

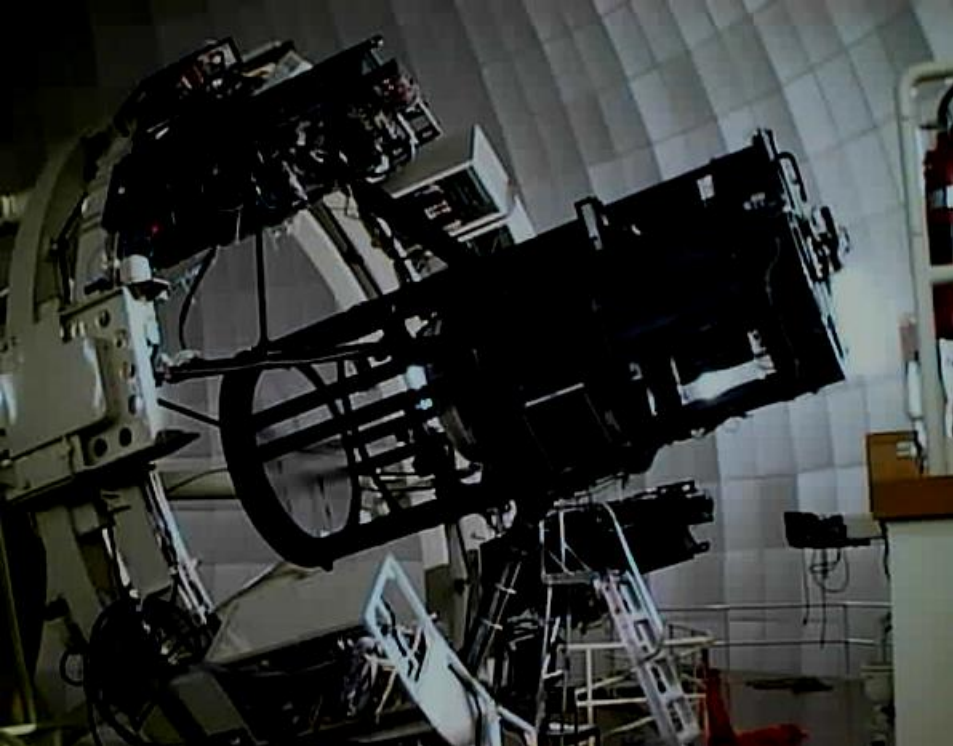
Things to do with data: Biomedical research databases & data sharing

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<http://www.brisshit.le.ac.uk> @brisskit

Oxford, 3rd Dec 2014





Aladin v5.0 *** BETA VERSION (based on v5.023) ***

File Edit Image Catalog Overlay View Tool Help

Location 14:02:35.01 +54:2

Object name resolver Ctrl+R
 Simbad automatic pointer
 Tooltip on sources
 Auto-scroll on mouse pan
 Script Console... FS
 Macro controller...

VO tools
 Remote tools
 Plugins

VO tool controller...

VisIVO 3D visualisation tool [INAF/CINECA].
 VOPlot plotting tool [VO-India]
 TOPcat tabular data viewer [Starlink/Astrogrid]
 SPLAT spectral analysis tool [Starlink/PPARC/JAC]

filter
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Pixel unknown full

Zoom 1x

Search

MAIN ID	OTYPE	RA	DEC	COO ...	COO ...	C...	PMRA	PMDEC
[HG69] NGC 1969 146	HII	14 02 36.7	+54 21 55	3000	3000	171		
HGCK 179	HII	14 02 36.3	+54 21 46	3000	3000	171		
HGCK 180	HII	14 02 36.5	+54 22 00	3000	3000	171		
NGC 5451	Part...	14 02 36.1	+54 21 51	3000	3000	171		
HGCK 178	HII	14 02 35.8	+54 21 54	3000	3000	171		

(c)1999-2008 ULP/CHRS - Centre de Données astronomiques de Strasbourg 27 sel / 3030 src 8Mb

Why open?

- As a first step towards this intelligent openness, data that underpin a journal article should be made concurrently available in an accessible database
- We are now on the brink of an achievable aim: for all science literature to be online, for all of the data to be online and for the two to be interoperable. [p.7]
- Royal Society June 2012, *Science as an Open Enterprise*,
<http://royalsociety.org/policy/projects/science-public-enterprise/report/>
- Issues linking data to the scientific record:
 - Data persistence
 - Data and metadata quality
 - **Attribution and credit for data producers**
- Geoffrey Boulton (Edinburgh), Lead author:
 - “Science has been sleepwalking into crisis of replicability...and of the credibility of science”
 - “Publishing articles without making the data available is *scientific malpractice*”

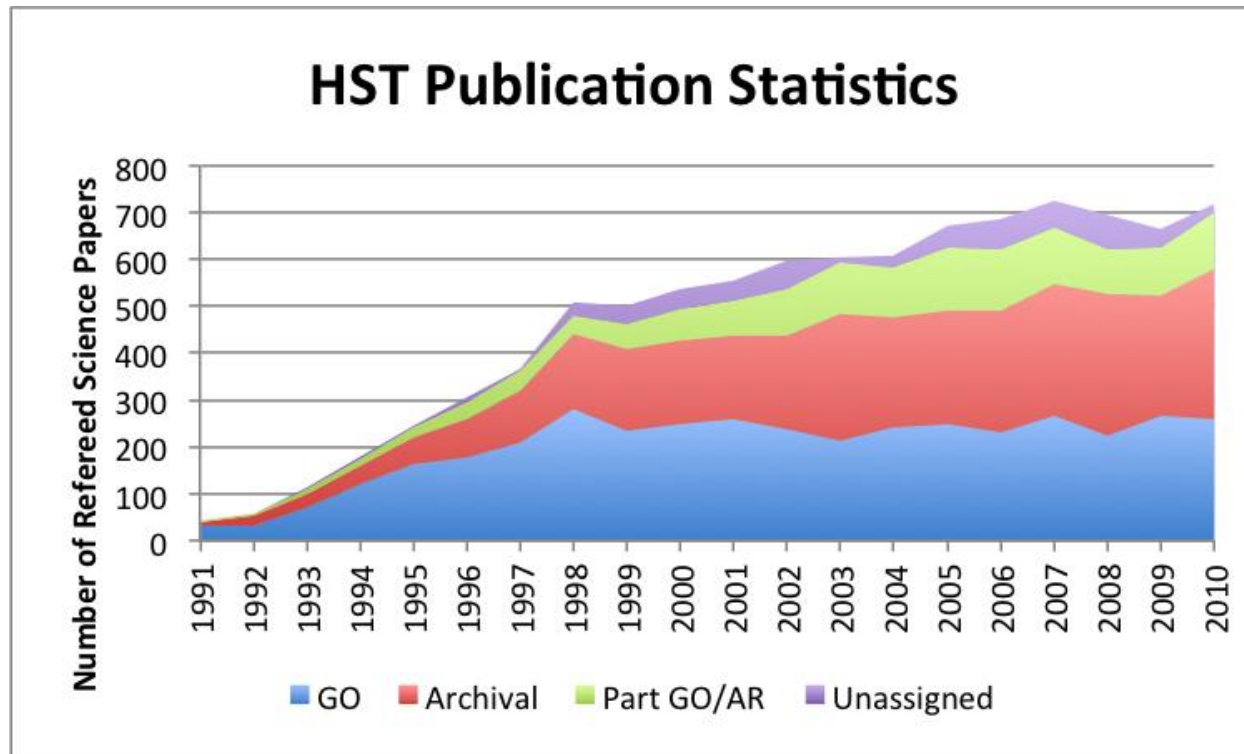


Science as an
open enterprise

June 2012

THE
ROYAL
SOCIETY

Data Reuse: asking new questions



Hubble Space Telescope

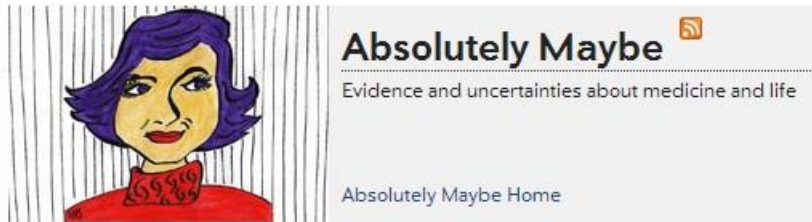
- Papers based upon reuse of archived observations now exceed those based on the use described in the original proposal.
 - <http://archive.stsci.edu/hst/bibliography/pubstat.html>
- See also work by Piwowar & Vision re life sciences: “Data reuse and the open data citation advantage”
 - <http://peerj.com/preprints/1/>

Oh, and.... says so :P


The logo for G8 UK United Kingdom 2013, featuring the text 'G8 UK' in large blue letters with a red underline, and 'UNITED KINGDOM 2013' in smaller blue letters below it.

We are committed to openness in scientific research data to speed up the progress of scientific discovery, create innovation, ensure that the results of scientific research are as widely available as practical, enable transparency in science and engage the public in the scientific process.

- To the greatest extent and with the fewest constraints possible **publicly funded scientific research data should be open**, while at the same time respecting concerns in relation to privacy, safety, security and commercial interests, whilst acknowledging the legitimate concerns of private partners.
- Open scientific research data should be easily discoverable, accessible, assessable, intelligible, useable, and **wherever possible interoperable to specific quality standards**.
- To ensure successful adoption by scientific communities, open scientific research data principles will need to be underpinned by an appropriate policy environment, including **recognition of researchers fulfilling these principles, and appropriate digital infrastructure**.



