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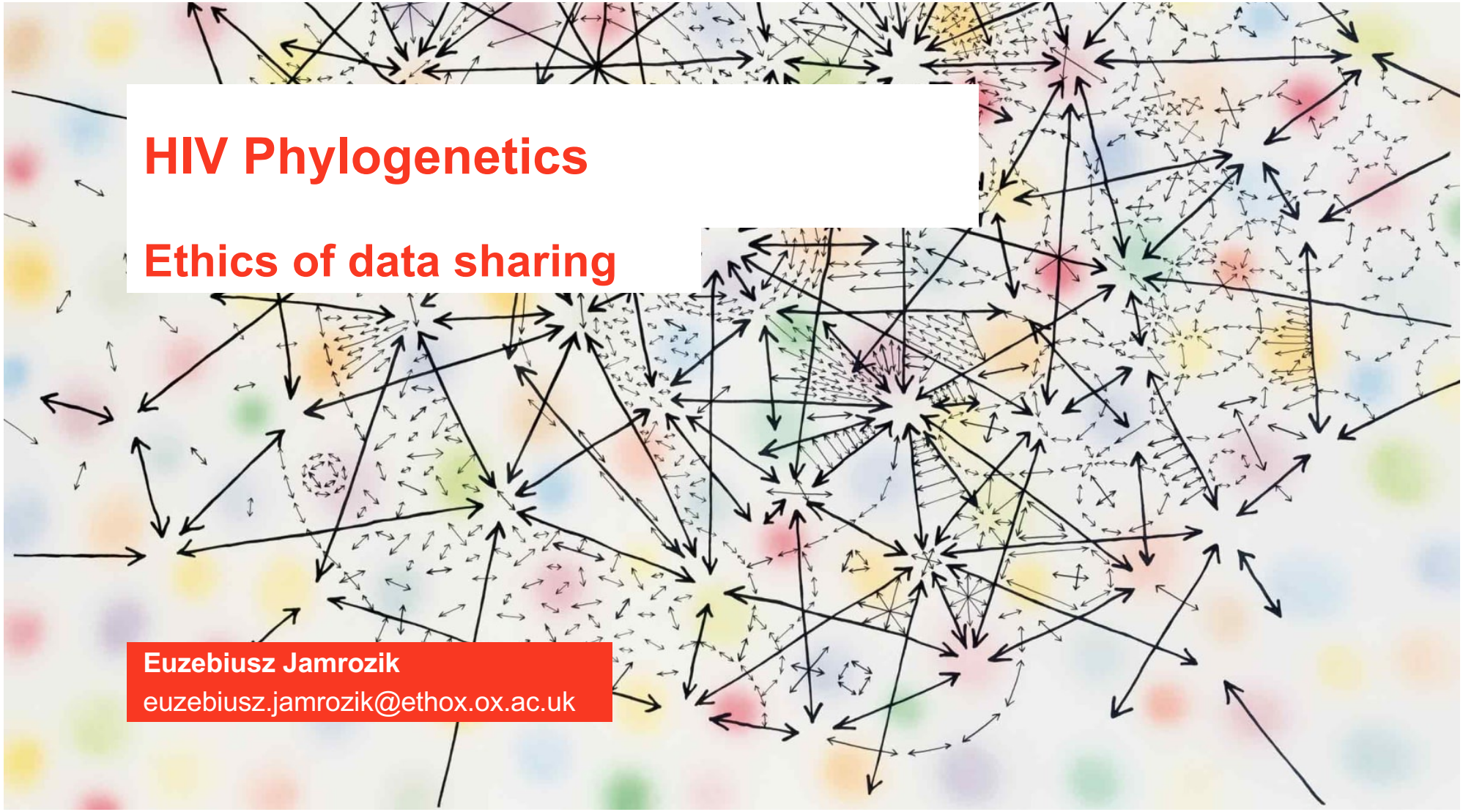

