Ethical data use, Good data governance

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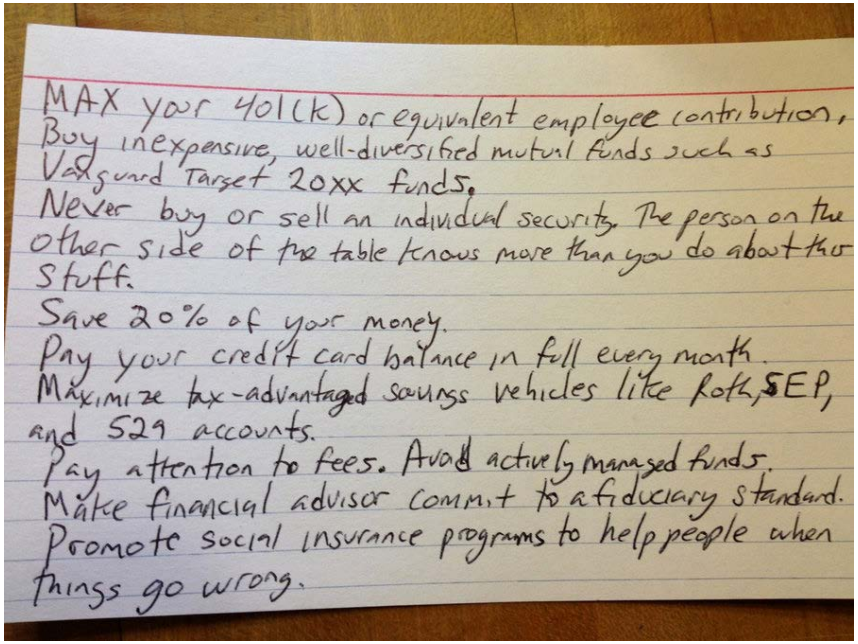
Governance structures:

- SOPs for data access
- Data protection
- Documentation
- Ethical oversight

The index card of good data governance



With a nod to Harold Pollack….

KEY POINTS FOR GOOD DATA GOVERNANCE

1. The study participant knows what I am using their health data for, and is ok with it

Informed consent process:

Explicit

- Which data
- Where are the data collected
- What time frame

Simple language

- Research question
- Opt-in, not opt-out
- Withdrawal from study at any time
- No negative consequences of declining

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GOVERNANCE – Ethics

- Confidentiality
- Beneficence
- Potential harms
- Vulnerable populations

  Poor health, low SES

DoH Research approval
HRECS and Ethics approval
Informed consent/anonymisation/aggregation

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GOVERNANCE – legal compliance

POPI *Protection of Personal Information act*

Responsible Party: DoH

Primary purpose: data collected for provision of health care

PAIA *Promotion of access to information act*

Record keeping of how individuals' data are used

- records of all data access

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4. All datasets and drives are password protected and encrypted

Easy software solutions, e.g.

7zip

Password protection and AES encryption for all data files

Excel (RedCAP or MySQL is better!)

Spreadsheets with password protection

Bitlocker

Encrypt all drives where data are stored, including flash drives for data transfer