Opening a can of data-sharing worms

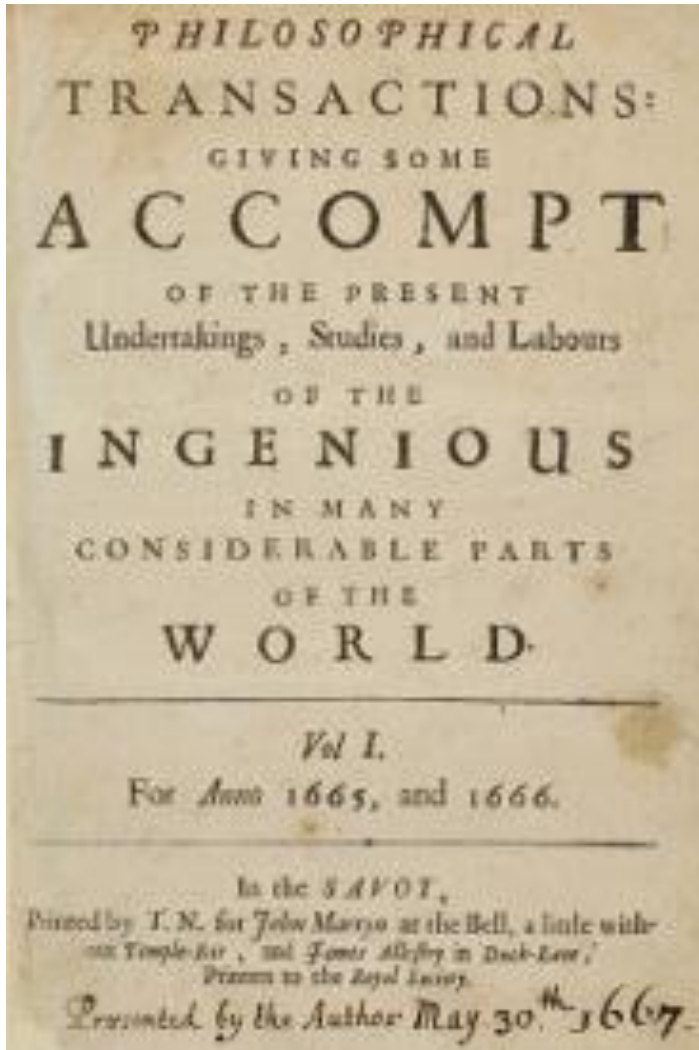
By Hilda Bastian | September 10, 2013 |  2

Scale of the problem: who, what, when where....?

<http://blogs.scientificamerican.com/absolutely-maybe/2013/09/10/opening-a-can-of-data-sharing-worms/>

- Timothy Vines and colleagues studied reproducibility of data sets in zoology and changes through time
 - gathered 516 papers published between 1991 and 2011
 - then they tried to track the data down...
- Even tracking down the authors was a challenge
 - Over time a dwindling minority of papers were accompanied by author email addresses that still functioned
- only 37% of the data - even from papers in 2011 - were still findable and retrievable
 - proportion dropped each earlier year
- For papers published in 1991
 - only 7% of the data could be determined to truly still be in existence and retrievable
 - few authors could be found, and most of them were reporting that their data were lost or inaccessible

This isn't new...



Henry Oldenburg

- inveterate correspondent
- now think of as scientist
- Had idea to publish Philosophical Transactions (1665):
 - Should be written in vernacular not Latin
 - Underlying evidence must be concurrently published
 - Helped propel Europe at the time
 - Concept of scientific self correction
 - able to write it's errors
- Wrote: “thought fit to employ the [printing] press.....Universal Good of Mankind”
 - How do we achieve these ends in the post-Gutenberg era?

Data as a “public good” (2011)



RESEARCH COUNCILS UK

Excellence with Impact

Home > Research and Funding > RCUK Common Principles on Data Policy

RCUK Common Principles on Data Policy

Making research data available to users is a core part of the Research Councils' remit and is undertaken in a variety of ways. We are committed to transparency and to a coherent approach across the research base. These RCUK common principles on data policy provide an overarching framework for individual Research Council policies on data policy.

Principles

- Publicly funded research data are a public good, produced in the public interest, which should be made openly available with as few restrictions as possible in a timely and responsible manner that does not harm intellectual property.
- Institutional and project specific data management policies and plans should be in accordance with relevant standards and community best practice. Data with acknowledged long-term value should be preserved and remain accessible and usable for future research.
- To enable research data to be discoverable and effectively re-used by others, sufficient metadata should be recorded and made openly available to enable other researchers to understand the research and re-use potential of the data. Published results should always include information on how to access the supporting data.
- RCUK recognises that there are legal, ethical and commercial constraints on release of research data. To ensure that the research process is not damaged by inappropriate release of data, research organisation policies and practices should ensure that these are considered at all stages in the research process.
- To ensure that research teams get appropriate recognition for the effort involved in collecting and analysing data, those who undertake Research Council funded work may be entitled to a limited period of privileged use of the data they have collected to enable them to publish the results of their research. The length of this period varies by research discipline and, where appropriate, is discussed further in the published policies of individual Research Councils.
- In order to recognise the intellectual contributions of researchers who generate, preserve and share key research datasets, all users of research data should acknowledge the sources of their data and abide by the terms and conditions under which they are accessed.
- It is appropriate to use public funds to support the management and sharing of publicly-funded research data. To maximise the research benefit which can be gained from limited budgets, the mechanisms for these activities should be both efficient and cost-effective in the use of public funds.

Search:

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This website

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Terms and Conditions of Research Council fEC Grants

Terms and Conditions of Research Council Training Grants

Open Access

RCUK Common Principles on Data Policy

Efficiency 2011-15

Research and funding

Research Careers

Public Engagement with Research

Knowledge Exchange and Impact

International

Press and Media

Publications

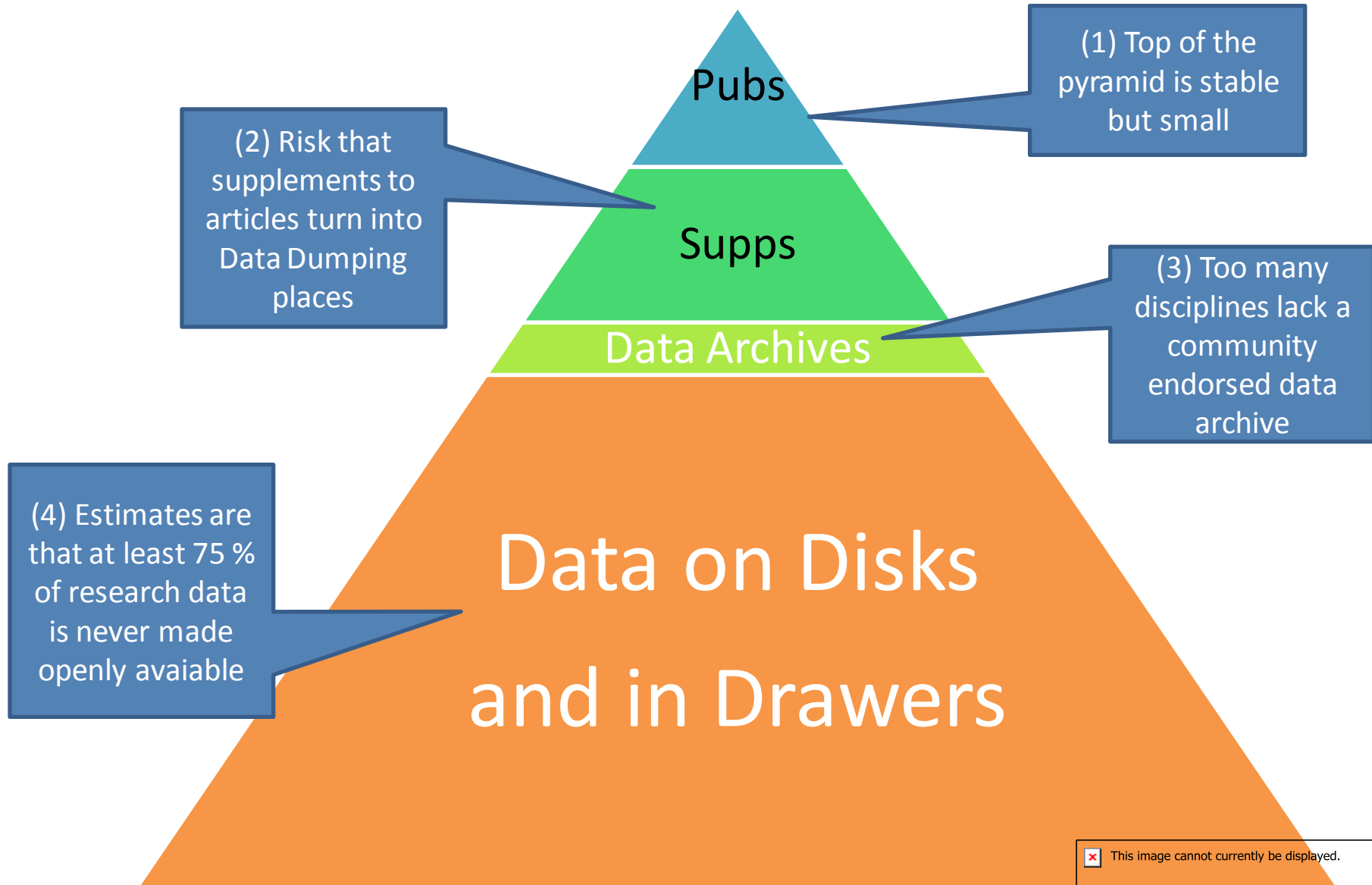
About


- Public good
- Preservation
- Discovery
- Confidentiality
- First use
- Recognition
- Public funding

So what do we mean by publishing data?

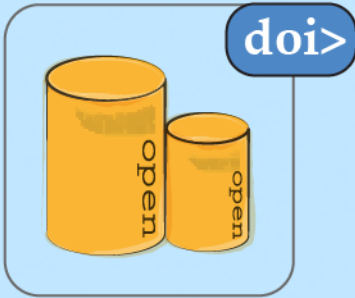
- The familiar:
 - Supplementary tables via journal or
 - Archived raw or calibrated facility data
 - Discipline specific and institutional / national archives
- Data under the graph?
 - In order to reproduce and adapt article analysis
- “Research ready” open data
 - In order to reuse and repurpose
 - for interdisciplinary researchers, community, business
 - Ideally peer reviewed?

