Who Owns Data?

Public Voices, Power and Innovation

April 15, 2026

Great Ormond Street Institute of Child Health
University College London

SPRINT
Single Patient Record Integrity,
Trust & Transparency

UCL
GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH

DARE UK

ITALO
Improving Transparency Around
Linkage Outputs

Acknowledgements

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Co-organisers

Catherine Stewart, Miranda Leung, Aaron Koay

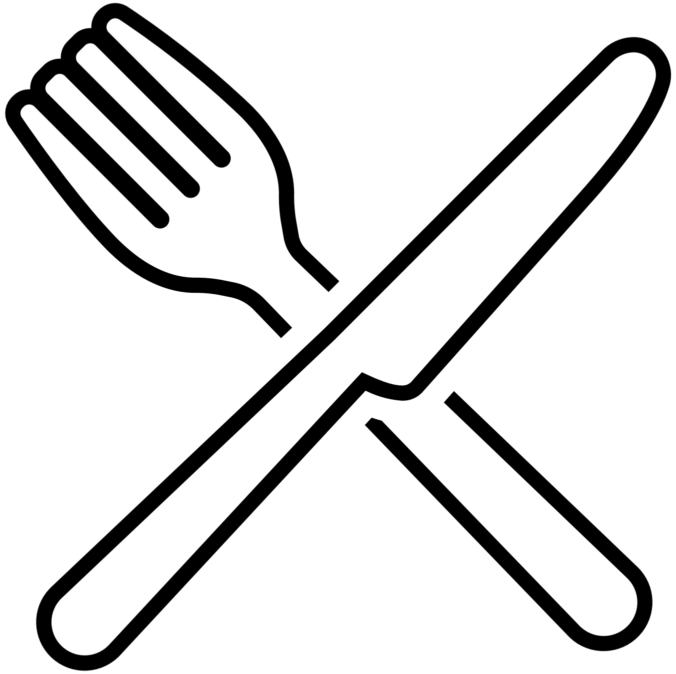
Support

SPRINT, ITALO, Health Equity Special Interest Group, UCL bioethics society

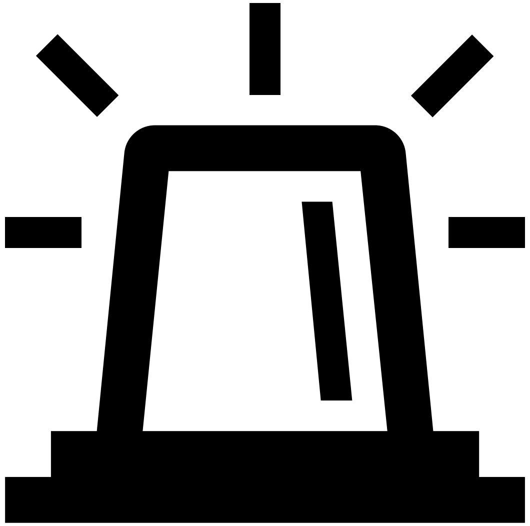
Agenda & Speakers

Wednesday 15th April, 2026

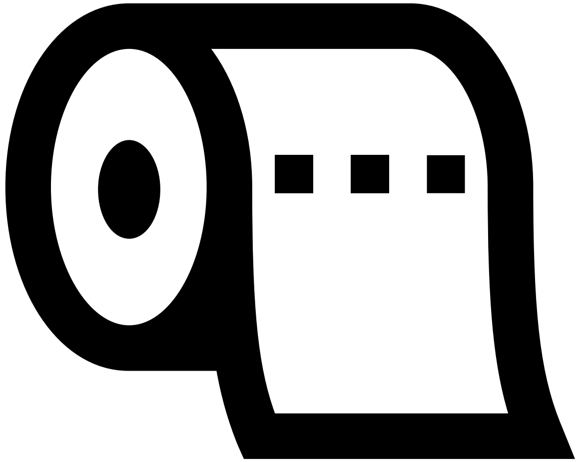
9:00 - 9:30 am	Registration
9:30 - 9:40 am	**Welcome & Housekeeping**
9:40 - 10:05 am	**Who Owns Data? Contemporary Issues** Speaker: Jo Lam - UCL
10:05 - 10:50 am	**Balancing Intellectual Property & Innovation** Speaker: Jonny Pearson - NHS England
10:50 - 11:00 am	Break
11:00- 11:50 pm	**Public Voices in Use of Administrative Data** Speakers: Farheen Yameen, Georgina Ferguson-Glover, Jan Speechley - Public Contributors
11:50 - 12:35 pm	Lunch
12:35 - 1:30 am	**International Digital Data, Linkage & Ethics** Speaker: Molly Pugh-Jones - STOPAIDS
1:30- 2:20 pm	**PEDRI PPI Good Practice Standards** Speakers: Shayda Kashef & Anna Woolman - PEDRI
2:20- 3:15 pm	**Keynote** Speakers: Andy Boyd - UK LLC & HDR UK
3:15 - 4:00 pm	Networking