HIV Phylogenetics

Ethics of data sharing

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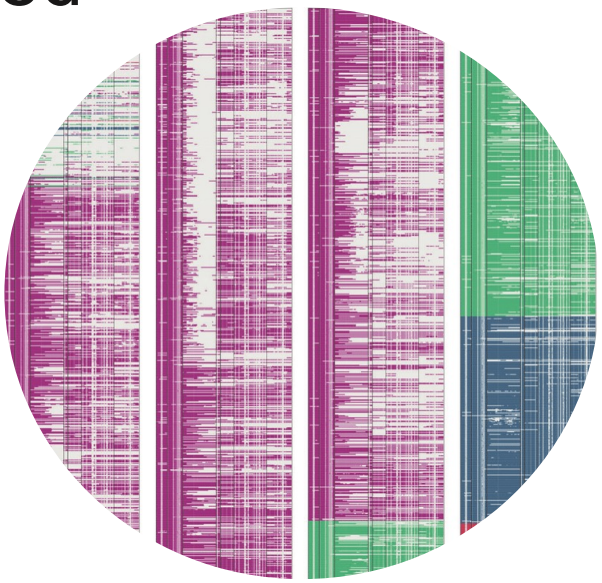
Background

Technical aspects of how data are collected, linked, analysed, and shared

influence

Ethical considerations such as:

- Potential benefits
- Potential harms
- Respect for persons
  - Privacy, stigma, etc.



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Open science: ethical tradeoffs

- **Maximise benefits** by transparent data sharing
  - Increased validity
  - Increased (meta-)analysis
  - More (and more accurate) results

- **Minimise harms** by reducing
  - Identifiability & stigma
  - Misuse of data

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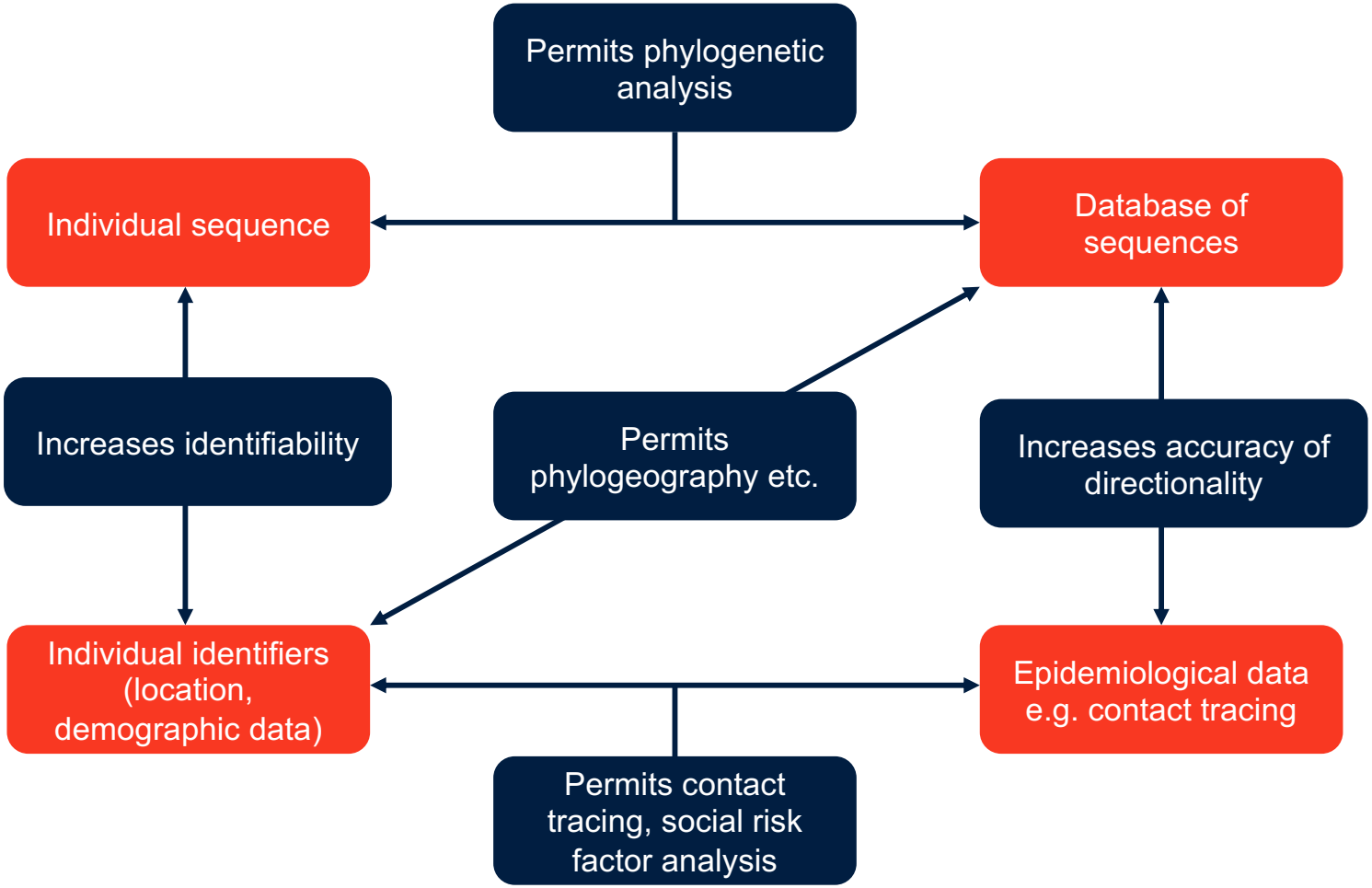
Linkage