ODE Data Publication Pyramid:

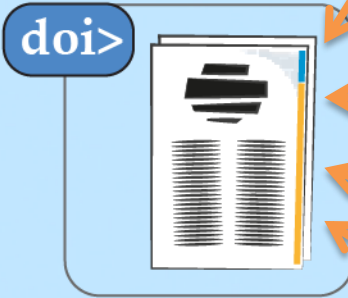


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Repository



Metajournal



56 citations



3 Wikipedia mentions



152 tweets



31 Facebook likes



19 Zotero readers

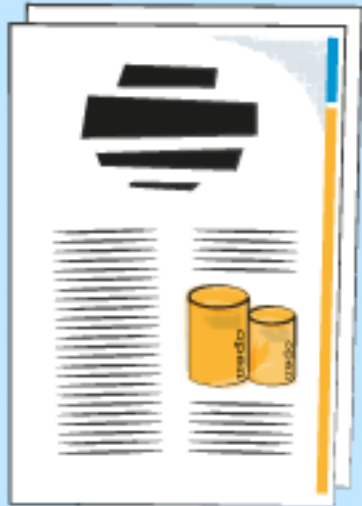


Books



Research articles

Structure of a data paper:



A data paper...

- ... describes the methodology with which a dataset was created.
- ... describes the dataset itself.
- ... details the reuse potential of the data.
- ... is often authored by a data scientist.
- ... is citable, enabling reuse to be tracked.

A data paper is not...

- ... a research paper. A data paper only describes a dataset. But it will reference research papers that are based on the data.
- ... simply replication of the information in a data repository.

Peer review

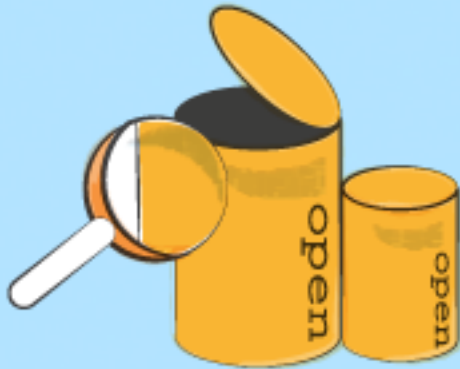


1. The paper contents

- a. The methods section of the paper must provide sufficient detail that a reader can understand how the resource was created.
- b. The resource must be correctly described.
- c. The reuse section must provide concrete and useful suggestions for reuse of the resource.

2. The deposited resource

- a. The repository must be suitable for resource and have a sustainability model.
- b. Open license permits unrestricted access if possible (e.g. CC0), or guarantees controlled access if unavoidable.
- c. A version in an open, non-proprietary format.
- d. Labeled in such a way that a 3rd party can make sense of it.
- e. Must be actionable.



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Tweets

mike galsworthy
@mikegalsworthy

#Opendata Hooray! New data journal just launched (Journal of Open Public Health Data) <http://t.co/ydmdINwPqM> @up_jophd @openscience @UKODI

Jul 15th

JOPHD
@up_jophd

Just launched: the Journal of Open Public Health Data is now live! <http://t.co/JOL9uo4plyv>

Jul 15th

Ubiquity Press u[
@ubiquitypress

New report out on realising an #OpenData culture from

The Journal of Open Public Health Data (JOPHD) features peer reviewed data papers describing public health datasets with high reuse potential. We are working with a number of specialist and institutional data repositories to ensure that the associated data are professionally archived, preserved, and openly available. Equally importantly, the data and the papers are citable, and reuse is tracked.




Most recent articles

 Alexander, Wint
Projected Population Proximity Indices (30km) for 2005, 2030 & 2050
11 Jul 2013

 Wint, Morley, Alexander
Four Rodent and Vole Biodiversity Models for Europe
11 Jul 2013

 Knowles, Olafsdottir
Data: 'Initial Clinical Referral Standards after Newborn Screening...'
09 Jul 2013

 Tadic, Knowles, Rahi
Data from the Multiprofessional

Most popular articles

 Alexander, Wint
Projected Population Proximity Indices (30km) for 2005, 2030 & 2050
11 Jul 2013

 Wint, Morley, Alexander
Four Rodent and Vole Biodiversity Models for Europe
11 Jul 2013

 Tadic, Knowles, Rahi
Data from the Multiprofessional Workshop: 'Paediatric...'
09 Jul 2013

 Knowles, Olafsdottir
Data: 'Initial Clinical Referral Standards

Ads

It's a long road....

What do researchers need to make this all possible?

- Incentives - citations, promotion, support - long way to go
- Institutional and funder policy framework - mostly there now
- Appropriate discipline specific community centres of expertise - rare, mostly limited to big science niches or very broad but poorly sustained
- Institutional support services for the basics - pilots to date
- Software tools that are open and can be adapted - on the way
- *Welcoming and reasonable journal homes!*



PREPARDE: Peer REview for Publication & Accreditation of Research Data in the Earth sciences

Jonathan Tedds (Leicester), Sarah Callaghan (BADC), Fiona Murphy (Wiley), Rebecca Lawrence (F1000R), Geraldine Stoneham (MRC), Elizabeth Newbold (BL), Rachel Kotarski (BL), Matthew Mayernik (NCAR), John Kunze, Carly Strasser (CDL), Angus Whyte (DCC), Becca Wilson (Leicester), Simon Hodson (Jisc) and #PREPARDE project team + Geraldine Clement Stoneham (MRC), Elizabeth Newbold, Rachel Kotarski (BL) on data peer review

<http://www.le.ac.uk/projects/preparde>



From Mayernik et al. 2014 Most cited Bulletin of the American Meteorological Society (BAMS) articles. Data from Web of Science, gathered on June 11, 2013

<http://journals.ametsoc.org/doi/abs/10.1175/BAMS-D-13-00083.1>

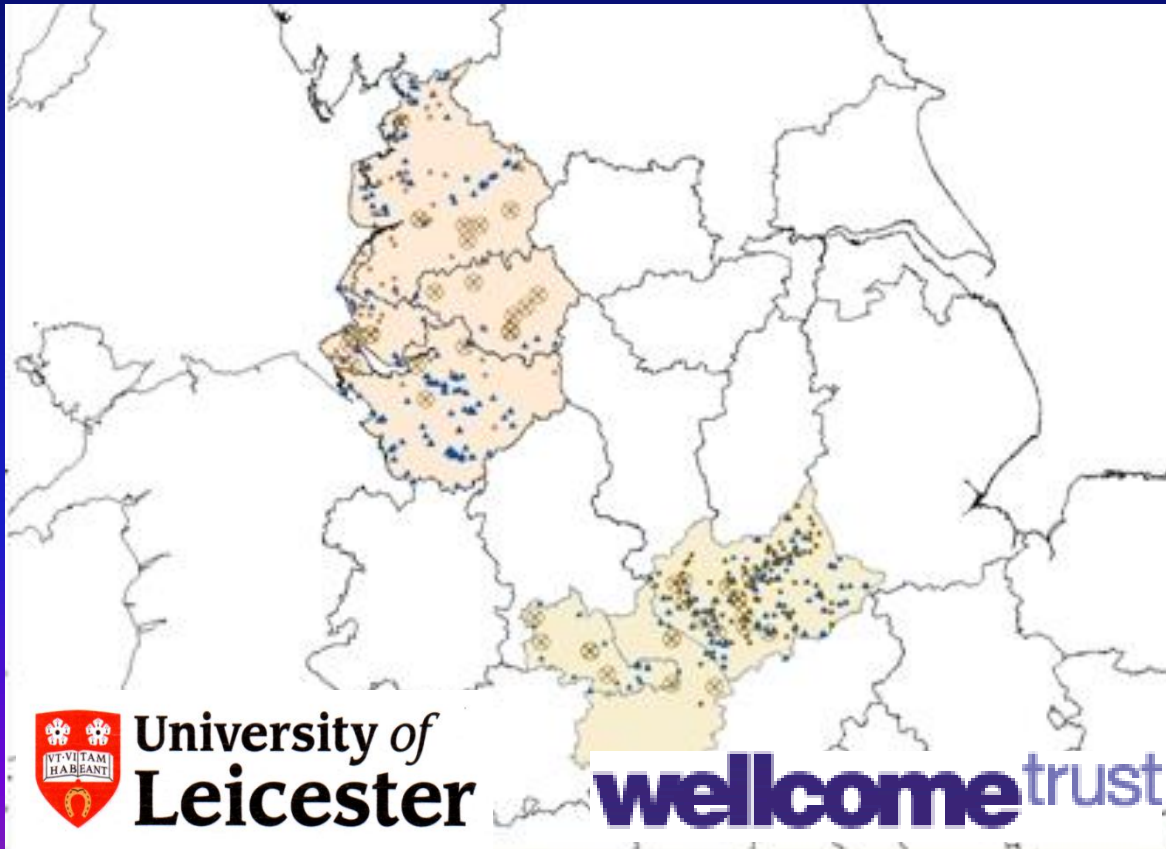
Article	Data paper?	Citations	Article details
1	Yes	10,113	Kalnay, E; et al. The NCEP/NCAR 40-year reanalysis project, 1996.
2	No	3,201	Torrence, C; Compo, GP. A practical guide to wavelet analysis, 1998.
3	No	2,367	Mantua, NJ; et al. A Pacific interdecadal climate oscillation with impacts on salmon production, 1997.
4	Yes	1,987	Kistler, R; et al. The NCEP-NCAR 50-year reanalysis: Monthly means CD-ROM and documentation, 2001.
5	Yes	1,791	Xie, PP; Arkin, PA. Global precipitation: A 17-year monthly analysis based on gauge observations, satellite estimates, and numerical model outputs, 1997.
6	Yes	1,448	Kanamitsu, M; et al. NCEP-DOE AMIP-II reanalysis (R-2), 2002.
7	No	1,014	Baldocchi, D; et al. FLUXNET: A new tool to study the temporal and spatial variability of ecosystem-scale carbon dioxide, water vapor, and energy flux densities, 2001.
8	Yes	902	Rossow, WB; Schiffer, RA. Advances in understanding clouds from ISCCP, 1999.
9	Yes	900	Rossow, WB; Schiffer, RA. ISCCP cloud data products, 1991.
10	No	877	Hess, M; Koepke, P; Schult, I. Optical properties of aerosols and clouds: The software package OPAC, 1998.
11	No	815	Willmott, CJ. Some comments on the evaluation of model performance, 1982.
12	No	815	Trenberth, KE. The definition of El Nino, 1997.
13	Yes	785	Woodruff, SD; Slutz, RJ; et al. A comprehensive ocean-atmosphere data set, 1987.
14	Yes	776	Meehl, G.A.; et al. The WCRP CMIP3 multimodel dataset - A new era in climate change research, 2007.

