



because good research needs good data

## Introduction to Research Data Management Incentives and Barriers

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## My home – the DCC

▷ Missed capacity for research services in UK institutions

▷ Not just a UK problem – an international one

▷ Training, shared services, guidance, policy, standards, futures



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## What will we cover?

1. What's research data management?
2. How does it relate to open science?
3. Why does it matter:
  - » To you
  - » To all of us
4. What gets in the way of good practice?

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## An alternative summary

**Being Selfish**

**Being Just Good Enough**

**... and still benefiting others**

**What's possible now**

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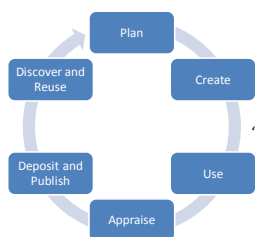
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## What is research data management?



"the active management and appraisal of data over the lifecycle of scholarly and scientific interest"

"an explicit process covering the creation and stewardship of research materials to enable their use for as long as they retain value."

**Data management is part of good research practice**

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## Why manage research data?

- ▷ To make research easier!
- ▷ To stop yourself drowning in irrelevant stuff
- ▷ In case you need the data later
- ▷ To avoid accusations of fraud or bad science
- ▷ To comply with the law or regulations
- ▷ To share data so others can use and learn from it
- ▷ To get credit for producing the data
- ▷ Because it's a condition of research funding

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## Why does this matter?

- ▷ Research quality
  - » How close can we get to the truth?
- ▷ Research speed
  - » How quickly can we get to the truth?
- ▷ Research finance
  - » How much does the truth cost?
- ▷ Improving one or more of these is of interest to all actors:
- ▷ Researchers as data creators
- ▷ Researchers as data reusers
- ▷ Research institutions
- ▷ Funders – hence government and society

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## Data loss

Digital data are fragile and susceptible to loss for a wide variety of reasons

- ▷ Natural disaster
- ▷ Facilities infrastructure failure
- ▷ Storage failure
- ▷ Server hardware/software failure
- ▷ Application software failure
- ▷ Format obsolescence
- ▷ Legal encumbrance
- ▷ Human error
- ▷ Malicious attack
- ▷ Loss of staffing competencies
- ▷ Loss of institutional commitment
- ▷ Loss of financial stability
- ▷ Changes in user expectations



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## Definitions of research data?

- ▷ "Research data, unlike other types of information is collected, observed, or created, for purposes of analysis to produce original research results."



- ▷ "Research data is defined as recorded factual material commonly retained by and accepted in the scientific community as necessary to validate research findings; although the majority of such data is created in digital format, all research data is included irrespective of the format in which it is created."



- ▷ "Evidence which is used or created to generate new knowledge and interpretations. 'Evidence' may be intersubjective or subjective; physical or emotional; persistent or ephemeral; personal or public; explicit or tacit; and is consciously or unconsciously referenced by the researcher at some point during the course of their research."




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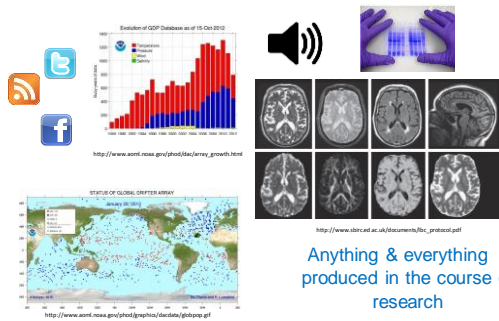
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## So, what might this include?

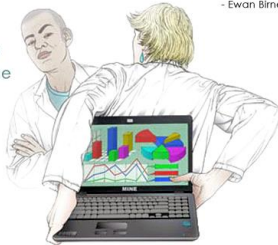


## Why make data available?

"It was \*never\* acceptable to publish papers without making data available."

