UNSW
Centre for Social
Research in Health

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# Setting the scene:

## Key data studies terminology

# Why focus on data?

- Data are central to HIV responses
- Who gets counted? (and who does not?)
- Growth of data and granularity of data
- Surveillance and privacy
- Security, hacking, and data ‘leaks’
- New uses of data (e.g., predictive analytics, machine learning, genAI)
- How do we embed social justice through how we generate and use data?

New South Wales

This article is more than **9 years old**

HIV activists oppose identification changes to NSW health database

Proposal means names and addresses of people who have the virus would be kept on file, reversing a decades-old policy

News | Health

**American leaked records of 14,200 HIV patients, says Singapore**

*The records included HIV test results and personal identification details of people majority of whom are foreigners.*

Brochez was HIV-positive and used his Singaporean doctor husband's blood sample to pass blood tests so he could work in Singapore [File: Paula Bronstein/Getty Images]

28 Jan 2019

**LGBTQI+ Australians are tired of being ignored. Here’s why counting them in the census is so important**

The 2026 Census presented a crucial opportunity to count the LGBTQI+ population in Australia for the first time.

Instead, the Albanese government has opted to disregard important questions on gender and sexual identity. Once again, LGBTQI+ Australians will be invisible in population data, sparking outrage in the community.

Police would not agree to stop accessing COVID SafeWA app data, Premier Mark McGowan says

By Kenith Png COVID-19

Wed 16 Jun 2021

WA Premier Mark McGowan says the SafeWA app should only be used for contact tracing. *(ABC News: Eliza Laschon)*

MOLECULAR HIV SURVEILLANCE:
A GLOBAL REVIEW OF HUMAN RIGHTS IMPLICATIONS

WWW.HIVJUSTICEWORLDWIDE.ORG/MHS

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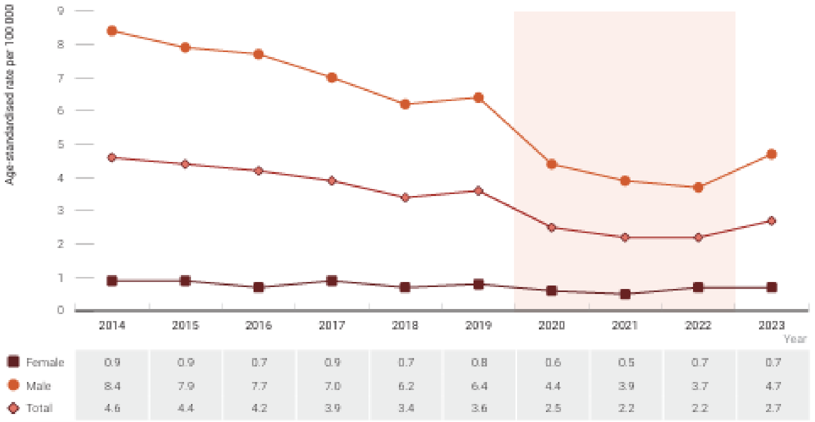
# Defining Data

"*any* thing or process (from a sun or rain pattern, to a beating heart, to a lesson delivered in a class) can be made into data"[1]

- Any information collected, observed, generated, or created and used to analyse or make decisions.
- Numbers, symbols, images, recordings, objects, clinical records, social media posts and profiles, purchase records.

Data do not naturally exist, but rather *become* data through the process of designating it *as* data.

**Figure 1** HIV notification rate per 100 000 population by gender, 2014 – 2023



| | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 | 2020 | 2021 | 2022 | 2023 |
|---|---|---|---|---|---|---|---|---|---|---|
| ■ Female | 0.9 | 0.9 | 0.7 | 0.9 | 0.7 | 0.8 | 0.6 | 0.5 | 0.7 | 0.7 |
| ● Male | 8.4 | 7.9 | 7.7 | 7.0 | 6.2 | 6.4 | 4.4 | 3.9 | 3.7 | 4.7 |
| ◆ Total | 4.6 | 4.4 | 4.2 | 3.9 | 3.4 | 3.6 | 2.5 | 2.2 | 2.2 | 2.7 |

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[1] Mejias & Couldry. 2019. Datafication. *Internet Policy Review*.