Enabling Open Data Publishing

- Active Data Management Planning
 - built in at proposal stage
 - Local institutional tweaks of funder and local templates
 - Implemented and evolved in project
 - Data Management Plan as a live, evolving object
 - Annotate data on the fly – lab notebook approach
 - Curated & preserved using permanent identifiers
 - Appropriate repository and data collection descriptors

HALOGEN (History, Archaeology, Linguistics, Onomastics, GENetics):

Throwing light on the past through cross-disciplinary databasing



- ◆ Portable Antiquities Scheme (British Museum)
- ◆ Place-names (Nottingham)
- ◆ Surnames
- ◆ Genetics
- ◆ IT hosting and GIS
- ◆ Best practice: #JISCMRD, UKRDS, DCC, international

<http://halogen.le.ac.uk>



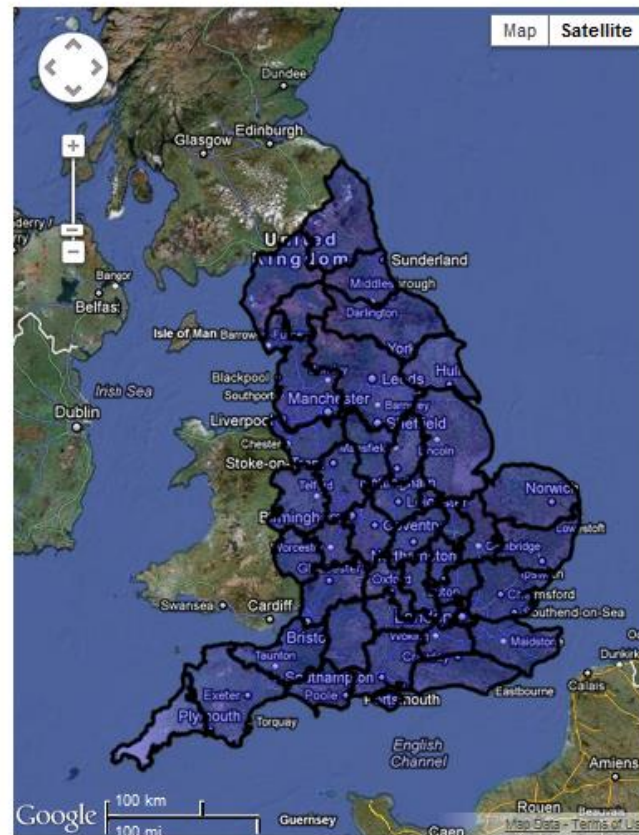
University of
Leicester

welcometrust

JISC

Key to English Place-Names

Data provided by the Institute for Name-Studies at the University of Nottingham.



County boundaries - © Great Britain Historical GIS Project,
University of Portsmouth.

Search by county:

Click on the counties on the map, or select from the list. Hold Ctrl to select multiple counties from the list.

ALL COUNTIES

Bedfordshire
Berkshire
Buckinghamshire
Cambridgeshire
Cheshire
Cornwall

Search by language:

(Hold Ctrl to select multiple languages.)

ALL LANGUAGES

Celtic
French
Old English
Old Norse
Latin
Anglian

Search by element:

Hover your mouse over the elements for their definition, or look at the list of [valid elements](#). Hold Ctrl to select multiple elements from the list.

ALL ELEMENTS

-aco-
-an
-binde
-dwestle
-ek
-ell

Search by place name:

Exact match



BENEFITS

- *New research opportunities*
 - Cross database work – seed new research samples
- *Scholarly communication/access to national resources*
 - Key to English Place Names (Nottingham)
 - Portable Antiquities Scheme (British Museum)
- *Verification, re-purposing, re-use of data*
 - Cleaning & enhancing private research datasets for reuse & correlation
 - No re-creation of data
 - Increased transparency
 - excellent training for best practice in research data management
- *Increasing research productivity*
 - Build in cleaning, annotation, enhancement into normal research workflows
 - research datasets may immediately be reusable and interoperable
- *Impact & Knowledge Transfer*
 - Reuse IT infrastructure
- *Increasing skills base of researchers/students/staff*



Reward = Leverhulme Trust funding £1.3m!

The Impact of Diasporas on The Making of Britain



Evidence

Memories

Inventions



University of
Leicester



The University of
Nottingham

Top Tip: how to get researchers' attention?

Modify Costing No. 9 (Application Version)

Research Data Management

IMPORTANT: The University and funding bodies require that researchers demonstrate that they have planned for the management of research data over the project life cycle. Please indicate if:

1. Your research may use or generate research data that is sensitive or confidential (including Commercial in Confidence)?
2. The project will require advice in planning and costing your IT and research data management requirements (including secure and reliable storage) either before, during or after completion?

Responding 'Yes' to the above questions will be logged with IT Services for the appropriate team to make contact.
Please tick this box if you wish to hide the title of the research project in this notification Hide Title

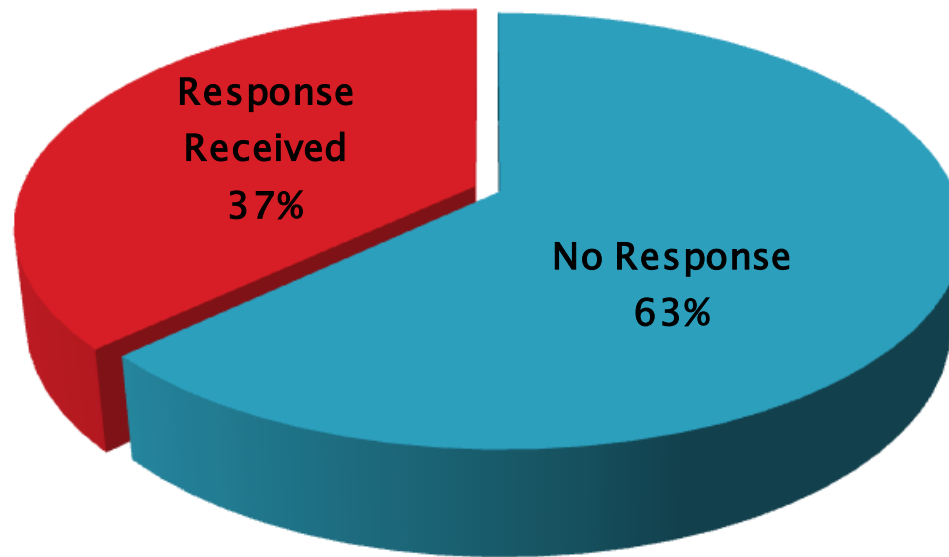
Please contact the [IT Academic and Research Liaison team](#) for advice in good time before submission.

Continue Cancel



Research costing – only part of the answer

Researcher Responses to Contacts Made



Find & Share

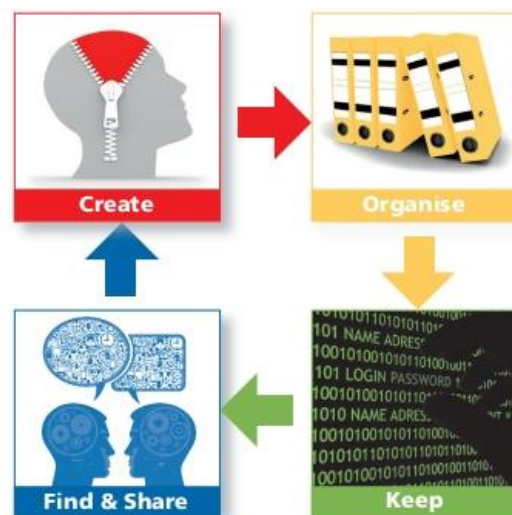


Do you know how to...

- find existing information resources related to your research?**
Where can you find research data that you can repurpose or combine with your own to produce new research?
- share data with your collaborators securely and effectively?**
Whether building a collaborative proposal, generating results for others to comment on or sharing the final outputs of your research – how will you link with your colleagues ahead of wider sharing?
- deposit your research data and outputs in an open repository?**
Is there an appropriate disciplinary or institutional repository and what do you need to do to deposit your research output? Plan ahead to avoid refactoring...
- publish your research, and get it cited as well?**
Institutions and data centres must make research data reusable to others while providing credit to the researchers who did the work. Your future career could depend on it!

Chances are you could use some helpful pointers in all of these!

To find information, support, advice and training, as well as links to external resources, go to www.le.ac.uk/researchdata



email: researchdata@le.ac.uk

What would you do if you lost your research data tomorrow?

Take the research data health check... and find help to secure, share and exploit your valuable research.



Create



Have you...

- fully understood your research funders' data management requirements?**

Government and funders require that publicly funded research is made available for reuse – are you up to date with their latest policies? Your future funding might depend on it!

- written a data management plan?**

Your funder may already require this but build it in from the proposal stage to avoid headaches in the future.

