



ViPAR: a software PLATFORM FOR THE VIRTUAL POOLING and ANALYSIS OF RESEARCH DATA

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“Any time scientists disagree, it's because we have insufficient data. Then we can agree on what kind of data to get; we get the data; and the data solves the problem.

Either I'm right, or you're right, or we're both wrong. And we move on ... ”

Neil deGrasse Tyson





TELETHON KIDS INSTITUTE PERTH, WESTERN AUSTRALIA





Overview

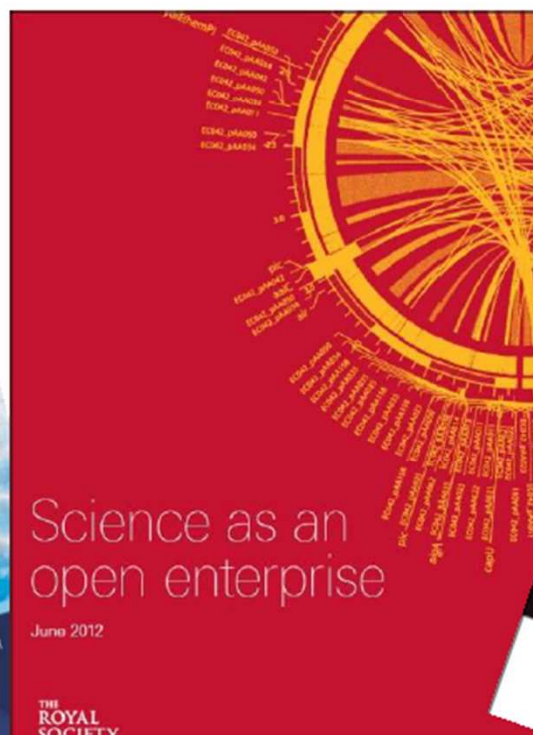


- **Recent media on Data Sharing**
- **Technologies for Data Sharing**
- **How did I end up in this space ? (case study)**
- **Methods for Sharing and Analysing data together**
- **ViPAR**
- **Demo**





Recent media on data sharing



“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.”

RCUK Common Principles on Data Policy
<http://www.rcuk.ac.uk/research/datapolicy/>





Media on DATA SHARING (CONT)

THE LANCET

Volume 377, Issue 9778, 14-20 May 2011, Pages 1633-1635

[doi:10.1016/S0140-6736\(11\)60647-8](https://doi.org/10.1016/S0140-6736(11)60647-8) | [How to Cite or Link Using DOI](#)

[Permissions & Reprints](#)

Comment

Science as a public enterprise: the case for open data

Geoffrey Boulton^a, , Michael Rawlins^b, Patrick Vallance^c, Mark Walport^d

^a Grant Institute, Edinburgh University, Edinburgh EH9 3JW, UK

^b National Institute for Health and Clinical Excellence, London, UK

^c GlaxoSmithKline, London, UK

^d Wellcome Trust, London, UK

Available online 12 May 2011.

THE LANCET

Volume 377, Issue 9765, 12 February 2011-18 February 2011, Pages 537-539

[doi:10.1016/S0140-6736\(10\)62234-9](https://doi.org/10.1016/S0140-6736(10)62234-9) | [How to Cite or Link Using DOI](#)

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Comment

Sharing research data to improve public health

Mark Walport^a,  and Paul Brest^b

^a Wellcome Trust, London NW1 2BE, UK

^b Hewlett Foundation, Menlo Park, CA, USA





Media on DATA SHARING (CONT)

“Increasing availability and promoting efficient data use to maximise public health benefits”

Equitable: balance needs of researchers, communities and funders

Ethical: protect individual privacy and dignity while recognising need to improve health using these data

Efficient: improve quality, value and contribution of research by building on existing, and reducing competition and duplication





Unwanted SHARING OF DATA

arstechnica.com/security/2016/04/billion-dollar-bangladesh-hack-swift-software-hacked-no-firewalls-10-switches/

RISK ASSESSMENT —

Billion dollar Bangladesh hack: SWIFT software hacked, no firewalls, \$10 switches

The Bangladesh Bank's internal network security was sorely lacking.

PETER BRIGHT - 4/26/2016, 6:15 AM

71

The Bangladesh central bank had no firewall and was using a second-hand \$10 network when it was hacked earlier this year. Investigation by British defense contractor BAE Systems has also shown that the SWIFT software used to make payments was compromised, enabling the hackers to send money around the world without leaving any trace in Bangladesh.