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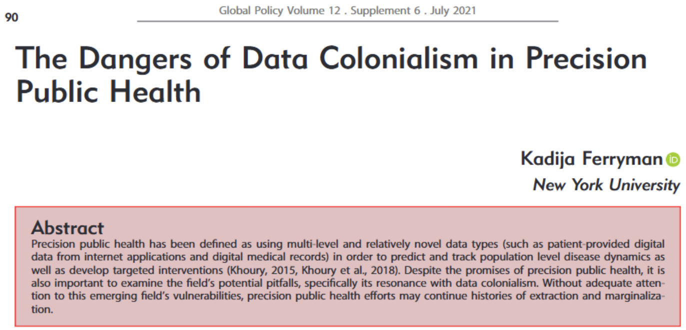
# Datafication

“the wider *transformation of human life* so that its elements can be a continual source of data. The beneficiaries of this are very often corporations, but also states and sometimes civil society organisations and communities.”[1]

1. Transformation of human life into data.
2. Generation of different kinds of value from data.

Data colonialism, e.g. high-income countries mining health data from low/middle-income countries.



90 Global Policy Volume 12 . Supplement 6 . July 2021

The Dangers of Data Colonialism in Precision Public Health

Kadija Ferryman
*New York University*

**Abstract**
Precision public health has been defined as using multi-level and relatively novel data types (such as patient-provided digital data from internet applications and digital medical records) in order to predict and track population level disease dynamics as well as develop targeted interventions (Khoury, 2015, Khoury et al., 2018). Despite the promises of precision public health, it is also important to examine the field’s potential pitfalls, specifically its resonance with data colonialism. Without adequate attention to this emerging field’s vulnerabilities, precision public health efforts may continue histories of extraction and marginalization.

December 22, 2023

How is your health data linked to Israeli occupation?

Exposing how health data and occupation are both profitable targets for the spy-tech giant Palantir

Text: Health Workers for a free Palestine (UK) & Image: Talia Woodin

Ferryman. 2021. The Dangers of Data Colonialism in Precision Public Health. *Global Policy*.
Lanzing. 2024. […] conceptualizing Palantir’s expansion into health. *Information, Communication & Society*.
[1] Mejias & Couldry. 2019. Datafication. *Internet Policy Review*.
Van Dijck. 2014. Datafication, dataism and dataveillance: Big Data between scientific paradigm and ideology. *Surveillance & Society*.

# Data justice

A lens through which to interrogate, engage with, and advance and challenge the justices and injustices relating to datafication.

e.g.,

- Who gets counted? Who gets a choice?
- How does the state protect citizens data (including from the state itself)?
- Who gets to be involved in decision-making regarding data?
- How does data relate to broader social justice, human rights & civil and economic liberties?

nature › npj digital medicine › perspectives › article

Perspective | Open access | Published: 28 February 2023

**Health data justice: building new norms for health data governance**

James Shaw & Sharifah Sekalala

*npj Digital Medicine* **6**, Article number: 30 (2023) | Cite this article

**6096** Accesses | **16** Citations | **19** Altmetric | Metrics

Research Papers

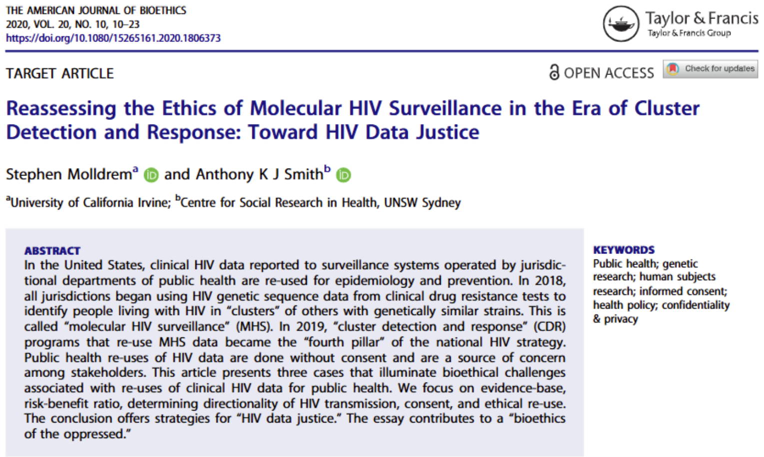
**Hepatitis C data justice: the implications of data-driven approaches to the elimination of hepatitis C**

**kylie valentine**, Emily Lenton, Kate Seear, Suzanne Fraser, Dion Kagan, Adrian Farrugia,

...show all

Pages 803-813 | Received 06 Apr 2023, Accepted 20 Nov 2023, Published online: 01 Dec 2023

Cite this article   https://doi.org/10.1080/09581596.2023.2287959   Check for updates