- gained ethics approval/consent?**

Writing a data management plan will aid planning and help you to navigate ethics and governance requirements.

- protected your intellectual property?**

Leaving intellectual property considerations for a rainy day could lose you appropriate credit, damaging career prospects and perhaps your financial future health!

Organise



Are your research files and data...

- clearly described, in terms of content (using standard metadata)?**

Ask yourself honestly: is there a danger of data being lost? Will you be able to remember how you generated your data, and will you or anyone else be able to find it in the future when you wish to reuse and share?

- clearly labelled with versions and dates?**

How will you remember which was **the** definitive version and which dataset was used in producing a given research outcome?

- logically structured and named?**

Once you've remembered **how** you generated data, can you still **find** the relevant files?

- future-proofed against broken links, using persistent identifiers?**

The persistent identification of digital resources can play a vital role in enabling their accessibility and re-usability over time using recommended data standards.

Keep



Do you know...

- how to restrict access to your research data to the right people?**

Have you consulted with university or data centre experts so that only the right people have access to your research?

- which data to keep and which data to discard?**

Managing research data effectively means being selective: **which** data to discard and **when** as well as **what** to keep and for **how long**?

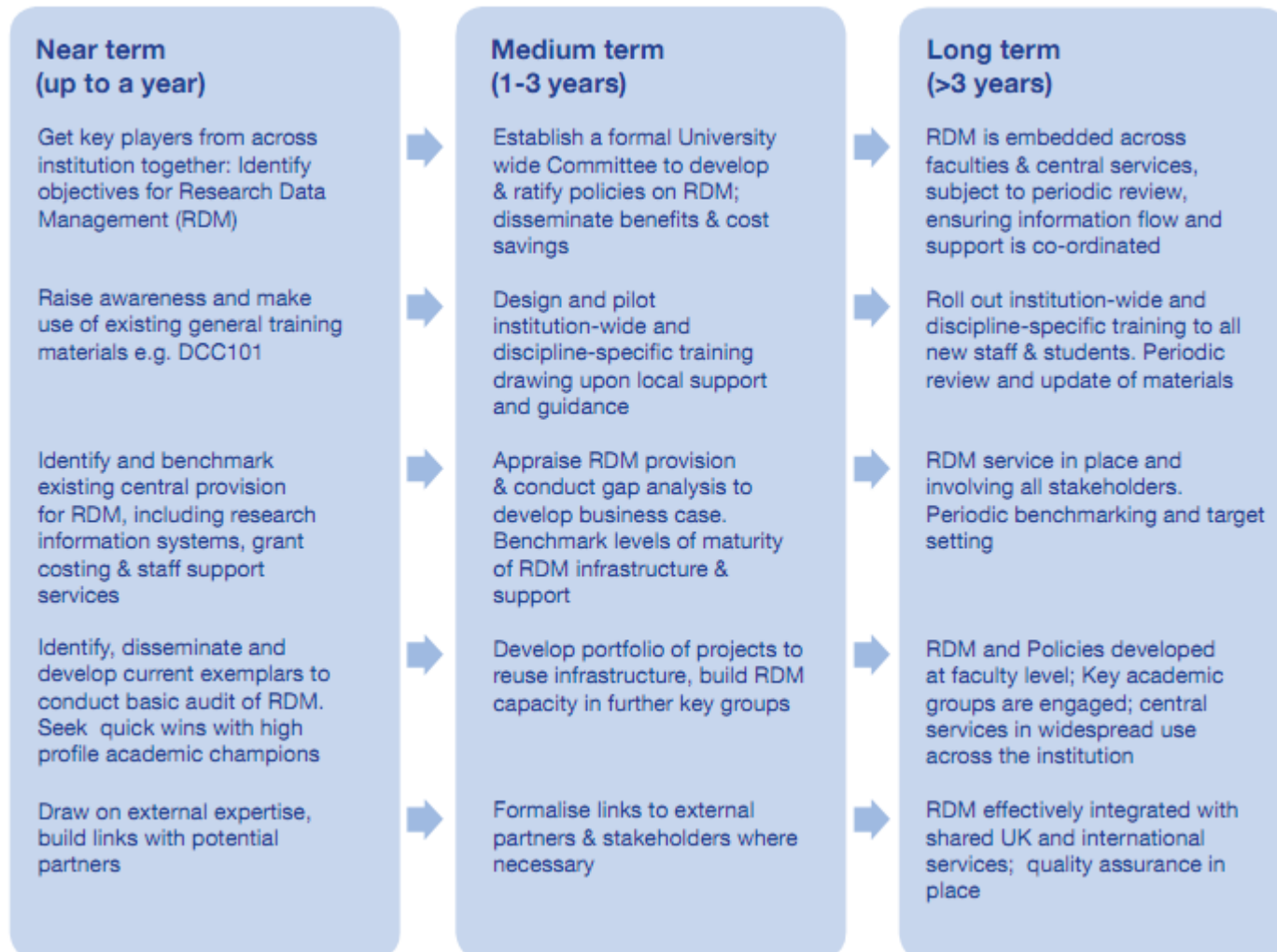
- how securely your data is stored?**

What happens if your storage media fail? How resilient is it? Could it get left on the train and could somebody else misuse it?

- how your data is backed-up?**

Have you made use of university and/or external resources to back up data so that you have multiple copies in case of loss or theft?

Suggested timeline for implementing institutional research data management



From Whyte & Tedds (2011), DCC Briefing

<http://www.dcc.ac.uk/resources/briefing-papers/making-case-rdm>

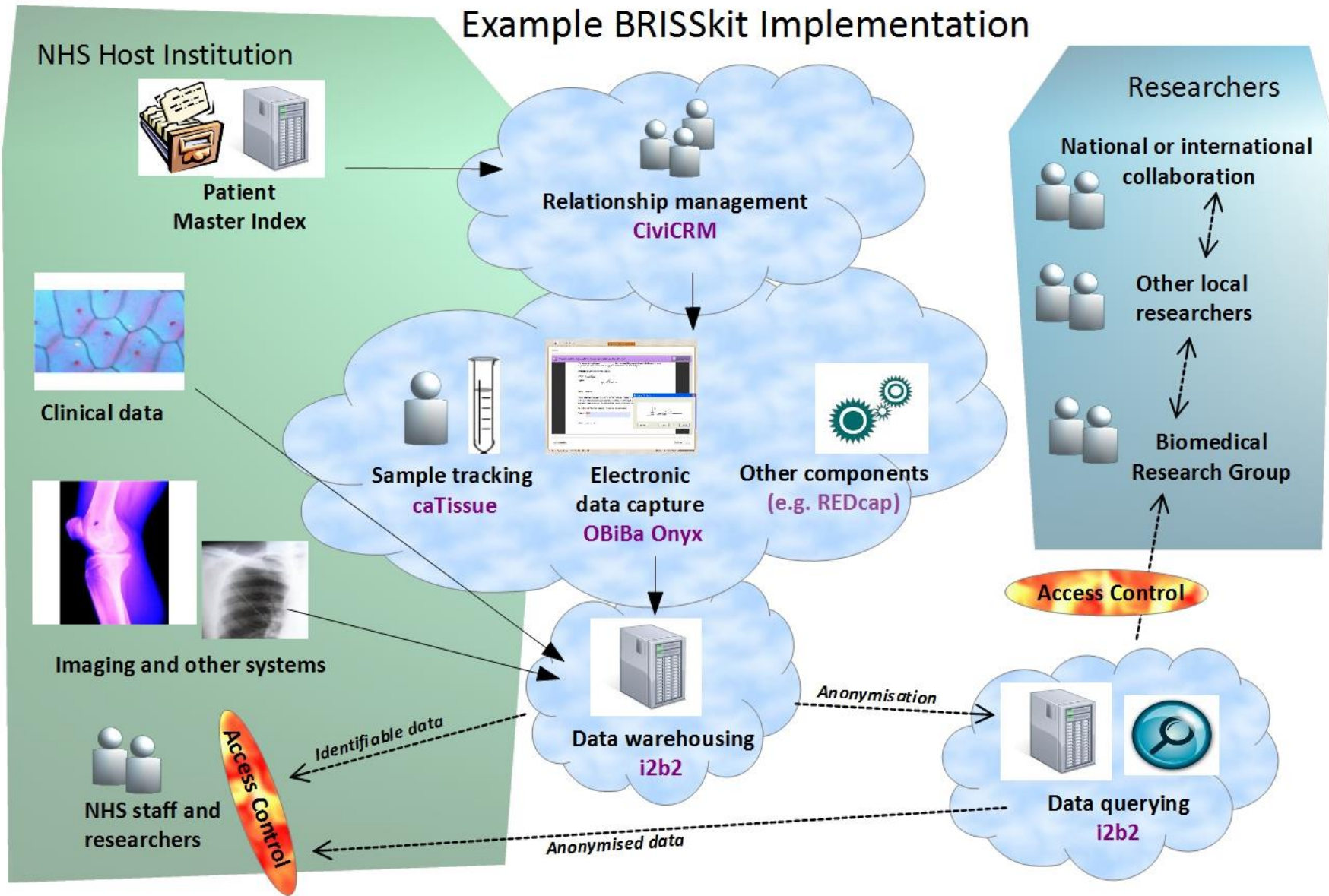
Challenge for institutions

- Rise to scientific and research challenge
 - Not just a management challenge
 - Responsibility for the knowledge they create
- Library
 - “Doing the wrong things through the wrong people”?
 - Challenge for library to enable:
 - curation of data and publications
 - active support from data scientists
 - from centralised to dispersed support
 - Expert centres essential!
- IT Service
 - Provide research data platforms for researchers:
 - Active storage
 - Enable collaboration
 - Connect to preservation services through Library

Enabling Open Data Publishing

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 - built in at proposal stage
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 - Appropriate repository and data collection descriptors