- Ewan Birney

#OpenData  
#OpenScience



Original image via doi:10.1038/461145a. "Research cannot flourish if data are not preserved and made accessible. Data management should be woven into every course in science." - Nature 461, 145

## Sharing leads to breakthroughs

### Sharing of Data Leads to Progress on Alzheimer's

By STEVE KOPPEL

Published online 12:00 PM

In 2009, a group of scientists and executives from the [National Institutes of Health](#), the [Food and Drug Administration](#), the drug and medical imaging industries, universities and nonprofit groups joined in a protest that experts say had no precedent: a collaborative effort to find the biological markers that show the progression of [Alzheimer's disease](#) to the human brain.



Now, the effort is bearing fruit with a wealth of recent scientific papers on the early diagnosis of Alzheimer's using methods like PET scans and tests of spinal fluid. More than 100 studies are under way to test drugs that might slow or stop the disease. And the collaboration is already serving as a model for similar efforts against [Parkinson's disease](#). A \$40 million project to look for biomarkers for Parkinson's, sponsored by the [Michael J. Fox Foundation](#), plans to enroll 100 study subjects in the United States and Europe.

[www.nytimes.com/2010/08/13/health/research/13alzheim.html?pagewanted=all&\\_r=0](http://www.nytimes.com/2010/08/13/health/research/13alzheim.html?pagewanted=all&_r=0)

*"It was unbelievable. It's not science the way most of us have practiced in our careers. But we all realised that we would never get biomarkers unless all of us parked our egos and intellectual property noses outside the door and agreed that all of our data would be public immediately."*

Dr John Trojanowski, University of Pennsylvania

...and increases the speed of discovery

## Sharing demonstrates integrity

### The case for open data: the Duke clinical trials

9 May 2011 | in Blogs  
By: Kevin Ashley

A recent story in the Times Higher Education Supplement<sup>1</sup>, backed up by leader comment, provides a highly readable summary of a long and complex case of flawed clinical research and the difficulties encountered by those trying to expose the flaws. It also provides a strong argument for being open with data and code at an early stage, even where sensitive data is involved.

Since this research involved cancer chemotherapy, the lives of people and their quality of life whilst undergoing treatment potentially depended on the truth of the research findings. As the article shows, testing the findings would have been far easier and quicker had the original data, and the methods used to analyse it, been made available from the outset. Expensive clinical trials could have been avoided. Potentially, better treatments could have been brought to trial more quickly since the false promise of this particular intervention was clear.

It's often felt that whilst some subjects may be prime candidates for openness with data, those involving human subjects, and in particular clinical medicine, present too many ethical and regulatory challenges. Examples such as this show that such a position is wrong. Even if ethical and regulatory barriers exist, wider ethical issues – the provision of unnecessary human suffering being one – demand that we be as open as possible with clinical data. In this case, no identifying information needed to be released to allow others to validate or investigate this work. Even when the

#### Most Read

- Rebuilding for Research: observations on an RLIN report
- Realigning Libraries for the Data Decade
- New look: Managing Research Data
- What's New Issue 42: February 2012
- How can we evaluate data repositories? Posters from DroidUK

#### Site Comments

Incremental project

Incremental project

Incremental project

Incremental project

Incremental project

## Not doing so has consequences...

#### Everything

#### Images

#### Maps

#### Videos

#### News

#### Shopping

#### More

#### Shortcuts in Email, iRC

#### Change location

#### The web

#### Pages from the UK

#### All results

#### Related searches

#### More search tools

#### Breaking news: lawsuit filed against Duke for fraudulent cancer study

www.naturenews.com/03591\_cancer\_cruelty... filed from

11 Sep 2011 – The plaintiffs claim Duke researchers were engaged in fraudulent and negligent behavior when they set up a clinical trial using cancer patients ...

How a New Hope in Cancer Fell Apart - NYTimes.com

www.nytimes.com/2011/09/06/health/research/ligaments.html

7 Jul 2011 – But the research at Duke turned out to be wrong. Its gene-based tests proved worthless, and the research behind them was discredited.

