Data Saving and Sharing in a Digital Age: Issues and Implications

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Seminar, Ministry of Health Wellington 11 February 2009









Presentation outline



Background paper

- Outline of TEC-funded pilot project
- Significance of data saving and sharing
- Some issues and implications
- Response of a UK research funder
 - Medical Research Council
- NZ Social Science Data Service (NZSSDS)
 - Data acquisition and preservation
 - Data access and analysis
 - Training
- Nesstar Demonstration
- Questions?

TEC Data Service Project



Objectives and components

- Acquire and protect key data sets
- Trial the exchange and analysis of data via BeSTGRID
- Establish sustainable model
- Training for provision and use of services

Outcome – Data Service

- Key social science data sets archived
- Those data sets readily accessible
- User community with necessary skills

Key partners

- Social science departments
- BeSTGRID project team
- Australian Social Science Data Archive (ASSDA)

Background to significance



Technology

- Common digital medium for all data
- High-performance computing
- Exchange of data via internet

Government policy

- "Knowledge" economy
- Value of science investment
- Funders insisting on saving and sharing

Science community

- Power of secondary data analysis
- Re-use of expensive data
- Primary collections harder
- Transparency and integrity

Wider implications



Research funders

• Insist on saving and sharing of data by grant holders?

University authorities

• Encourage saving and sharing among employees?

Ethics committees

• Favour preservation and re-use of research data?

Scientific community

Save, share and document data, take to secondary analysis?

Information managers

Will library be custodian of research data? Role of ITSS?

Data service concept

Is there a sustainable business/professional model?

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MRC Data Sharing Initiative:

The Forward Strategy

MAKING BETTER USE OF MRC-FUNDED RESEARCH DATA

www.mrc.ac.uk/PolicyGuidance/EthicsAndGovernance/DataSharing allan.sudlow@headoffice.mrc.ac.uk

Why Preserve or Share Research Data?



- Reduce Duplication
 - Effort of Data Creation and Analyses
- Secondary Analysis
 - Comparative & Confirmatory analysis
 - Testing of new & alternative hypotheses, tools & methods
 - Meta-analysis e.g. systematic analysis of clinical trials data
- Data enrichment
 - Linking datasets
 - Large-scale pooling for complex or comprehensive analyses
- Asset management

Data Access Principles



- Governance of access to & use of MRC-funded research data must balance the interests of data providers, users & research participants (personal data).
- Access policies & practices must be transparent, equitable, practicable & provide clear decisions, consistent with MRC data sharing policy.
- Access policies must comply with statutory and other regulatory requirements, and good research practice.
- Principles supported by online, example-led guidance on:
 - Dataset discovery
 - > Governing access and use of data
 - Data sharing agreements
 - > Data from research involving people
 - > Funding data access

Forward Strategy: Vision



- 1. Discovery of MRC research data along with metadata and other essential documentation
- 2. Managed access to, and use of, data for high-quality secondary research
- 3. Curation to enable informed re-use of preserved data
- 4. Long-term preservation of high-value MRC-funded datasets
- 5. Development of tools, standards and guidance needed to support these activities.

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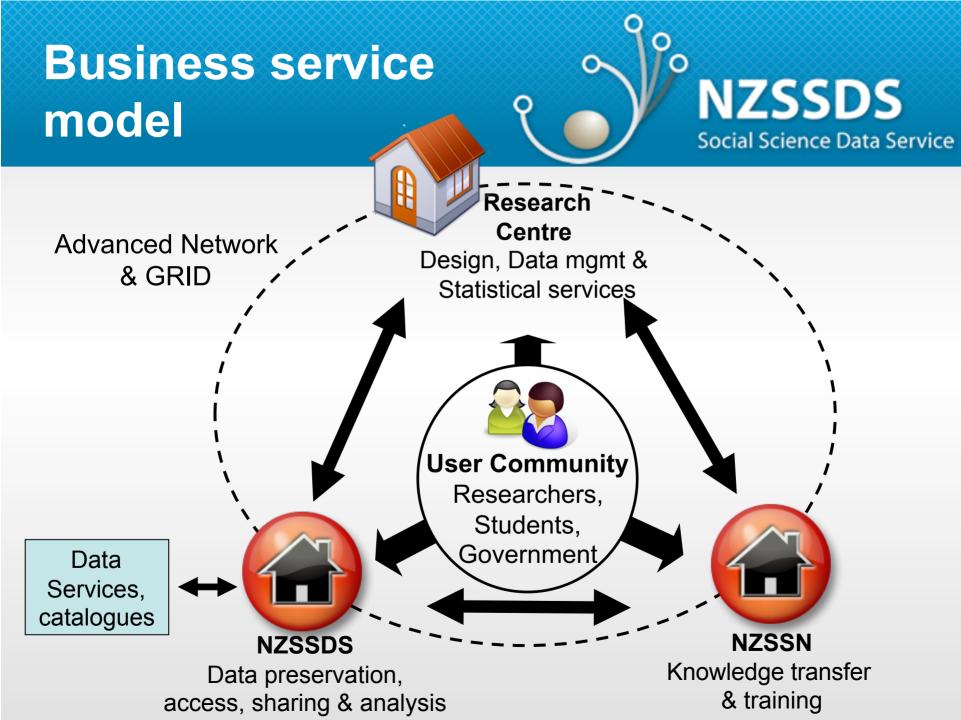


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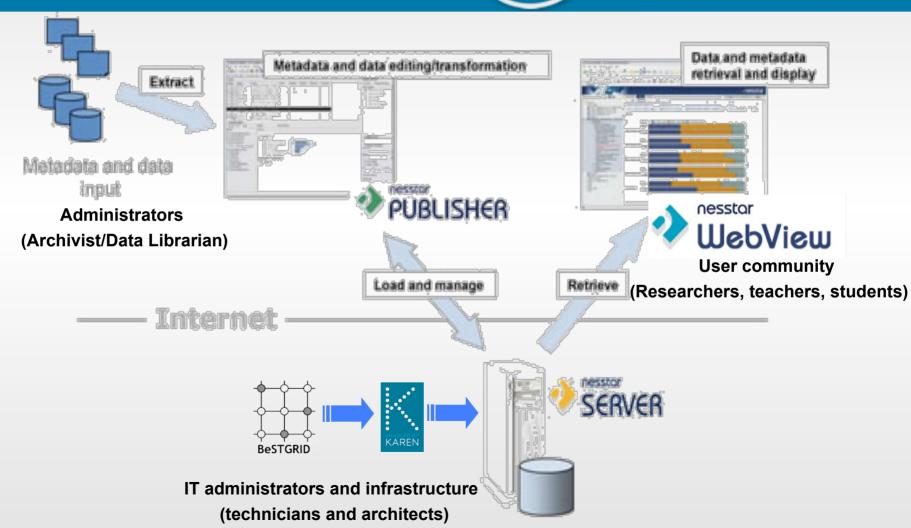
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Middleware - NESSTAR





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Nesstar Demonstration

- WebView; metadata, analysis and download
- Questions?

International Community



- ASSDA Australian Social Science Data Archive; http://assda.anu.edu.au
- CESSDA Council of European Social Science Data Archives; http://www.cessda.org
- IASSIST International Association of Social Science Information Service and Technology; http://www.iassistdata.org
- ICPSR Inter-University Consortium for Political and Social Research; http://www.icpsr.umich.edu/

Using the service – more info?



- Contact Martin, <u>admin@nzssds.org.nz</u>
- For further information about NZSSDS please visit:

http://www.nzssds.org.nz

Questions?