Example BRISKit Implementation



<http://www.brisikit.le.ac.uk>

BRISKit CiviCRM: patient cohort management

Home > CiviCRM

CiviRecruitment Dashboard

[Add Recruitment](#) [Find My Recruitments](#)

All Recruitments with Upcoming Activities
 My Recruitments with Upcoming Activities

Summary of All Recruitments

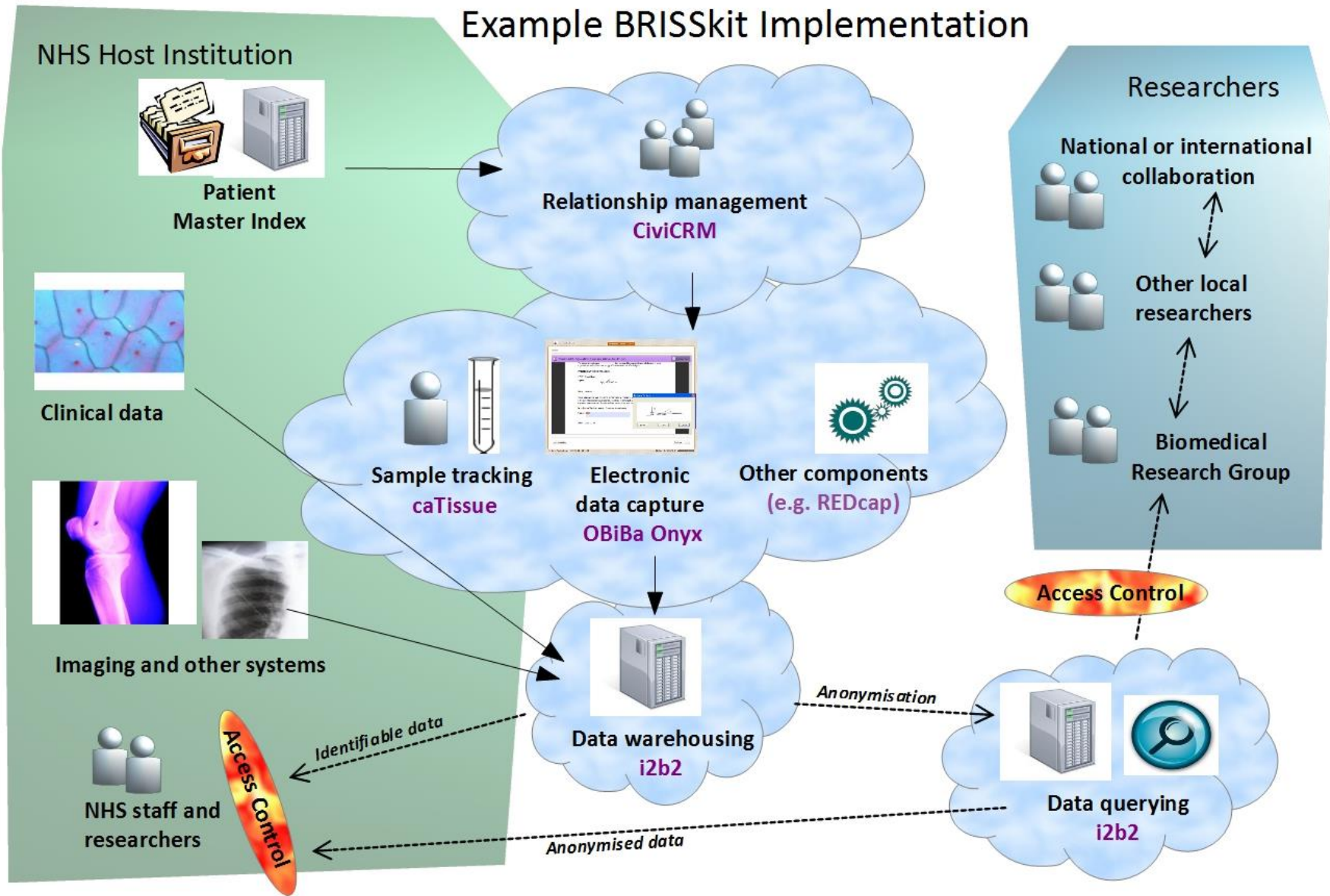
	Ongoing	Resolved	Urgent	Self-withdrawn	Completed	Screen fail	In study	Investigator withdrawn	Lost to followup	Other
Housing Support	0	0	0	0	0	0	0	0	0	0
Adult Day Care Referral	0	0	0	0	0	0	0	0	0	0
RespiratoryResearch	39	0	0	0	1	0	0	0	0	0

All Recruitments With Upcoming Activities

Client	Subject	Status	Type	My Role	Recruitment Manager	Next Sched.	
▶ BLOMPENHEFFLE, JANICE 01509 377665 Recruitment ID: 1	Automatically added to RespiratoryResearch study	Ongoing	RespiratoryResearch	---	NIHR Leicester Respiratory Biomedical Research Unit	Organise appointment November 8th, 2013 12:00 AM	Manage Delete more ▶
▶ HOGGLESROUT, ANGELINA 0116 2888333 Recruitment ID: 2	Automatically added to RespiratoryResearch study	Ongoing	RespiratoryResearch	---	NIHR Leicester Respiratory Biomedical Research Unit	Consent to be added to recruitment DB November 8th, 2013 12:00 AM	Manage Delete more ▶

- Manages studies: enables end-to-end contact management for volunteers and research participants
- track approaches, contact, responses, recruitment, exclusions
- object model that reflects community building and non-profit relationships

Example BRISKit Implementation



<http://www.brisikit.le.ac.uk>

BRISKit OpenSpecimen: sample management

The screenshot displays the OpenSpecimen 1.0 web application interface. The browser address bar shows the URL: `catussue31:8080/openspecimen/Login.do?loginName=saj.issa@gmail.com&password=Login1234567`. The application header includes the logo "OpenSpecimen by krishagni solutions" and navigation tabs for "Administration", "Biobanking", "Search", and "Admin Admin".

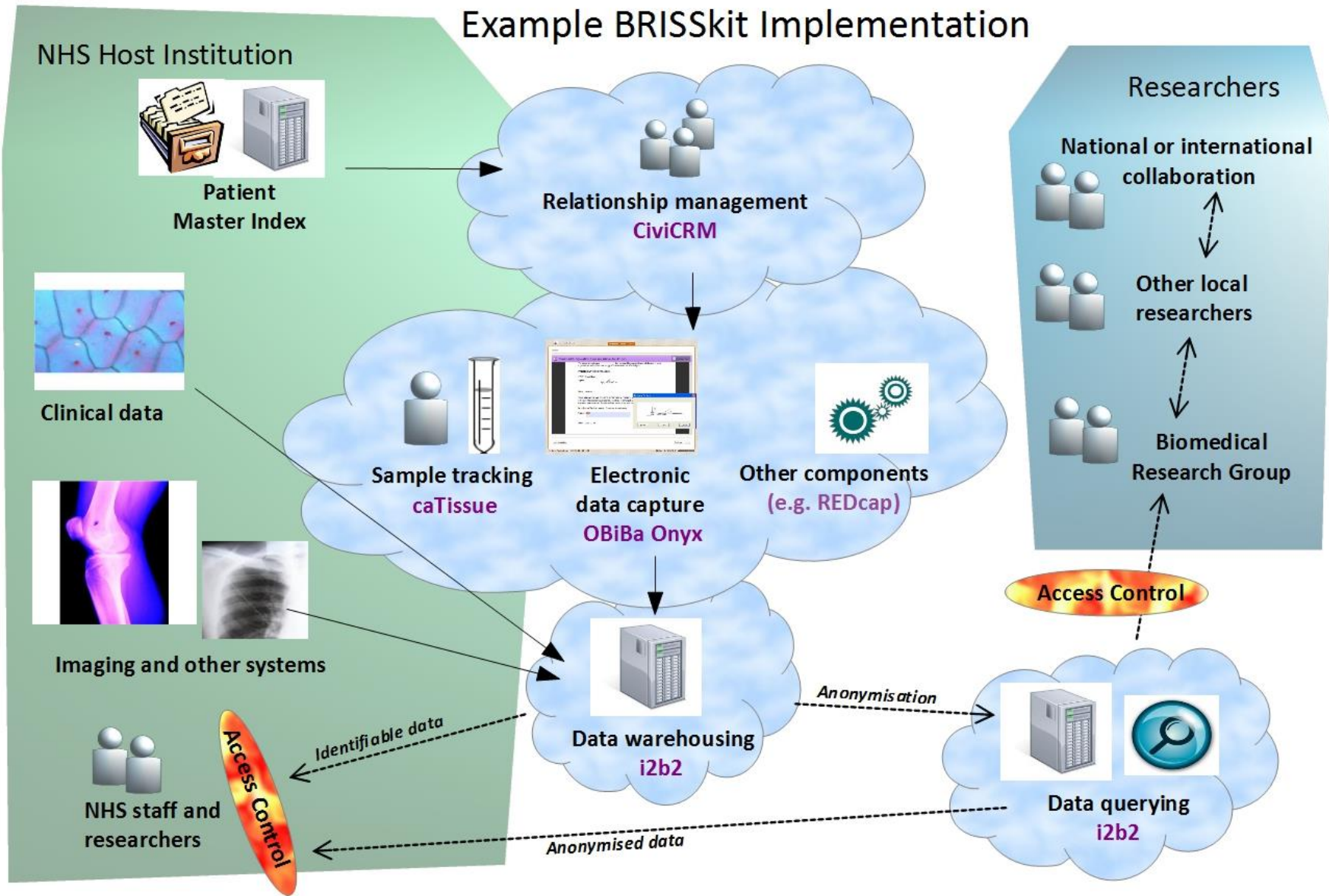
The main content area is divided into several sections:

- Collection Protocol:** A dropdown menu showing "c1short" with a "Watch Tutorial" link.
- Participant:** A dropdown menu showing "Issa,(1_1)" with "Register Participant" and "View Participant" buttons.
- Specimen Tree:** A tree view showing a hierarchy of specimens. The selected specimen is "168_6n(Fixed Cell Block)", which is a child of "1687j(Fixed Cell Block)".
- Specimen Details:** A form with the following fields:
 - Parent Label: 1687j
 - Lineage: Aliquot
 - Label: 168_6n
 - Barcode: 1_1999888
 - Class: Cell
 - Type: Fixed Cell Block
 - Tissue Site: Not Specified
 - Pathological Status: Not Specified
 - Tissue Side: Not Specified
 - Initial Quantity: 1.0 cell count
 - Created On: [DD-MM-YYYY]
 - Concentration: µg/µl
 - Is Available?:
 - Available Quantity: 1.0 cell count
 - Collection Status: Collected
 - Activity Status: Active
 - Storage Position: Virtually Located
 - Comments: [Text area]
 - External Identifier(s): [Add New](#)
 - Biohazard(s): [Add New](#)
- Create Child Specimen(s):** Radio buttons for "None", "Aliquot", "Derivative", and "As per Protocol".
- Print Labels:**
- Buttons:** "Submit" and "Add To Specimen List".