In February, unknown hackers broke into the Bangladesh Bank and almost got away with just shy of \$1 billion. In the event, their fraudulent transactions were cancelled after they managed to transfer \$81 million when a typo raised concerns about one of the transactions. That money is still unrecovered, but BAE has published some of its findings.

The SWIFT organization is owned by 3,000 financial companies and operates a network for sending financial transactions between financial institutions. Institutions using the network must have existing banking relationships; SWIFT transactions do not actually send money but instead send payment orders that must then be settled by having the institutions involved moving money between accounts.

SWIFT's security stems from two major sources. Notionally, it's a private network, and most banks set up their accounts such that only certain transactions between particular parties are permitted. The network privacy means that it should be hard for someone outside a bank to attack the network, but if a hacker breaks into a bank—as was the case here—then that protection evaporates. The Bangladesh central bank has all the necessary SWIFT software and authorized access to the SWIFT network. Any hacker running code within the Bangladesh bank also has access to the software and network.



Unwanted SHARING OF DATA

arstechnica.com/security/2016/04/billion-dollar-bangladesh-hack-swift-software-hacked-no-firewalls-10-switches/

RISK ASSESSMENT —

Billion dollar Bangladesh hack: SWIFT

sof
swi

Banner Health Identifies Cyber Attack

The Ba

PETER BR

71



August 03, 2016

PHOENIX (August 3, 2016) - Banner Health announced today that it is mailing letters to approximately 3.7 million patients, health plan members and beneficiaries, food and beverage customers and physicians and healthcare providers related to a cyber attack. Banner Health immediately launched an investigation, hired a leading forensics firm, took steps to block the cyber attackers and contacted law enforcement.

On July 7, 2016, Banner Health discovered that cyber attackers may have gained unauthorized access to computer systems that process payment card data at food and beverage outlets at some Banner Health locations. The attackers targeted payment card data, including cardholder name, card number, expiration date and internal verification code, as the data was being routed through affected payment processing systems. Payment cards used at food and beverage outlets at certain Banner Health locations during the two-week period between June 23, 2016 and July 7, 2016 may have been affected. A list of the outlets that were affected can be found at www.BannerSupports.com. The investigation revealed that the attack did not affect payment card payments used to pay for medical services.

On July 13, 2016, Banner Health learned that the cyber attackers may have gained unauthorized access to patient information, health plan member and beneficiary information, as well as information about physician and healthcare providers. The patient and health plan information may have included names, birthdates, addresses, physicians' names, dates of service, claims information, and possibly health insurance information and social security numbers, if provided to Banner Health. The physician and provider information may have included names, addresses, dates of birth, social security numbers and other identifiers they may use. The investigation also revealed that the attack was



Unwanted SHARING OF DATA

arstechnica.com/security/2016/04/billion-dollar

RISK ASSESSMENT —

Billion dollar Banner Health software switch

The Banner Health

PETER BRIDGES

71



August 03, 2016

PHOENIX (August 3, 2016) — Banner Health patients, health plan member information, and providers related to a cyber security firm, took steps to block the

On July 7, 2016, Banner Health systems that process payment information targeted payment card data. The data was being routed through outlets at certain Banner Health have been affected. A list of investigation revealed that t

On July 13, 2016, Banner Health information, health plan member providers. The patient and health names, dates of service, claims provided to Banner Health. The physician and provider information may have included names, addresses, dates of birth, social security numbers and other identifiers they may use. The investigation also revealed that the attack was

arstechnica.com/tech-policy/2016/08/australia-2016-census-personal-data-retention/

CONSENSUS —

Australians threaten to take leave of their census

2016 Australian census stores names and addresses, prompting privacy, security outrage.

JENNIFER BAKER (UK) - 8/4/2016, 10:15 PM



Paramount

126

Next Tuesday is the day Australians must fill in—correctly—their census forms, or face a fine. However, many may be willing to take that risk as the Australian Bureau of Statistics (ABS) will rather extraordinarily be storing names and addresses in addition to the usual census results.

Providers may have also stored this information, but "addresses" are allowed to opt in to



Unwanted SHARING OF DATA

arstechnica.com/tech-policy/2016/08/australia-2016-census-personal-data-retention/

arstechnica
RISK ASSESSMENT
Bill of Rights
Software
SWI
The Balance
PETER BRIDGEMAN

Sony Makes it Official: PlayStation Network Hacked

By Keir Thomas, PCWorld Apr 23, 2011 7:35 AM

When Sony's PlayStation Network was taken offline three days ago, all eyes fell on the Anonymous group, who've taken a dislike to Sony over its treatment of hardware hacker George Hotz. The network allows online play between PlayStation 3 consoles and boasts 70 million users, so this is no small inconvenience.