THE AMERICAN JOURNAL OF BIOETHICS
2020, VOL. 20, NO. 10, 10–23
https://doi.org/10.1080/15265161.2020.1806373

Taylor & Francis
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TARGET ARTICLE

OPEN ACCESS   Check for updates

**Reassessing the Ethics of Molecular HIV Surveillance in the Era of Cluster Detection and Response: Toward HIV Data Justice**

Stephen Molldrem[a] and Anthony K J Smith[b]

[a]University of California Irvine; [b]Centre for Social Research in Health, UNSW Sydney

**ABSTRACT**

In the United States, clinical HIV data reported to surveillance systems operated by jurisdictional departments of public health are re-used for epidemiology and prevention. In 2018, all jurisdictions began using HIV genetic sequence data from clinical drug resistance tests to identify people living with HIV in "clusters" of others with genetically similar strains. This is called "molecular HIV surveillance" (MHS). In 2019, "cluster detection and response" (CDR) programs that re-use MHS data became the "fourth pillar" of the national HIV strategy. Public health re-uses of HIV data are done without consent and are a source of concern among stakeholders. This article presents three cases that illuminate bioethical challenges associated with re-uses of clinical HIV data for public health. We focus on evidence-base, risk-benefit ratio, determining directionality of HIV transmission, consent, and ethical re-use. The conclusion offers strategies for "HIV data justice." The essay contributes to a "bioethics of the oppressed."

**KEYWORDS**
Public health; genetic research; human subjects research; informed consent; health policy; confidentiality & privacy

Dencik et al. 2022. Data Justice. Sage Publications.
Molldrem & Smith. 2020. Reassessing the Ethics of Molecular HIV Surveillance. *The American Journal of Bioethics*.
Shaw & Sekalala. 2023. Health data justice: building new norms for health data governance. *npj Digital Medicine*.
valentine et al. 2023. Hepatitis C data justice. *Critical Public Health*.

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# Data Sovereignty

How institutions / countries manage and control data, make policies/laws about data; data governance.[1]

“The First Nations principles of ownership, control, access, and possession – more commonly known as OCAP® – assert that First Nations have control over data collection processes, and that they own and control how this information can be used.”[2]

Troubling western standards of consent:

Stories from qualitative data and genetic material from biological samples not only implicate individuals, but also communities and families.[3]

*Special Issue - Indigenous Sociology: Contemporary Theoretical Perspectives*

Journal of Sociology
2020, Vol. 56(2) 184–196
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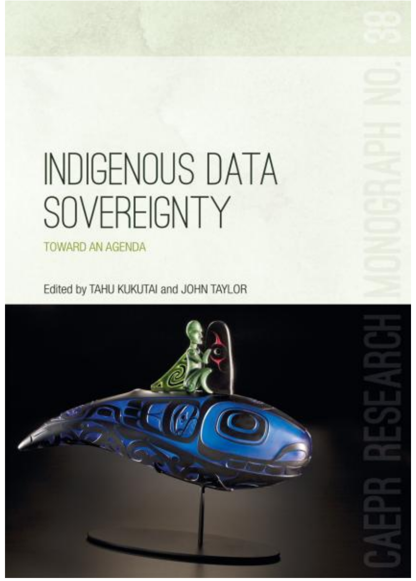
**There’s ‘consent’ and then there’s consent: Mobilising Māori and Indigenous research ethics to problematise the western biomedical model**

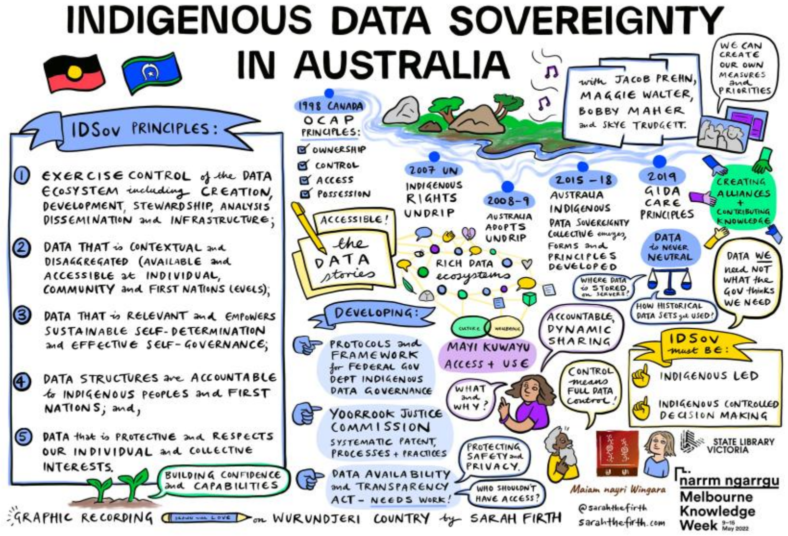
**Kiri West-McGruer**
Te Wānanga ō Waipapa, University of Auckland, New Zealand