- Holds data on primary, derived and aliquot specimen, including linear and 2d barcodes
- Storage inventory, order tracking e.g. 30,000+ NIHR UHL Cardiovascular Biomedical Research Unit samples stored and recorded

<http://www.briskit.le.ac.uk>

Example BRISKit Implementation



<http://www.brisikit.le.ac.uk>

BRISKit RedCap: survey management

Questionnaire Simple

Project Setup Online Designer Upload Data Dictionary

VIDEO: How to use this page

This page allows you to build and customize your data collection instruments one field at a time. You may add new fields or edit existing ones. New fields may be added by clicking the **Add Question** buttons. You can begin editing an existing field by clicking on the **Edit** icon. If you decide that you do not want to keep a field, you can simply delete it by clicking on the **Delete** icon. To reorder the fields, simply **drag and drop** a field to a different position within the form below. **NOTE: While in development status, all field changes will take effect immediately in real time.**

Rather than building your survey from scratch, you may instead download one from the **REDCap Shared Library**. **Download** a new instrument from the REDCap Shared Library. (NOTE: The questions included in the downloaded instrument will completely replace all survey questions below.)

Preview instrument

Add Question Add Matrix of Questions

Variable: aunits

How many units of alcohol do you have on a typical day when you are drinking?

- 1-2
- 3-4
- 5-6
- 7-8
- 9+

reset

Add Question Add Matrix of Questions

Variable: apy

How often did you have a drink containing alcohol in the past year?

- Monthly or less
- 4 times per month
- 4 times per week
- 4 or more times per week

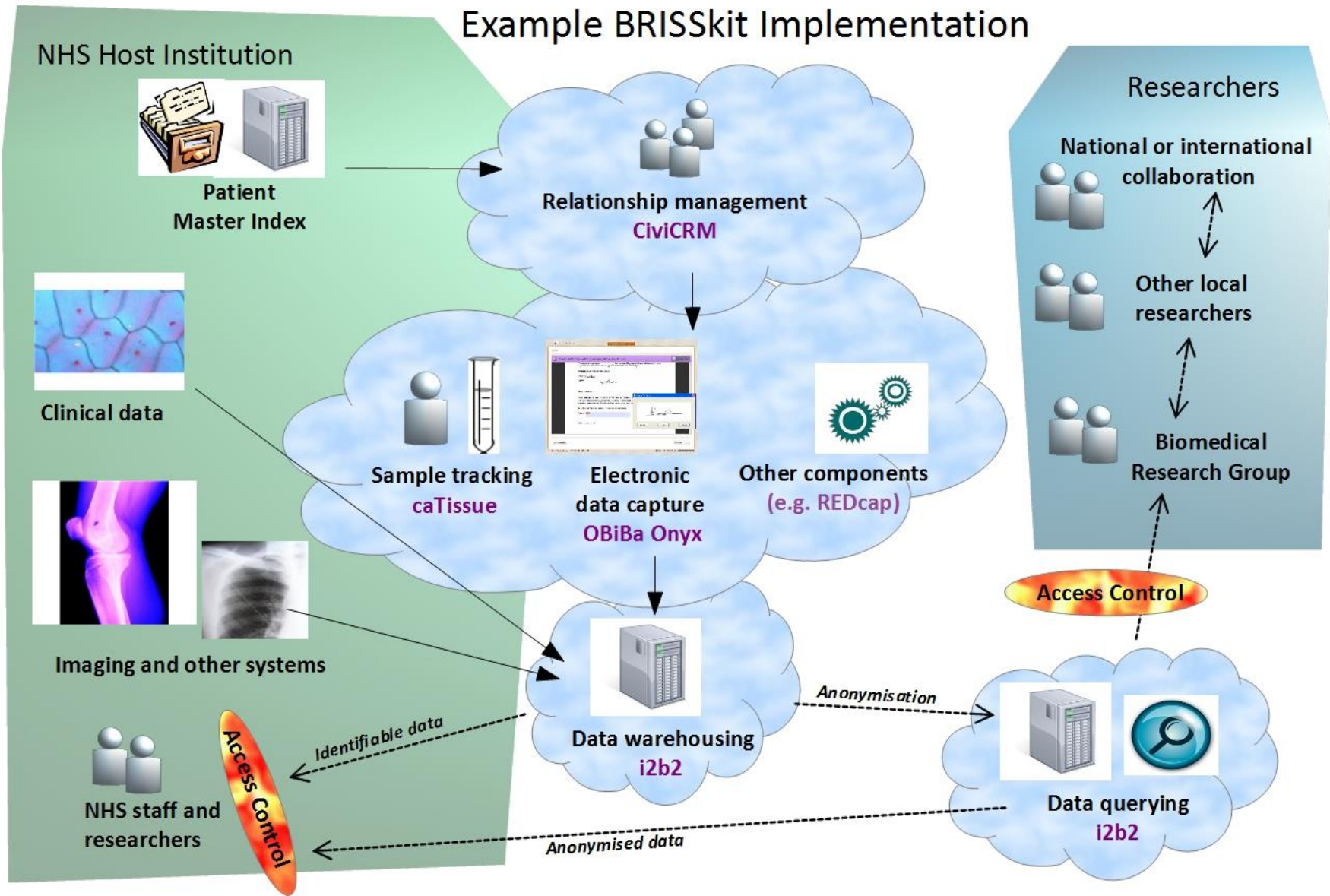
reset

Web-based, secure questionnaire data entry by research or nursing staff

E.g. used for all patient recruits in NIHR UHL Respiratory Biomedical Research Unit - mobile computing on wards and outpatient clinic

<http://www.briskit.le.ac.uk>

Example BRISKit Implementation



<http://www.brisikit.le.ac.uk>

BRISKit i2b2: data warehousing & querying

The screenshot displays the BRISKit i2b2 Query & Analysis Tool interface. The browser window shows the URL `i2b2pg/i2b2/webclient_brisskit/`. The tool's header includes the project name "Project: Brisskit Demo", the user "User: i2b2 User", and navigation links for "Find Patients", "Analysis Tools", "Message Log", "Help", and "Logout".

The main interface is divided into three primary sections:

- Navigate Terms:** A tree view on the left showing various data sources and terms, including "CiviCRM Demographics", "HES Data", "Open Specimen", "Study", and "Z. GP Data".
- Query Tool:** The central workspace for building queries. It shows a query named "Avera-Male-GP No@14:34:56" with a temporal constraint of "Treat all groups independently". The query is composed of three groups:
 - Group 1:** "Average Daily Steps > 6000 steps"
 - Group 2:** "Male"
 - Group 3:** "GP Notes [Contains: heart]"The groups are connected by "AND" operators, and each group has a "one or more of these" indicator.

- Query Status:** A panel at the bottom showing the results of the query execution:
- Finished Query:** "Avera-Male-GP No@14:34:56" (2.6 secs)
- Compute Time:** 0.7 secs
- Patient Set for "Avera-Male-GP No@14:34:56"**
- Number of patients for "Avera-Male-GP No@14:34:56"**: patient_count: 126

Data from multiple data sources combined into multiple ontologies for flexible and sophisticated searching, cohort discovery and research

BRISKit USPs

- Integrated support for core research processes
- Well-established mature open source applications as protoyped in e.g. Cardiovascular: fully UK customised
- A platform for seamless management and integration between applications
- An API allows integration with existing clinical systems
- Easy set up, use and administration through browser (including on mobile devices)
- Capability of being hosted in any compliant cloud provider including UHL (NHS information governance)
- Direct secure links through Jisc via Janet network

BRISKit Funding & Partners

- **New HEFCE/Jisc investment** approved for 2014 - 2016
 - Jisc endorsed service
 - Co-design with reorganised Jisc
 - Key Janet Framework partners Farr, Crick, Infinity
- **University of Leicester Cancer Biobank**
 - Tissue sample management built on caTissue, OpenSpecimen
- **NIHR Respiratory Biomedical Research Unit**
solutions: University Hospitals Leicester NHS Trust
 - linked to UoL Health Sciences Exceed Study
 - Links to Loughborough-Leicester Lifestyle BRU

BRISKit highlighted collaborations

- **University of Bristol**
 - ALSPAC Birth Cohort Studies
 - DataShield: simultaneous remote, secure access to multiple large international cohorts
 - SAIL-Farr secure NHS data hosting
- **University Hospitals Leicester NHS Trust**
 - Case Study Module Development
 - UoL Health Sciences Exceed Study
 - NIHR BRUs: Cardiovascular, Respiratory, Lifestyle (Loughborough-Leicester)
 - Leicester Diabetes Centre
- **UoL Data to Knowledge for Practice strategic theme**
 - UoL Genomics, UHL NHS Trust - IBM IT Partnership

