Session II: Infrastructure sustainability

Sharing Clinical Trial Data Workshop, Nov 2019

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Wellcome’s commitment to Open Research

- Wellcome is a global charitable foundation dedicated to improving health for everyone.
- We want the outputs of the research we fund to be accessed and used in ways that maximise benefit to health & society.
- We are a passionate champion and advocate of open access and data sharing, with long-standing policies in place.
Researcher challenges

Costs of sharing data 12%
Lack of time to deposit 16%
Not knowing which repository to use 20%
Unsure about copyright and licensing 23%
Organising data in a presentable and useful way 28%

Costs of sharing

- Career path for data stewards
- No minimum stds agreed

- Sustainability
- For profit involvement
- No minimum stds agreed

- System for rewarding

DMP/Curation/preparation for sharing

Storage, managing sharing

Secondary use
Curation cost example

Aim
To evaluate the time and cost of preparing a clinical trial data pack ready for sharing

Findings
SANAD (published 2007) required 50 hours (est. £3,185)
MENDS (published 2012) required 39.5 hours (est. £2,540)

Further resource would be required if queries raised after data distributed