Electronic health files secure despite NBN hacking, minister insists

SEAN PARNELL AND BEN PACKHAM The Australian July 28, 2011 12:00AM

the data was being routed to

Gordon Brown's shock that his family medical records were hacked

Rebekah Brooks, then editor of The Sun, contacted the Browns, informing them that she had obtained medical details about their four-year-old son Fraser

By The Independent Reporting Team, Cahal Milmo, Martin Hickman, Oliver Wright and Ian Burrell

Tuesday, 12 July 2011

SHARE | PRINT | EMAIL | TEXT SIZE

birth, social security numbers and other identifiers they may use. The investigation also revealed that the attack was



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Funder expectations (UK)

● Full Coverage
 ◐ Partial Coverage
 ○ No Coverage

Research Funders	Policy Coverage		Policy Stipulations					Support Provided			
	Published outputs	Data	Time limits	Data plan	Access/sharing	Long-term curation	Monitoring	Guidance	Repository	Data centre	Costs
AHRC	●	●	●	●	●	◐	○	●	○	◐	◐
BBSRC	●	●	●	●	●	●	●	●	●	◐	●
CRUK	●	●	●	●	●	●	●	◐	●	○	○
EPSRC	●	●	●	◐	●	●	●	◐	○	○	●
ESRC	●	●	●	●	●	●	●	●	●	●	◐
MRC	●	●	●	●	●	●	○	◐	●	○	◐
NERC	●	●	●	●	●	●	●	●	●	●	◐
STFC	●	●	●	●	●	●	●	◐	●	◐	◐
Wellcome Trust	●	●	●	●	●	●	●	●	●	◐	●

<http://www.dcc.ac.uk/resources/policy-and-legal/overview-funders-data-policies>





JOURNAL EXPECTATIONS

An increasing number of journals expect data to be publicly available at time of publication



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[Unacceptable Data Access Restrictions](#)

[Explanatory Notes and Guidance](#)

[Recommended Repositories](#)

[FAQs for Data Policy](#)

Data Availability

The following policy applies to all of PLOS journals, unless otherwise noted.

PLOS journals require authors to make all data underlying the findings described in their manuscript fully available without restriction, with rare exception.

When submitting a manuscript online, authors must provide a *Data Availability Statement* describing compliance with PLOS's policy. If the article is accepted for publication, the data availability statement will be published as part of the final article.