BRISKit Information Governance & Security Management Work Stream

- Dr Andrew Burnham leading

1. **Information Governance Toolkit** - analysis of Department of Health (DoH/NHS) IGT requirements vs. BRISKit organisation/project and services/tools
 - a) Hosted Secondary Use Team/project ([Hosted IGT](#))
 - b) Acute Trust ([Acute Trust IGT](#))
2. **IG Training Tool** (NHS – University is registered)
3. **Pseudonymisation** requirements
4. **Data Management Plan**
5. **IT Security & standards** – Penetration Testing & Security Testing
6. **Other NHS Standards/Requirements:**
 - Care Records Guarantee
 - NHS Constitution
 - NHS Records Management
 - Patient Safety DSCN 14/2009, 18/2009

BRISKit Jisc endorsed organisation

Dual model for sustainability proposed (e.g. Ubuntu):

- **.org foundation owns & maintains code**
 - Trustee led
 - Educational
 - Core development
 - Code licensed by not-for-profit
- **.com provides range of service offerings**
 - Modular approaches and scalable tools with open source licenses make good investments
 - Partner with 3rd party technical support e.g. Krishagni (OpenSpecimen)
 - Corporate identity
 - Hosting via Janet/Infinity, SAIL (Farr), private

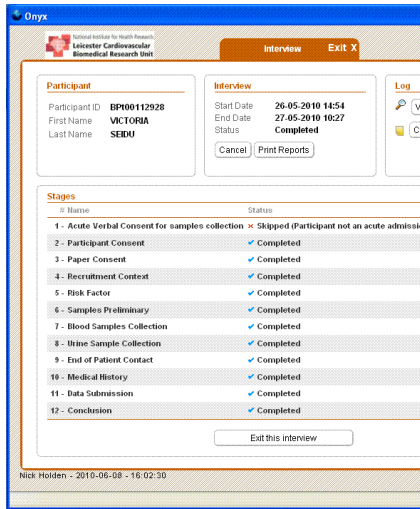
March 2015: i2b2 via public cloud (anon data)

- Users can now get free servers from public clouds, e.g. Amazon, Azure for Research etc
- In March 2015 BRISKit users will be able to
 - deploy their own i2b2 virtual app onto their own cloud server
 - upload their data through .csv files – default nominal ontology created
 - modify/align this ontology to standardised BioPortal codesets – e.g. SNOMED
 - perform queries on their data using the revised ontology through i2b2

Research: the semantic bridge

Survey data

Records participant consent, questionnaire data and primary specimen IDs

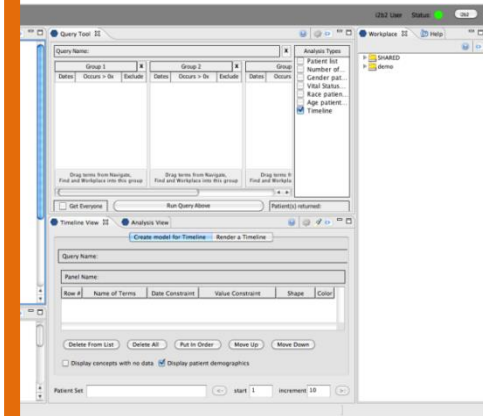


Bio-ontology!

- Classes
 - BrissKitQuestionnaire
 - RiskFactorAlcohol
 - RiskFactorCigars
 - RiskFactorCigs
 - RiskFactorDietExercise
 - RiskFactorFamilyHistory
 - RiskFactorOtherTobacco
 - RiskFactorSocioeconomic
 - RiskFactorTobacco
 - HPO
 - All
 - Phenotypic abnormality
 - Abnormality of the cardiovascular system
 - Abnormality of the hematopoietic system
 - ICD10
 - Diseases of the circulatory system
 - Diseases of the skin and subcutaneous tissue
 - Factors influencing health status and contact with health services
 - Persons encountering health services in other circumstances
 - LOINC
 - LOINCCLASSTYPES
 - Clinical Class
 - Functional status (e.g. Glasgow)
 - Gastrointestinal endoscopy
 - Medical Devices
 - SNOMED-CT
 - Clinical finding
 - Functional finding
 - Hepatorrhaphy
 - Observable entity
 - Organism
 - Social and personal history finding
 - Substance
 - Tobacco smoking behavior - finding
 - Tobacco use and exposure - finding

2 data query

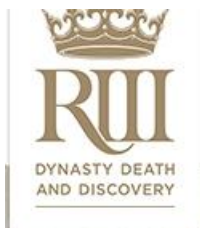
part selection and querying



Towards an i2b2 NHS community

- With datasets uploaded into a range of i2b2 instances
- Users will be able to publish their i2b2 datasets
- A community of public cloud i2b2 users will emerge, within which users can publish, exchange and augment data and ontologies
- These merged datasets can then be used to service NHS-wide cohort search, selection and quality management
- Re-identification of cohorts will remain with original sources of i2b2 data

- BRISKit Community Event & Health Research Hack: Public Cloud i2b2, 23-24 Feb 2015, College Court, Leicester
- Co-located European i2b2 Community User Group Meeting + BRISKit Leicester June/July 2015!



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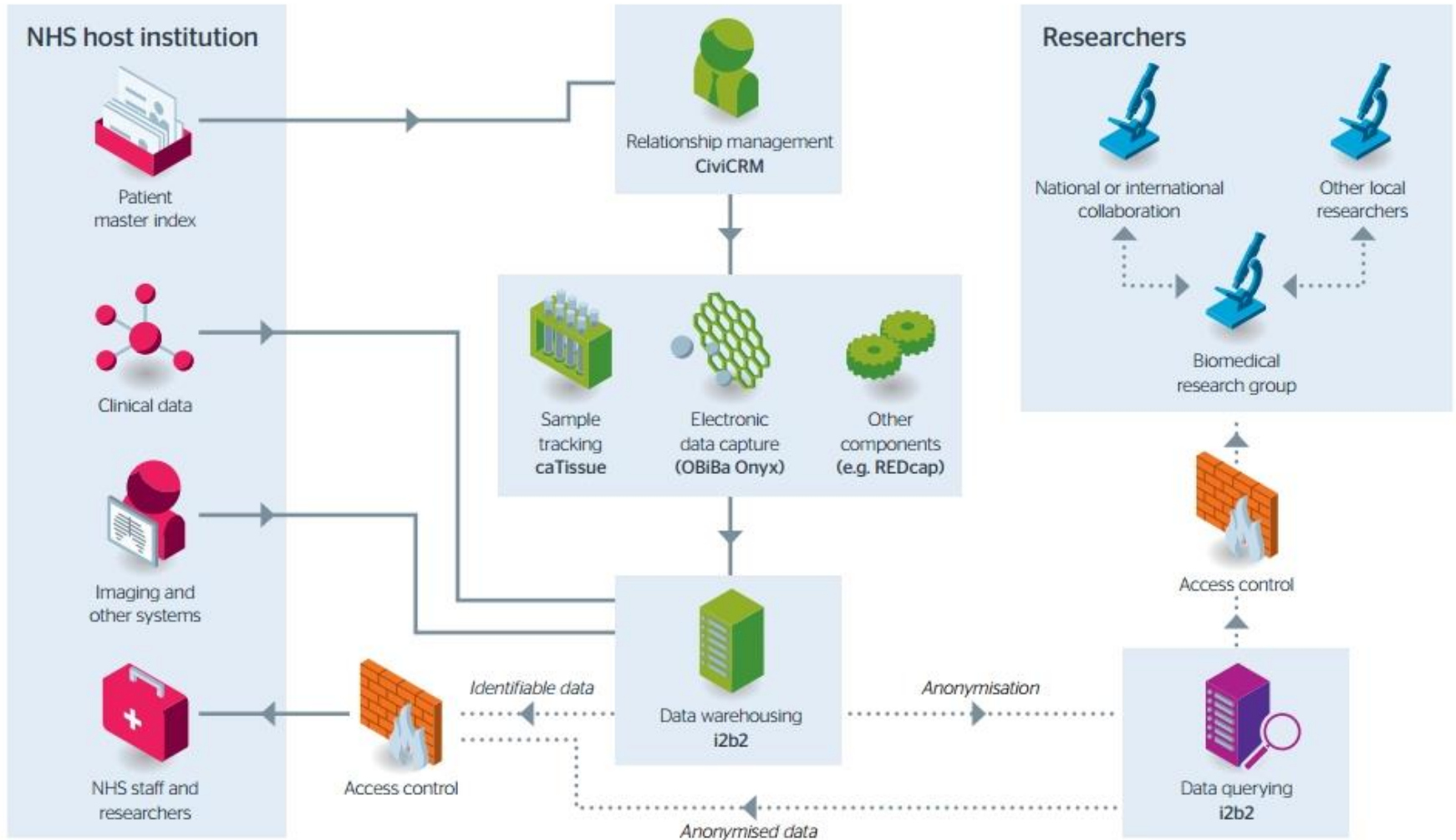
BRISKit Hack: Public Cloud i2b2 Focus

- <http://www.brisskit.le.ac.uk/node/35>
- created ideas pre and post event via [healthresearchhack](#) google group
- 6 hack solutions in 2 days using BRISKit stack, e.g.
 - i2b2 integration using demo data from HES and cancer research clinical trials data (UCL, Birmingham, Goettingen, Leicester)
 - smartphone app to scan v.tiny barcodes from the end of sample vials and import info into caTissue
 - integrate CiviCRM study management and REDCap questionnaire tool (UHL Respiratory BRU)
 - create a simple CiviCRM study creator as a Drupal plugin

Sign up to www.jiscmail.ac.uk/brisskit-announce

Jisc

Biomedical research software as a service **BRISSKit** A Jisc funded project



Find out more brisskit.le.ac.uk email us at brisskit@le.ac.uk Follow us at [@BRISSKit](https://twitter.com/BRISSKit)

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