

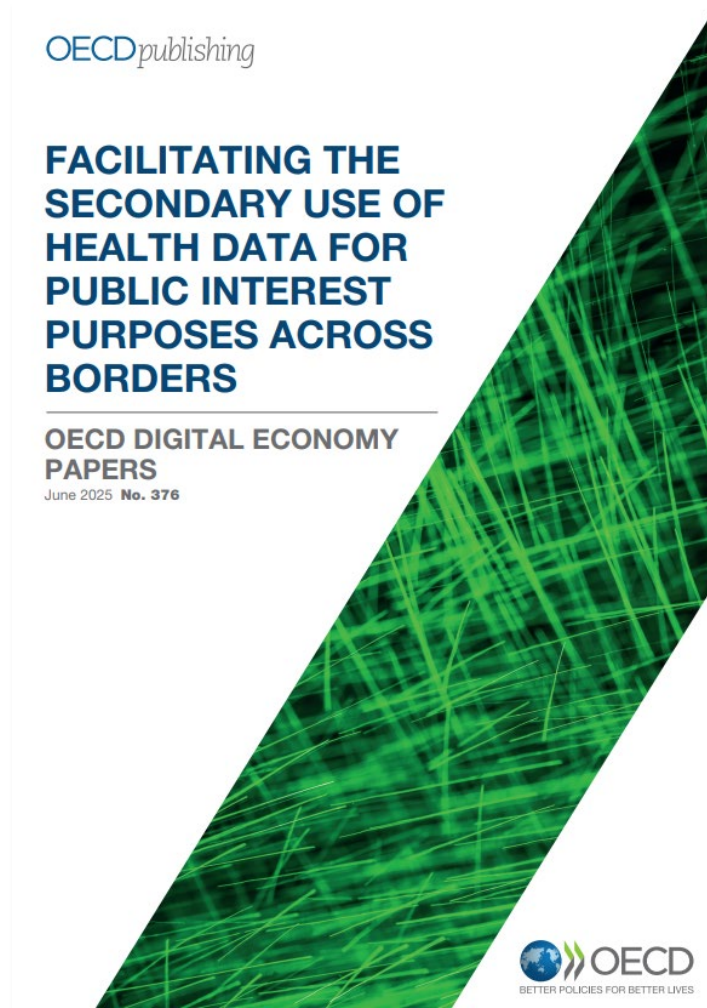
Perspectives on Enabling the Secondary Uses and Disclosures of Health Data

GPA 2025, Seoul

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Background report



Benefits of access to data for secondary purposes

- Access to health data enables innovation in treatments
- It also has population health and economic benefits that are important



Lawful bases for data access

Consent is one lawful basis to access data, but it has well documented practical disadvantages in the context of secondary analysis of existing data



Lawful bases for data access

- Another approach is to use privacy enhancing technologies (PETs) to allow the sharing and processing of non-personal information
- The technologies have advanced to reduce the skill level required by users



Lawful basis does not equal social license



What happens without a social license

There are well documented examples of patients, healthcare providers, and civil society creating real obstacles and resistance to data access



NHS patient data to be made available for sale to drug and insurance firms

Privacy experts warn there will be no way for public to work out who has their medical records or how they are using it

THE CONVERSATION

Academic rigour, journalistic flair

NHS care.data still leaks like a sinking ship, but ministers set sail regardless

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What happens without a social license

There are well documented examples of patients, healthcare providers, and civil society creating real obstacles and resistance to data access

The logo for National Post, featuring the words "NATIONAL POST" in a serif font on a yellow rectangular background.

Canada's public health agency admits it tracked 33 million mobile devices during lockdown

The Public Health Agency of Canada accessed data such as cell-tower location to monitor people's activity during lockdown, it said

How the federal government failed to protect our mobility data



COLLECTION AND USE OF MOBILITY DATA BY THE GOVERNMENT OF CANADA AND RELATED ISSUES

Report of the Standing Committee on Access to Information, Privacy and Ethics



uOttawa

How to build social license for using and disclosing data for secondary purposes ?

- Clear guidance for using PETs to incentivize applications of effective methods (rather than simplistic methods that are ineffective and easy to attack)
 - regulators identified codes of practice as an important tool for them
 - for example, the upcoming Ontario de-identification guidelines
- Start early in building trust with the public – privacy regulators can play an important role here
 - the public needs to trust the relevant institutions
- Tell positive stories about the benefits of data access, and not just the negative stories
- Promote health data literacy among the public (what is health data, better able to detect misinformation)

How to build social license for using and disclosing data for secondary purposes ?

- Transparency and communication – we need effective marketing of health data sharing !
 - as raised in two Canadian investigations
- Change the negative narrative about the commercial uses of health data
 - some bad actors dominate the discourse on this topic
 - sustainable innovation requires private sector involvement
- We need to accept that not everyone will buy in – trying to address the exceptions means that progress will be limited
 - some purposes will not align with people's values
- Ensuring nimble ethics review process are implemented – this goes beyond privacy but is important



QUESTIONS