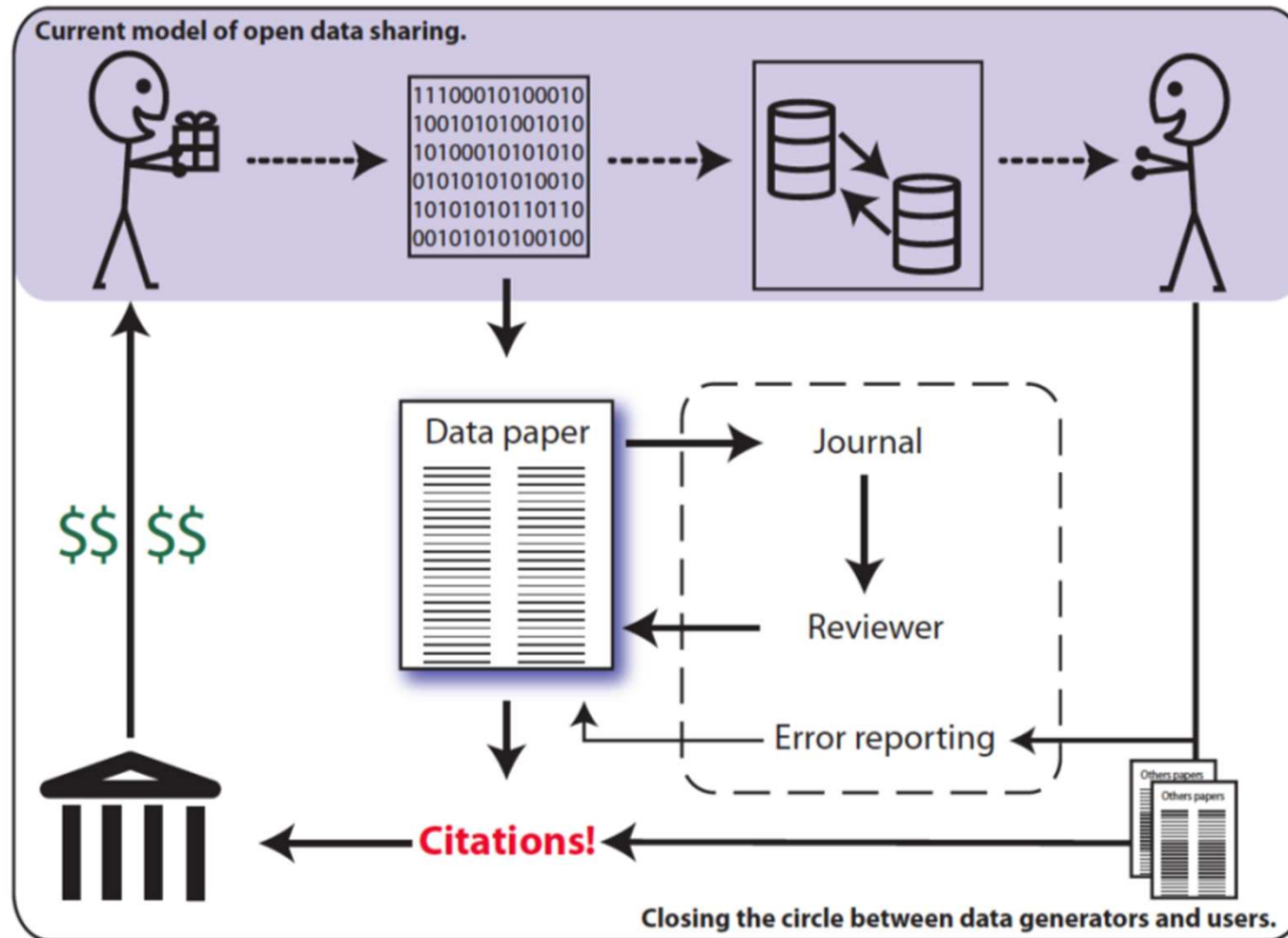
Refusal to share data and related metadata and methods in accordance with this policy will be grounds for rejection. PLOS journal editors encourage researchers to contact them if they encounter difficulties in obtaining data from articles published in PLOS journals. If restrictions on access to data come to light after publication, we reserve the right to post a correction, to contact the authors' institutions and funders, or in extreme cases to retract the publication.

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<http://journals.plos.org/plosone/s/data-availability>



Data SHARING JOURNALS



Gorgolewski, Milham, and Margulies, 2013 Front. Neurosci.





Large Consortia



- To elucidate subtle genetic & environmental effect on common diseases → larger sample sizes req'd



- Power comes from the pooled sample size (ie an individual level meta-analysis)
- Multi-site, multi-national means potential ethical, legal and privacy barriers to sharing research data





DISINCENTIVES TO SHARING?

- Policies aren't always compelling
- Labor not always recognised / rewarded
- Authorship: Nominally only First / Last really counts
- Tenure: Metrics Reward Individual not teams
- HIPAA and similar: Scary and significant individual penalties for data loss
- Deidentification: Is it truly possible?

