Disclosure control in complex medical outputs

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Data Research Access & Governance Network

UK Research and Innovation DARE UK

Overview

- Medical research and positioning
  - Current practices
  - Alignment with TRE standards
- Examples
- Solutions?
- Future considerations

Medical research

Traditionally:

- Revolves around direct informed consent and primary data collection
- Some bad examples of mismanagement data and ethics… Henrietta Lacks for example
- Easy to see direct benefit/ public good

Sharing medical data and disclosure control

- Varied practices from depositing raw data in the public domain to secure access
- Tools are being developed- uptake poor
- Unforeseen consequences encountered
- Benefit to society

Genomic Data

- Tissue sample extracted, analysis is then conducted
- Microarray data of specimen often deposited/ shared in the public domain (remember knowledge advancing continually)
- Descriptive variables provided

Data collection: The DRAGoN Hospital for Exhausted Researchers

Participant characteristics:

Participant number	Gender	Age	Prognosis
1	Male	48	Bad- chronic insomnia
2	Female	31	Good

Xlsx attachment with participant 1 microarray, participant 2 microarray etc.

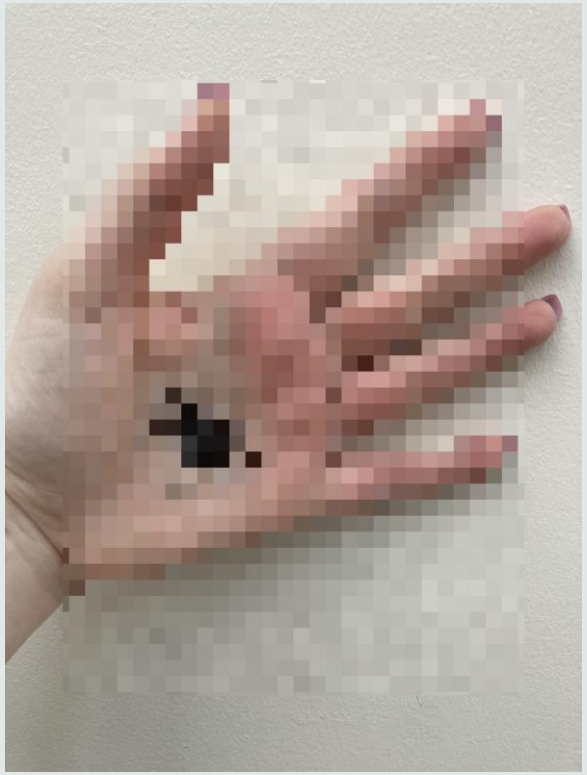
Statistical Disclosure Control?

- Basic SDC principles- counts and thresholds
- Kaplan-Meier curves often result in low numbers, potential for low number of observations between each step.
- Not directly disclosive as alone, requires linking to contextual information (provided in the report).
- Recommendations exist- O'Keefe et al (2012) smoothing and adding CI. SDAP (2019) thresholds meet.
- Online tools- generating a Kaplan-Meier curve with SDC inbuilt

Dermatology photographs

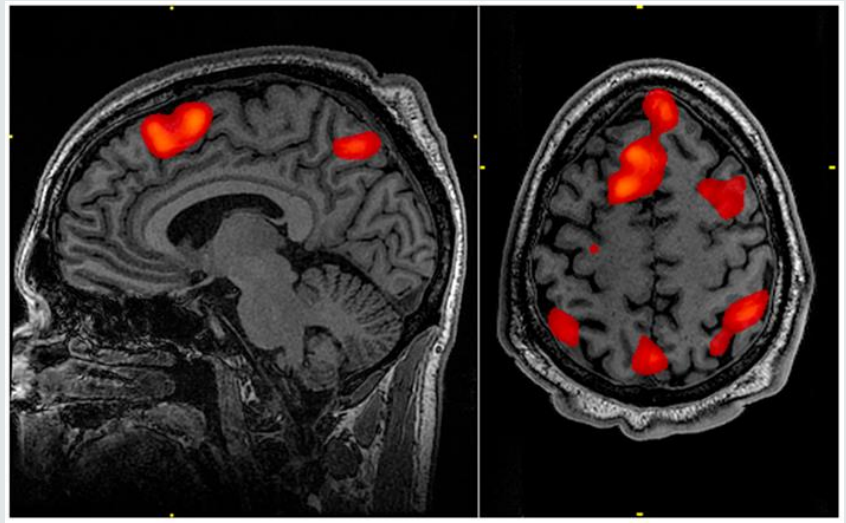
- Online photo repository providing examples of different skin disorders.
- Used as an aid to help experts and public identify different ailments.
- Huge public benefit
- However unintended consequence was found…

Statistical Disclosure Control?
Solutions?



