THE ADMINISTRATIVE BURDEN OF SHARING SENSITIVE DATA: CHALLENGES AND SOLUTIONS?

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IDCC 2018, BARCELONA
BACKGROUND TO THE RESEARCH DATA SERVICE

2013-2015 pilot service funded by Jisc
2015 onwards mainstream funded

Senior Research Data Librarian
Research Data Librarian
Assistant Research Data Librarian
Senior Technical Researcher

FAULTY AND DISCIPLINE SPECIFIC TRAINING

DMP ADVICE

OPEN?

RESEARCH DATA REPOSITORY
THE AIM
HOW CAN WE SHARE SENSITIVE DATA?

‘data relating to people, animal or plant species, data generated or used under a restrictive commercial research funding agreement, and any data likely to have significant negative public impact if released’
DATA RELATING TO PEOPLE

Sarah Simpson
AGE: 40
ADDRESS: 34 Toll Grove, Hull
OCCUPATION: Unemployed
STATUS: Married

Helen Carter
AGE: 31
ADDRESS: 2 Church Rd, Blythe
OCCUPATION: Unemployed
STATUS: Unmarried

Perry Jones
AGE: 29
ADDRESS: 411 Old St, Leeds
OCCUPATION: Designer
STATUS: Unmarried

David Bramwell
AGE: 43
ADDRESS: 10 Woolton Rd, Leeds
OCCUPATION: Teacher
STATUS: Unmarried

Henry Lloyd
AGE: 22
ADDRESS: 9 Fastanka St, Bath
OCCUPATION: Student
STATUS: Unmarried

Jennifer Cage
AGE: 37
ADDRESS: 2 Church St, Hull
OCCUPATION: Estate Agent
STATUS: Married
HIGH LEVEL OF ANONYMISATION?
IS IT STILL USEABLE?
WHAT DID PARTICIPANTS CONSENT TO?
RESTRICT ACCESS TO BONA FIDE RESEARCHERS
BENEFITS

- Researchers freed from administration
- Give an alternative to ‘contact the author’
- Provide long term access
- Provide an independent decision making body
THE PROCESS
TASK AND FINISH GROUP

- 3 x meetings comprised of:
  - Faculty Research Ethics Committees
  - Research Enterprise and Development - Research Governance, Contracts
  - IT services – Advanced Computing Research Centre, IT Governance and Risk
  - Library Services
  - Recommendations to the Ethics of Research Committee
  - Based on Expert Advisory Group for Data Access guidance (EAGDA)

- Form a Data Access Committee as an independent decision making body
- Draw up a Standard Data Access Agreement
- Collaborate on workflows to support sensitive data release
  - Data Access Committee / Task and Finish Group has a large overlap, as invested in the process and are the right balance of experts
CONTROLLED DATA
WORKFLOW

APPLICATION

<table>
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<th>Status</th>
<th>Count</th>
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<tr>
<td>Approved</td>
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<td>In progress</td>
<td>5</td>
</tr>
<tr>
<td>Rejected</td>
<td>2</td>
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1. Request form received
2. Acknowledge receipt
3. Access form request checks
4. Data Steward assessment (not a veto!)
5. Compile information for the Data Access Committee
6. Convene the Data Access Committee
7. Notify the applicant of the decision
8. Send a Data Access Agreement to the nominated Institutional Signatory
9. Receive back signed agreement
10. Obtain countersignature
11. Inform Data Steward
12. Arrange data delivery
THE RESULTS
ADMINISTRATIVE FLEXIBILITY

- Applicant
- Data Steward
- Secretary’s Office
- Research Contracts
- NHS Ethics Committees
- Human Resources
GET FROM A TO D – PITFALLS
**APPLICANT**

- Data Access Request Form
- Ethical Approval letter
- Funding, commissioning or sponsorship documents
- Research protocols
- Any other supporting information which adds weight

**SUPPORTING INFORMATION**

**DATA STEWARD**

- Ethical Approval plan/letter
- Patient Information Sheet
- Blank consent form
- Third party agreements/contracts
- Funding letter/collaboration agreements
COMPILING INFORMATION FOR THE DATA ACCESS COMMITTEE

Evidence of Institutional Affiliation: Contact Directory screenshot, email address, date
- Different approaches to contact directories- sign-on, opt-out
- Personal or departmental email addresses used
- Change of name
- Honorary status

Suitable Institutional Signatory: Contracts department, legal department, Research Office
- Head of Department
- Blanket Research Office email addresses

Application and documentation cross-referencing:
- Ethical approval and research title match
- Applicant is the PI, not an ECR or administrative staff
- Dates are consistent, and protocol/ethics match the application dates
LESSONS LEARNED