**Abstract**

Challenging western research conventions has a strong documented history in Indigenous critical theory and Kaupapa Māori research discourse. This article will draw from the existing research in these fields and expand on some of the core critiques of the biomedical model in Māori research environments. Of interest are the tensions produced by an over-reliance on individual informed consent as the panacea of ethical research, particularly when the research concerns communities who prioritise collective autonomy. These tensions are further exacerbated in research environments where knowledge is commodified and issues of knowledge ownership are present. Continuing a critique of the informed consenting procedure, this article considers its role in emulating a capitalist exchange of goods and perpetuating a knowledge economy premised on the exploitation of Indigenous people, resources and knowledge. Finally, this article will consider emerging ethical concerns regarding secondary data use in an era of big data.



INDIGENOUS DATA SOVEREIGNTY
TOWARD AN AGENDA
Edited by TAHU KUKUTAI and JOHN TAYLOR
CAEPR RESEARCH MONOGRAPH NO. 38



[2] First Nations Information Governance Centre. https://fnigc.ca/ocap-training/

[1] Hummel et al. 2021. Data sovereignty: A review. *Big Data & Society*.

Kukutai & Taylor. 2016. Indigenous Data Sovereignty: Toward an Agenda. ANU Press.

Walter & Suina. 2018. Indigenous data, indigenous methodologies […]. *International Journal of Social Research Methodology*.

[3] West-McGruer. 2020. Mobilising Māori and Indigenous research ethics. *Journal of Sociology*.

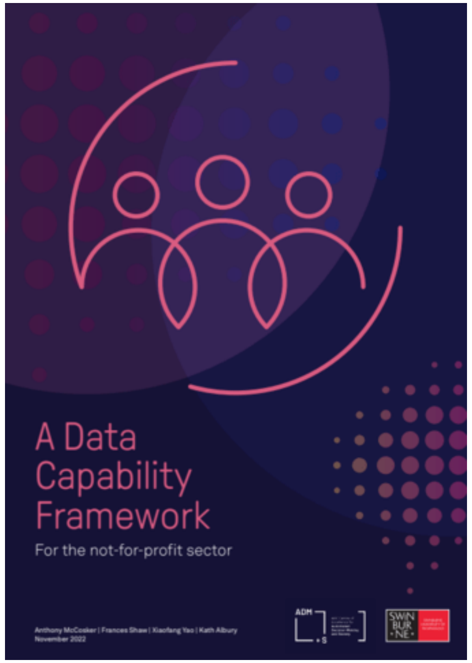
ANTAR. Data Sovereignty. https://antar.org.au/issues/closing-the-gap/data-sovereignty/

# Data Capabilities

“Data capability is the combination of the technical and material conditions, the skills, knowledge and proficiencies, and the strategic and ethical oversight driving the creation and use of data for improving knowledge, problem solving and decision-making.”[1]

How do we embed data capabilities in our workforce?

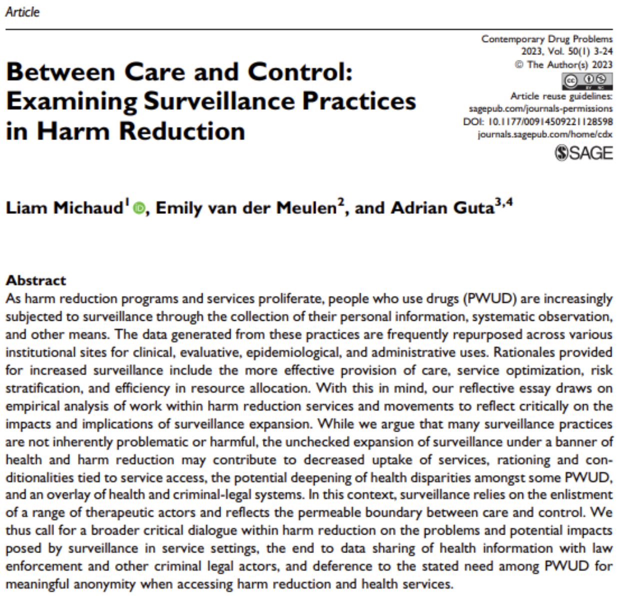
Eg. harm reduction services enlist workers (including peers) in surveillance practices of people who inject drugs, such as collecting data necessary for evaluation to support funding requirements.[2]