FMRI scan

- Huge amount of data
- Brain anatomy and structure (remember knowledge advancing continually)
- Variation in sharing online repositories open access.
- Concern for disclosure is based on rebuilding face based on structure

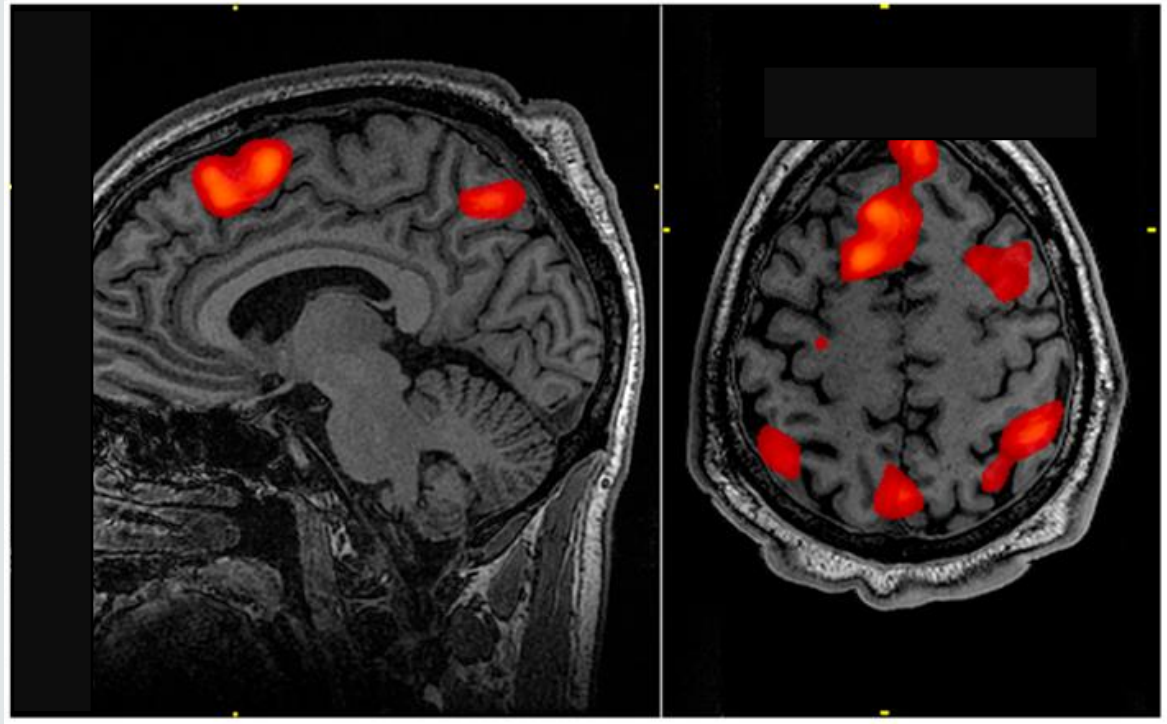


Digital Facial Reconstruction Sorbonne University

FMRI solutions?

Scalp the face! Remove/ roughly the facial attributes

- Potential loss of data
- Disclosure elsewhere



Statistical Disclosure Control?

- SDC training and principles for medical data users!
- Unique attributes, highly detailed information, informed consent, understanding risk
- Use and implementation of tools and solutions
- Universal agreement on standards
  - What is anonymized data
  - Evaluation of data access
- Development of a network to support this work?

Thank you!

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This work is funded by UK research and Innovation [Grant Number MC_PC_23006] as part of Phase 1 of the DARE UK (Data and Analytics Research Environments UK) programme, delivered in partnership with Health Data Research UK (HDR UK) and Administrative Data Research UK (ADR UK).

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