Journalist Reports Duke Cancer Research Fraud: Duke Reads ...

www.associatedpress.com/03591\_cancer\_cruelty... filed from

11 Sep 2011 – The plaintiffs claim Duke researchers were engaged in fraudulent and negligent behavior when they set up a clinical trial using cancer patients ...

Breaking news: lawsuit filed against Duke for fraudulent cancer ...

www.gut.com/03591\_cancer\_cruelty... filed from

11 Sep 2011 – The plaintiffs claim Duke researchers were engaged in fraudulent and negligent behavior when they set up a clinical trial using cancer patients ...

Fraudulent Cancer Treatment Pushed by Major University

www.gut.com/03591\_cancer\_cruelty... filed from

11 Sep 2011 – The plaintiffs claim Duke researchers were engaged in fraudulent and negligent behavior when they set up a clinical trial using cancer patients ...

Duke Sued Over Cancer Trials - ABC News

abcnews.go.com/Health/Health/03591\_cancer\_cruelty... filed from

11 Sep 2011 – The trial, which began in 2007 and 2008, was based on work by Dr. Axel Potti – a former Duke cancer researcher who claimed to have ...

## Integrity – not without data

#### Bad Pharma

#### Ben Goldacre

#### Ben Goldacre

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"The case for open data: the Duke Clinical Trials" – blog post, Kevin Ashley, <http://www.dcc.ac.uk/news/case-open-data-duke-clinical-trials>

"Lies, Damned Lies and Research Data: Can Data Sharing Prevent Data Fraud?" – Doorn, Dillo, van Horik, UDC R(1); doi:10.2218/jdc.v8i1.256

## Benefits for you - make data citable

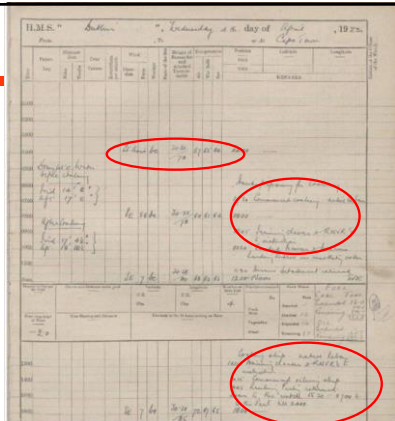
- ▷ Making data available increases citations
- ▷ Everyone – academic, funder, institution – loves citations
- ▷ Want evidence?
  - » Alter, Pienta, Lyle – 240%, social sciences \*
  - » Piwowar, Vision – 9% (microarray data)†
  - » Henneken, Accomazzi – 20% (astronomy) #

# Edwin Henneken, Alberto Accomazzi, (2011) Linking to Data - Effect on Citation Rates in Astronomy. <http://arxiv.org/abs/1111.3618>  
 \* Amy Pienta, George Alter, Jared Lyle, (2010) The Enduring Value of Social Science Research: The Use and Reuse of Primary Research Data. <http://hdl.handle.net/2027.42/78307>  
 † Piwowar H, Vision TJ. (2013) Data reuse & the open data citation advantage. PeerJ PrePrints 1:e1v1 <http://dx.doi.org/10.7287/peerj.preprints.1v1>

## The Old weather project

Data for research,  
not from research

2016-08-05



## Data reuse stories

- ▷ The palaeontologist who saved years of work with archaeological data
- ▷ The 19<sup>th</sup>-century ships logs that help us model climate change
- ▷ The 'noise' from research radar that mapped dust from Eyjafjallajökull

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## Data reuse - messages

Often your data tells stories that your publications do not

Discipline-bounded data discovery doesn't give us all we need or want

Not all data comes from other researchers

One person's noise is another person's signal

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## Should all data be open?