Ask your departmental admin to file codes securely

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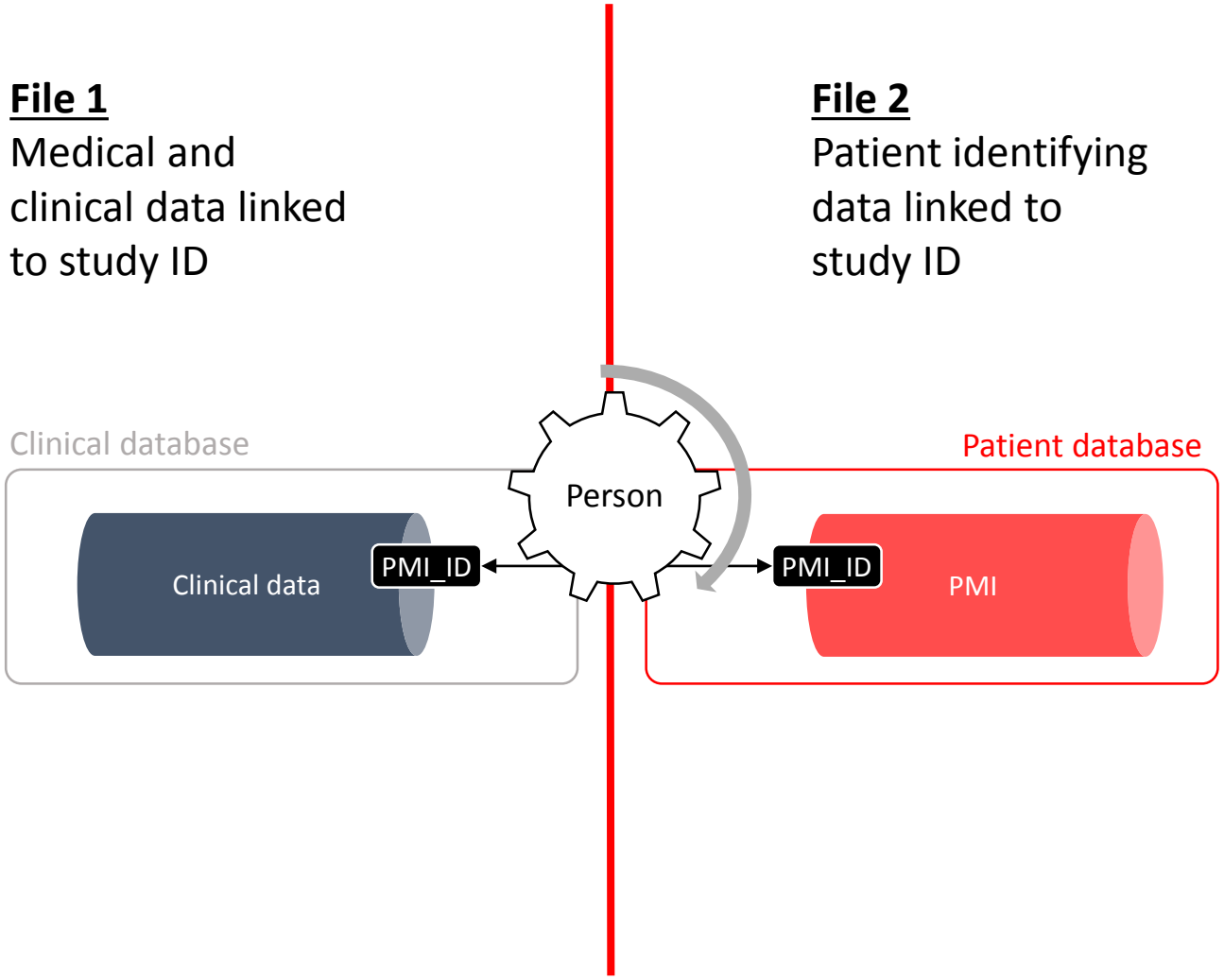
Separation of identifying and clinical data

File 1
Medical and clinical data linked to study ID

File 2
Patient identifying data linked to study ID



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6. **All anonymised data cannot be re-identified**

Can data be easily re-identified?

e.g. Genomic data

Anonymising genomic data is like trying to anonymise a fingerprint

e.g. Clinical data

A 37-year old lady with epilepsy - with a 9yr old daughter and a 5yr old son and frequently attending a particular clinic - can be easily re-identified.

Do not manage de-identified data in the same way as truly anonymised data, because it can be re-identified.

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7. I never use email to transfer identifiable health information, and I always send passwords separately (not by email).

Passwords

Never email passwords

Use sms or telephone call

Never send passwords together with data

Just don't.

UCT: Use filesender (filesend.uct.ac.za) to send password-protected, encrypted files with sensitive data

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Would you……?

Thank you