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Minimalism: data and linkage

Scientific and ethical rationale for
research data maximalism (including genomic data)

Minimalism might reduce risks by limiting:

- *Number of individuals' data* shared/linked
- *Types of data* linked
- *Level of detail* (e.g. fuzzy location data)
- *Duration* of linkage (e.g., "ephemeral phylogeny")

Image: Celeste Boursier Mougenot

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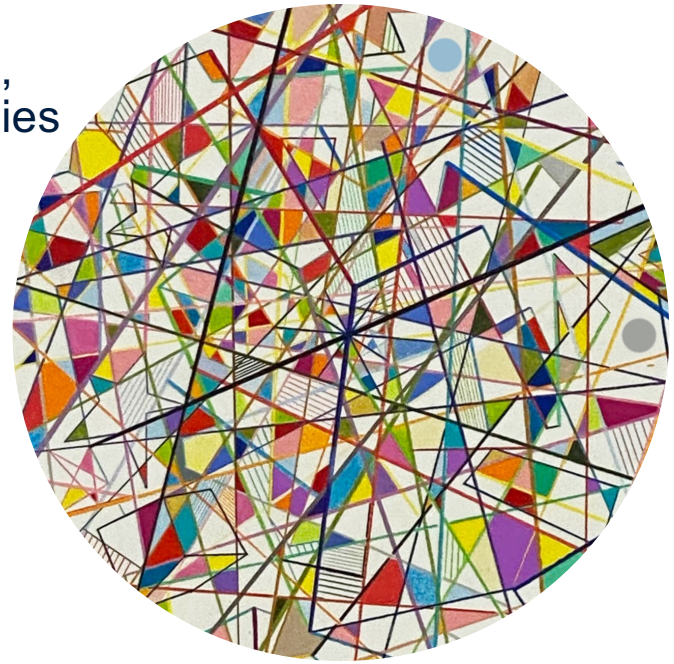
Institutions & Governance

Relevant data held by different (global) research groups, government/public health agencies, technology companies



Co-ordination problems in data sharing

- Different regulations
- Need for appropriate gate-keeper

Tension between benefits of local ownership of data

versus risks to local communities

Image: Tom Friedman

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Possible technological solutions

1) Federated databases & analysis
- Data held by different connected institutions
- Technical barriers (computing power) & funding barriers

2) Trusted research environments
- Data deposited in systems held by third parties
- Need to trust centralized database security

3) Data packages
- Defined reasons & degree of data sharing
- Funding & staffing barriers
- Ethical tensions including post-research storage of data

Image: Chiharu Shiota

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Conclusions

Different technical approaches influence ethical features & outcomes of phylogenetic analysis

Data minimalism (including linkage minimalism) is a key consideration

Several unresolved issues for future work

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