- ▷ NO
- ▷ Many reasons – most to do with human subjects
- ▷ But data existence should always be open
- ▷ Allows discovery & negotiation on use
- ▷ Avoids pointless replication

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## Ethics aren't always obvious

- ▷ Releasing genome data is ?OK when it's:
  - » An identified human subject
  - » An anonymous human subject
  - » Your pet dog
  - » Another mammal
  - » An insect
  - » A plant
  - » A virus

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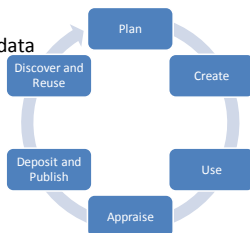
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## What is involved in RDM?

- ▷ Data Management Planning
- ▷ Data creation
- ▷ Annotating / documenting data
- ▷ Analysis, use, versioning
- ▷ Storage and backup
- ▷ Publishing papers and data
- ▷ Preparing for deposit
- ▷ Archiving and sharing
- ▷ Licensing
- ▷ Citing...




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## Data management planning

- ▷ Many funders expect a DMP to be produced as part of project development, most expect it to be submitted with the grant application
- ▷ Examples of good DMPs are available here:
  - » <http://www.dcc.ac.uk/resources/data-management-plans/guidance-examples>
- ▷ The DCC provides an online tool to guide you through the process of developing a funder-specific DMP



<https://dmponline.dcc.ac.uk/>

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## What data to keep

### Roles and Responsibilities

#### Researcher ('data creator')

- Provide enough information for others to assess the research data's scientific and scholarly quality and compliance with disciplinary or ethical norms.
- Provide relevant information for the repository to identify who will use the data and how i.e. the 'designated community', and any specific access requirements or constraints.
- Provide the research data in formats recommended by the data repository.
- Provide the metadata requested by the repository.

#### Data centre or repository

- Make explicit its mission in the area of digital archiving, and its selection policy for digital objects.
- Ensure compliance with legal regulations and contracts.
- Ensure the authenticity and integrity of the digital objects and the metadata.
- Assume responsibility from the data producer for ensuring the digital objects are accessible and available to a defined 'designated community'.
- Plan for long-term preservation of the digital assets.



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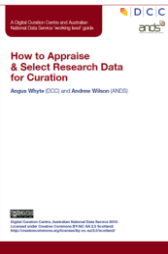
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## Appraisal and deposit



How to Appraise & Select Research Data for Curation  
Angus Whyte, Digital Curation Centre,  
and Andrew Wilson, Australian National  
Data Service (2010)

1. **Relevance to Mission** – including any legal/funder requirement to retain the data beyond its immediate use.
2. **Scientific or Historical Value** – significance and relationship to publications etc.
3. **Uniqueness** – can it be found elsewhere / if we don't preserve it, who will?
4. **Potential for Redistribution** – quality / IP / ethical concerns are addressed.
5. **Non-Replicability** – either impossible to replicate (e.g. atmospheric or social science data) or not financially viable.
6. **Economic Case** – costs of managing and preserving the resource stack up well against potential future benefits.
7. **Full Documentation** – surrounding / contextual information necessary to facilitate future discovery, access, and reuse is adequate.

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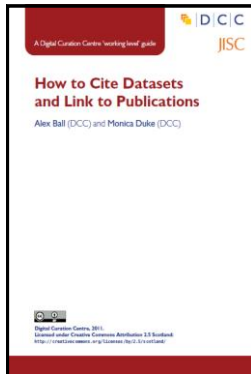
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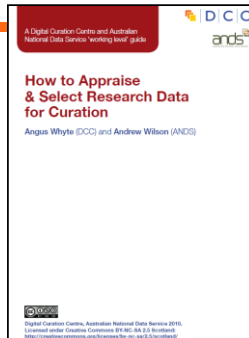
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Kevin Ashley - Kevin Ashley  
2.0



Digital Curation Centre, Australian National Data Service 2010.  
Licensed under Creative Commons Attribution 3.0 license  
<http://creativecommons.org/licenses/by/3.0/>

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## RDM and sharing : a best practice guide



BEST PRACTICE FOR RESEARCHERS



<http://data-archive.ac.uk/media/2894/managingsharing.pdf>

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## Acquire research data skills

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## Data repositories

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## Why hand data over for preservation?

