, 2019

## Govt is coming for your data





# Community oversight and trust

Denver Principles: 'nothing about us without us'

Communities not always engaged

Community engagement in the planning and oversight of research or information collection systems that affect them is important – it must be meaningful

We have to be able to give clear explanations and assurances to combat false narratives

Earlier the engagement better

If we run ahead with large scale molecular information collection without bringing community along we risk losing community trust - testing rates could drop

# Is it worth it?

Has the case been made?

By identifying resistant HIV strains we could better optimise targeted treatments

By understanding how HIV is moving around the world and through populations we might be able to target better prevention interventions

Perhaps identify risk factors?

Traditional epidemiology might be just as effective without the equivalent risk of prosecution, persecution and stigmatisation.

Why do we need to know this information? Because it's fascinating or because we can or because future benefits might emerge are not enough to justify the risk – we need clear benefits.

# Making molecular testing safer

## Community engagement and oversight

Storage and sharing of data should be restricted to the minimum amount necessary to achieve the initial purpose of the data.

Redress mechanisms should be in place to respond if someone's data is misused

Information that can identify certain communities should be coded

Links to legal services that work with PLHIV or other stigmatised and criminalised communities should already be in place to ensure people can protect their rights if data is misused or gets into the wrong hands

Data must be de-identified and people must be able to withdraw and delete data

Clinicians and researchers should engage with HIV criminalisation and take public positions and use influence to end it

Monitoring and policy should be in place to identify adverse consequences and to respond to them

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# Acknowledgements

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