# Protection of Privacy – perspective from the UK

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NAS- Forum on Neuroscience and Nervous System Disorders
Neuroscience Data in the Cloud– a Workshop
September 24, 2019

# Distinct use cases: one size does not fit all

## Single cohort/study

- Multiple data types
- Single IRB & consent
- Single or multiple institutions
- Single PI/ data access procedure

## Individual facility

- Restricted data types
- Multiple study types, IRBs, consents
- Multiple PIs, multiple funders
- Single institution

## (Sub)Field

- Restricted data types
- Multiple study types, IRBs, consents
- Multiple Pis, multiple funders
- Multiple institution

# Single study – UK Biobank example

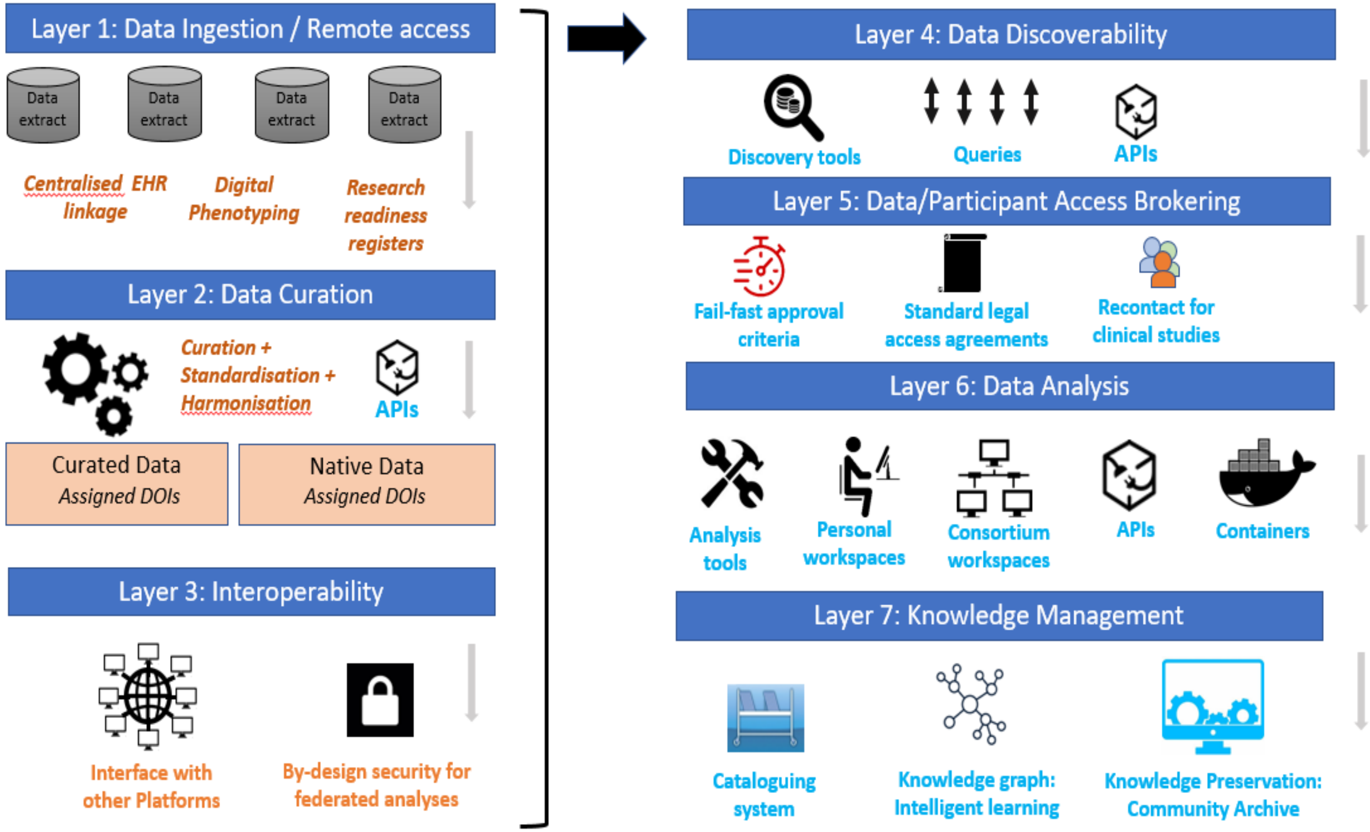
- Population cohort of 500,000 individuals, open by design
- 100K currently undergoing imaging sub-study (45K already scanned)
- Data includes demographics, extensive health questionnaire, blood sample, genetics, touch-screen assessments of cognition
- Data access:
    - Individuals apply (and pay admin fee) for access – 2 stage process
    - Data access committee
    - Distinction between sensitive and non-sensitive data
    - No disclosure
    - Bespoke arrangements with institutions for local copies of the data

# Single facility – WIN example

- Imaging facility, approx. 35 PIs
- Studies of all shapes and sizes (basic, clinical, commercial)
- Data includes demographics, MRI, MEG, PET, electophys, behavioural data
- Data access:
  - Developing centralized infrastructure to facilitate data sharing
  - Responsibility for privacy remains with the study PI

# Field platform

- 35 cohorts, >3M participants
- Platform infrastructure to facilitate data sharing, data aggregation and cross-cohort analyses
- ‘Single point of entry’ data access request system, but responsibility lies with the cohort PI



nature COMMUNICATIONS

ARTICLE

https://doi.org/10.1038/s41467-019-10933-3 OPEN

# Estimating the success of re-identifications in incomplete datasets using generative models

Luc Rocher[1,2,3], Julien M. Hendrickx[1] & Yves-Alexandre de Montjoye[2,3]

heavily incomplete dataset. On 210 populations, our method obtains AUC scores for predicting individual uniqueness ranging from 0.84 to 0.97, with low false-discovery rate. Using our model, we find that 99.98% of Americans would be correctly re-identified in any dataset using 15 demographic attributes. Our results suggest that even heavily sampled anonymized datasets are unlikely to satisfy the modern standards for anonymization set forth by GDPR and seriously challenge the technical and legal adequacy of the de-identification release-and-forget model.

# Perspective of participants

- Privacy, security, yes but…
- ‘Informed consent’
- Reindentification: Rights/opportunities of cohort participants

# Hard (but vitally important) sells

- Risk-benefit
- Industry partnerships are good for us all!
- Fear of the known/unknown unknowns
- Power to the participants