Lunch 11:50 – 12:35



Follow fire exit signs



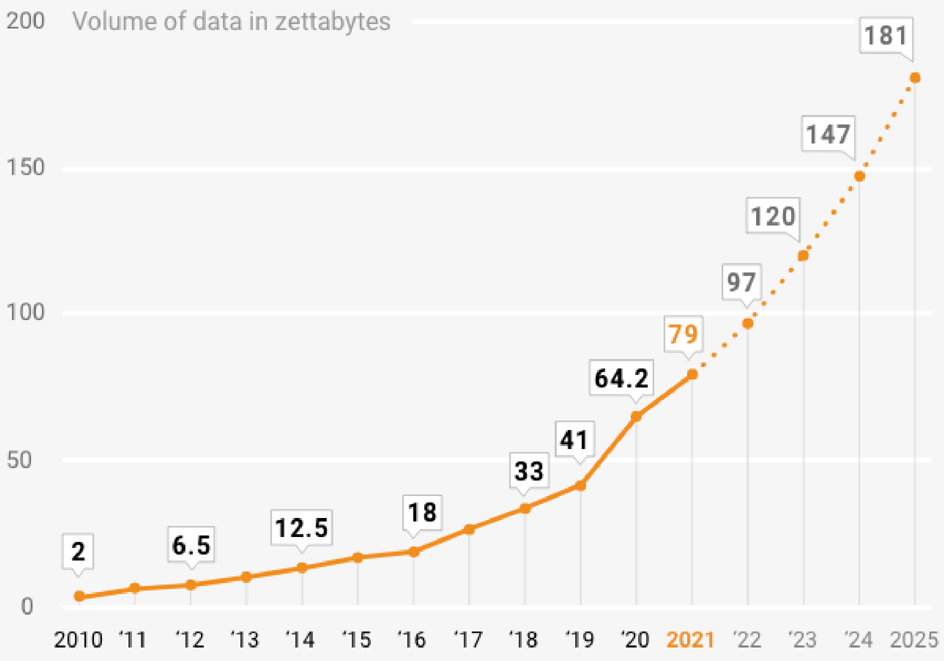
Toilets outside

Who Owns Data? Contemporary Issues

Dr Jo Lam
Co-Chair Single Patient Record Integrity, Trust and Transparency (SPRINT)
Co-Chair Improving Transparency Around Linkage Outputs (ITALO)

Volume of data created, captured, copied, and consumed worldwide

The volume of data generated, consumed, copied, and stored is projected to exceed 180 zettabytes by 2025



Source: statista.com

firstsiteguide.com

"Data is everything, everything is data"

GLOBAL government FORUM

Big but not scary: how to use big data to shape government policy and delivery

UK Parliament

Committees

UK Parliament > Business > Committees > Public Administration and Constitutional Affairs Committee > News Article

How can Government harness new data to improve policies?

6 July 2023

Palantir

Confidential health records from UK BioBank project exposed online

Exclusive: Guardian investigation finds data from flagship medical research leaked dozens of times

A strategy for Analysis in Government 2025 to 2028

Our vision:

The analytical community will provide better outcomes for the public by providing the best and most efficient analysis to inform decision making.

Data
Saves
Lives

Data saves lives

Our strategy to reshape health and care with data

Palantir

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Data
Saves
Lives

Who decides how to drink this cup...

Data saves lives

Our strategy to reshape health and care with data

Unethical Historical and Current Data Use

Calculations based on Sentinel-1 satellite imagery

Vovchansk

Nuremberg Law

Property [ownership] - civil law

Intellectual property [copyright]

None are fully satisfactory: data is inherently **non-rivalrous**, **non-exclusive** and **inexhaustible**

Fundamental right [*personal data*]

Contextual rights - exceptions

(Health) Data Ownership → Data Processing

Operational (direct care / service delivery):

- Often relies on public task / legal obligation (Article 6) plus health/social care condition (Article 9).
- CLDC is typically met via direct care expectations but still must be justified.

Research / secondary use:

- Often relies on **public task** (Article 6) plus **research condition** (Article 9(2)(j)) *with safeguards*; and you still must address CLDC (consent, s251, or anonymisation).

CLDC: Common Law Duty of Confidentiality

Section 251: what it is (and what it is not)

- s251 (via the Health Service (Control of Patient Information) Regulations 2002) can set aside the common law duty of confidentiality so identifiable confidential patient information can be used **without consent** for defined medical purposes (including some research), where justified.