- ▷ To preserve the data themselves “Data rot”
  - » Bitwise preservation
  - » Format migration
- ▷ To preserve contextual information
  - » Often held in a researcher’s head
  - » Notes often aren’t detailed enough
- ▷ Protecting digital objects requires specialist skills and particular information to be captured
- ▷ The aim is to enable the reuse of data

**Not everything can, or should be preserved!**

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## LEGAL ISSUES

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## Nature, this Wednesday 3<sup>rd</sup> August

Legal confusion threatens to slow data science

Researcher who spent months chasing permission to republish online data sets urges others to read up on the law.

Simon Overman

03 August 2016

Rights & Permissions



Daniel Himmelstein, pictured at his previous research post at the University of California, San Francisco.

Knowledge from millions of biological studies encoded into one network — that is Daniel Himmelstein's alluring description of *repositor*, a free online resource that melds data from 28 public sources on links between drugs, genes and diseases. But for a product built on public information, obtaining legal permissions has been surprisingly tough.

## Two types of issue

- ▷ Things that the law requires you to consider
- ▷ Things that the law allows you to do
- ▷ Can you think of any of these?

## Requirements

- ▷ Data protection
  - » If human subjects are involved
  - » Common European framework
  - » Informed consent essential
  - » Make consent broad to allow reuse
  - » Protect data
  - » Provide subject access
  - » Right of correction
  - » Beware – law under review in Europe

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## FOI & EIR

- ▷ FOI = Freedom of Information
- ▷ EIR = Environmental Information Regulations
- ▷ First is nation-state specific; second from European regulation
- ▷ Both have similar effects, but differ in detail

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## Consequences for researchers

- ▷ Your organisation must know what data it possesses
- ▷ It must know whether exceptions to access may apply
- ▷ It must know if some of the data belongs to others
- ▷ It must know what data once existed, but has now been deleted – and why
- ▷ These are difficult questions for most of us!

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## What the law allows - licensing

- ▷ Licences allow you to constrain how others use your data
- ▷ They range from very open to very restrictive
- ▷ You **MUST** own the data in order to be able to licence it

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## License your data for reuse



Outlines pros and cons of each approach and gives practical advice on how to implement your licence

### CREATIVE COMMONS LIMITATIONS

-  NC Non-Commercial  
*What counts as commercial?*
-  SA Share Alike  
*Reduces interoperability*
-  ND No Derivatives  
*Severely restricts use*

[www.dcc.ac.uk/resources/how-guides/license-research-data](http://www.dcc.ac.uk/resources/how-guides/license-research-data)

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## Data and copyright

- ▷ Ability to copyright data varies throughout the world
- ▷ Europe also offers 'database right' – applies even if data cannot be copyrighted.
- ▷ International licences help avoid this legal minefield
- ▷ Standard licences strongly recommended – we are not all legal experts

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## Types of data licence

- ▷ Creative Commons V4.0 CC-BY or CC0 strongly recommended
- ▷ Also in existence:
  - » Open Data Commons
  - » Open Government Licence

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## EXERCISE – BARRIERS TO SHARING

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## Finally...

- ▷ Well-managed data makes your research easier, now and in future
- ▷ Well-managed data is easier to share, more likely to be re-used
- ▷ Sharing data is good for you
- ▷ It's good for all of us
- ▷ It isn't as hard as you think – we're here to show you how!

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## How do you share data effectively?

- ▷ Use appropriate repositories, this catalogue is a good place to start
  - » [Re3data](http://www.re3data.org/) - <http://www.re3data.org/>
- ▷ Document and describe it enough for others to understand, use and cite
  - » <http://www.dcc.ac.uk/resources/how-guides/cite-datasets>
- ▷ Licence it so others can reuse
  - » [www.dcc.ac.uk/resources/how-guides/license-research-data](http://www.dcc.ac.uk/resources/how-guides/license-research-data)



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