A Data Capability Framework

For the not-for-profit sector

Anthony McCosker | Frances Shaw | Xiaofang Yao | Kath Albury
November 2022



*Article*

Contemporary Drug Problems
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**Between Care and Control: Examining Surveillance Practices in Harm Reduction**

**Liam Michaud[1], Emily van der Meulen[2], and Adrian Guta[3,4]**

**Abstract**

As harm reduction programs and services proliferate, people who use drugs (PWUD) are increasingly subjected to surveillance through the collection of their personal information, systematic observation, and other means. The data generated from these practices are frequently repurposed across various institutional sites for clinical, evaluative, epidemiological, and administrative uses. Rationales provided for increased surveillance include the more effective provision of care, service optimization, risk stratification, and efficiency in resource allocation. With this in mind, our reflective essay draws on empirical analysis of work within harm reduction services and movements to reflect critically on the impacts and implications of surveillance expansion. While we argue that many surveillance practices are not inherently problematic or harmful, the unchecked expansion of surveillance under a banner of health and harm reduction may contribute to decreased uptake of services, rationing and conditionalities tied to service access, the potential deepening of health disparities amongst some PWUD, and an overlay of health and criminal-legal systems. In this context, surveillance relies on the enlistment of a range of therapeutic actors and reflects the permeable boundary between care and control. We thus call for a broader critical dialogue within harm reduction on the problems and potential impacts posed by surveillance in service settings, the end to data sharing of health information with law enforcement and other criminal legal actors, and deference to the stated need among PWUD for meaningful anonymity when accessing harm reduction and health services.

Albury & Mannix. 2025. From Digital Health Literacy to a Digital and Data Capabilities […]. *Sexuality Research & Social Policy*.
[2] Michaud et al. 2023. Between Care and Control. *Contemporary Drug Problems*.
[1] McCosker et al. 2022. A Data Capability Framework for the non-for-profit sector. Swinburne University of Technology.

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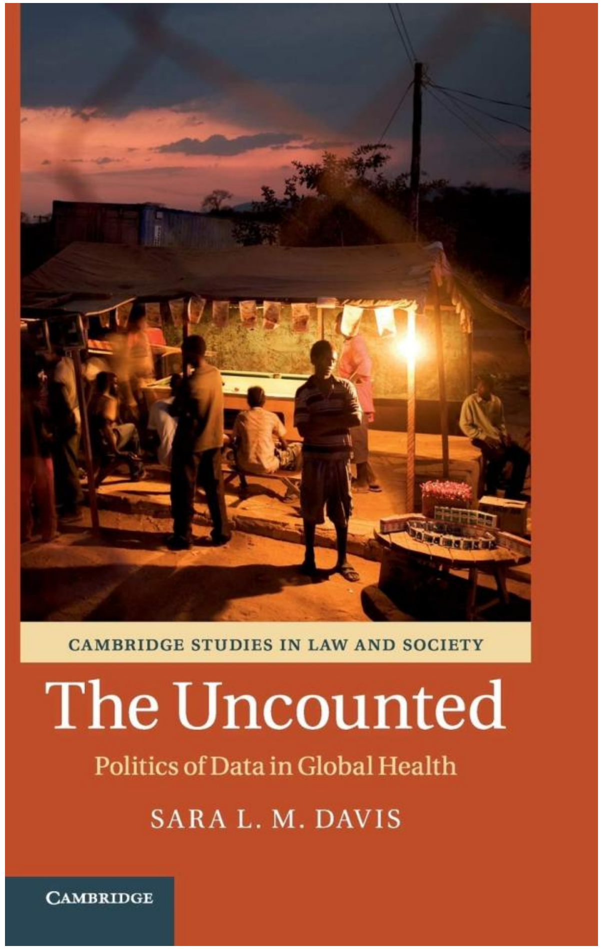
# Today’s session

- What are the ethical and social justice dimensions of HIV data?
- Who ‘owns’ data, or who has stewardship over HIV data?
- How do we incorporate data collection, analysis, and reporting within person-centred practices?
- How do we ensure that people living with HIV and other affected communities are involved in decision-making about data?
- How do we ensure ethical and equitable data for public health action?



# Disclosures

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