- Except – National Data Opt Out

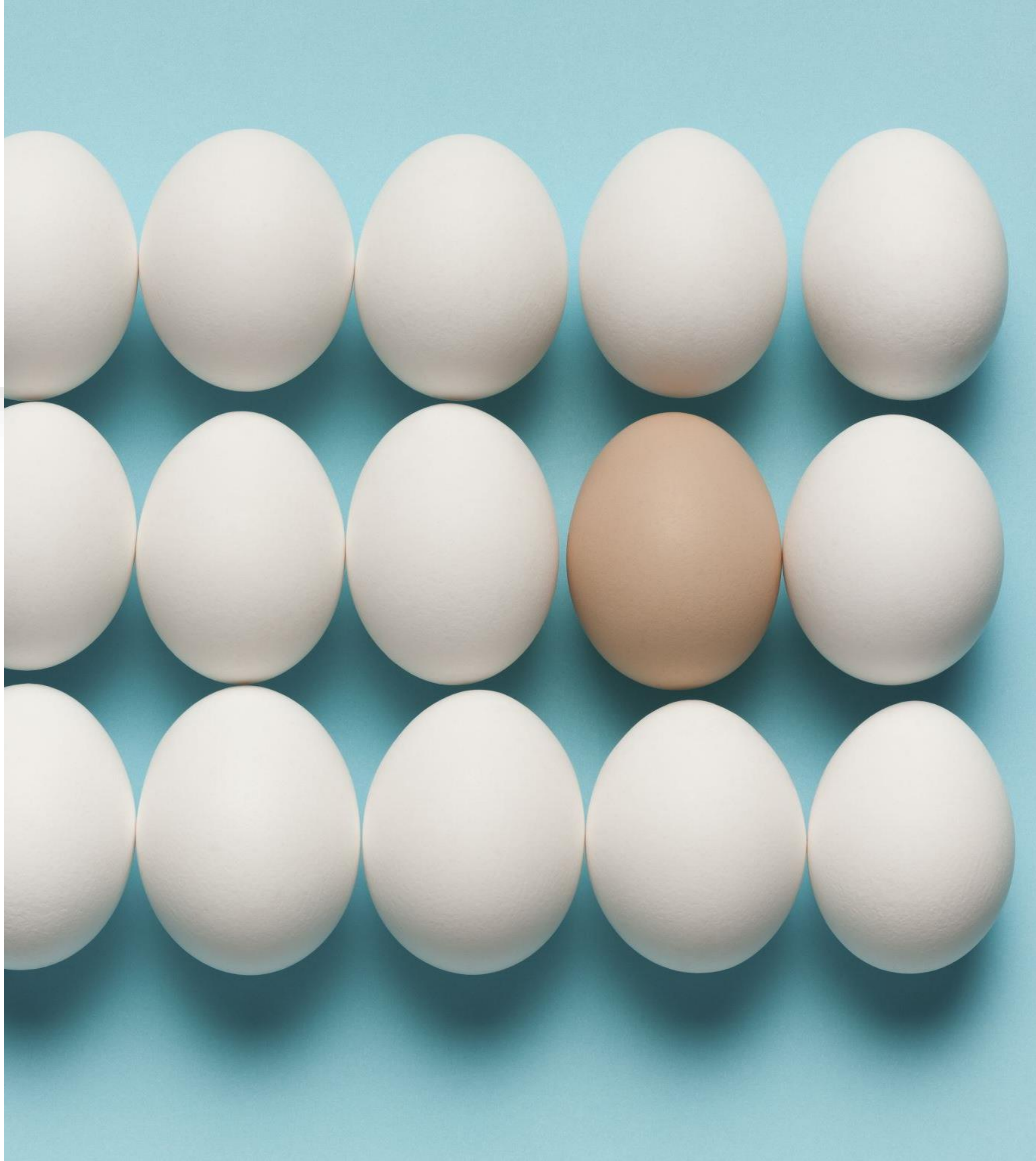
Dashboard

Latest opt-out count
3,477,989 as of 28/02/2026

Latest opt-out rate
5.58% as of 28/02/2026

Data up to: 28/02/2026

Cost of Opting Out



Opt-outs can introduce bias if non-random (trust, demographics, geography).

Chicken–egg problem: lack of trust → opt-outs → poorer data → worse services → further mistrust.

Geography

Pollution

Criminal Justice

Migration

Insurance

Income

Health

Benefits

Consumption

Genetics

Social Care

Education

Social Networks

Digital Footprints

Data Ownership Models

What feels “acceptable” varies

- Collective vs individual models of consent.
- Historical experiences with state surveillance or discrimination.
- Expectations of reciprocity: *who benefits and how fast?*

“When would you be comfortable with your local council using your data without asking you first? Why?”

Cultural Variations

NL- supercomputer enabled individual-level linkage
[No Opt Out option]

Banks & Private companies buying/using personal data directly from individuals.

Patient registries with complete nationwide coverage and individual-level linkage potential have existed in Finland since 1969, in Sweden since 1987, in Iceland since 1999, and in Norway since 2008

Questions to you for the rest of the day

Prime time to think the UK position and our positions as {data scientists}

Who needs to be in the room?

What needs to be prioritised?

How can we work with the public and communicate well?

We’d love to hear from you!

2-min Feedback Form

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Join our mailing list:

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Other thoughts & feedback:

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