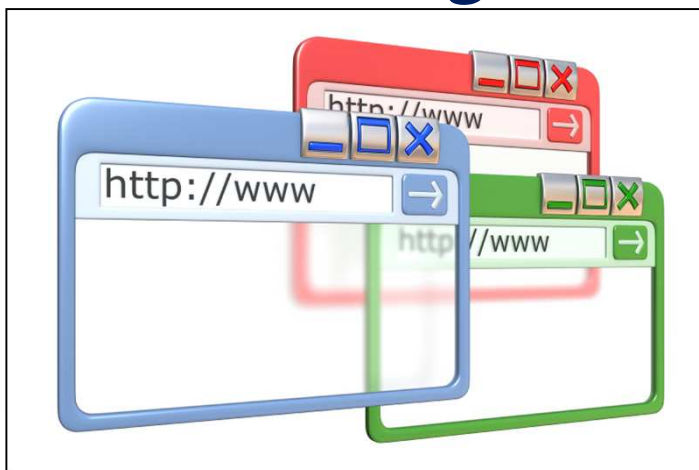




DIFFERENT PERSPECTIVES and DRIVERS

Technological

Economic



Legal

Personal



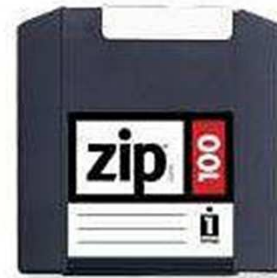
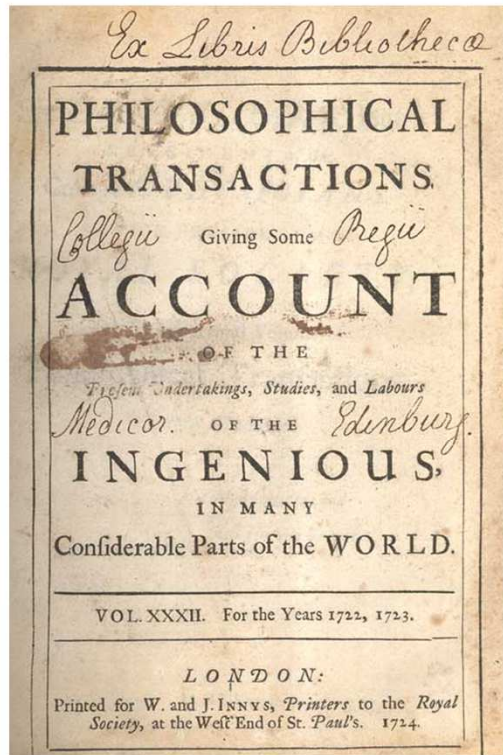


How do you ACTUALLY share data?





Data SHARING BY PHYSICAL media



Usually require local collaborator (proximity) for transfer (manual) or has potentially significant time delays (eg postage)





TECHNOLOGIES FOR SHARING DATA (BY ELECTRONIC means)



Removes the barrier of geography to allow shared “storage” of data. Doesn’t necessarily make it any easier to do anything once you have the data





EXAMPLES OF PROJECTS FACILITATING SHARING OF RESEARCH DATA (Aus)



ARCS – provides data storage, data transfer, collaboration and conferencing facilities

Biogrid – platform for integrating and analysing clinical, imaging and biospecimen data across jurisdictions

NeCTAR – cloud services for workflows, tools and servers





EXAMPLES OF SUCCESSFUL DATA SHARING META-RESOURCES

The image shows two overlapping website screenshots. The top-left screenshot is of the RDA (Research Data Alliance) website, displaying navigation menus, a search bar, and several news and event announcements. The top-right screenshot is of The Dataverse Project website, featuring a header with the project logo and a main section titled 'Open source research data repository software'. Below this, there are five categories: Researchers, Journals, Institutions, and Developers, each with a brief description and a 'Want to...' link. At the bottom, a 'DATVERSE REPOSITORIES - A WORLD VIEW' section shows statistics: 19 Installations, 1,600+ Dataverses, 61,000+ Datasets, and 1,700,000+ Downloads, along with a map showing repository locations.

RDA | Research Data Sharing without barriers - Google Chrome
RDA | Research | <https://rd-alliance.org>

RESEARCH DATA SHARING WITHOUT BARRIERS RDA EU RDA US CONTACT US LOGIN REGISTRATION

RDA RESEARCH DATA ALLIANCE

ABOUT RDA GET INVOLVED GROUPS RECOMMENDATIONS & OUTPUTS RDA FOR DISCIPLINES PLENARIES EVENTS NEWS & MEDIA

Upcoming RDA 8th Plenary Meeting: 15th - 17th September 2016, Denver, CO
REGISTER NOW - Early Bird registration closes 8 August 2016 | [New! RDA 8th Plenary Programme Online](#) | [New! Call for posters](#)

Call for nomination for the RDA Technical Advisory Board 2016 - View details and apply!

News

Survey on Security & Trust in Data Sharing: have your say on current security and privacy practices within the data communities!
03 August 2016
The RDA Working Group for Data Security and Trust is gathering informa

Council Update
01 August 2016
The RDA Council is the senior body of RDA responsible for the overall vision and direction of RDA.

RDA Events

First CODATA-RDA Research Data Science Summer School, 1-12 August, ICTP, Trieste
01 Aug 2016 - 09:00 to 12 Aug 2016 - 18:00
The CODATA-RDA Research Data Science Summer School is held at the ICTP, Trieste, Italy from 1st to... [Read more](#)

Innovating the wheat community through the RDA services and outputs, 13-14 July 2016, Maroussi, Greece
13 Jul 2016 - 08:00 to 14 Jul 2016 - 16:30
This event focuses on getting researchers and other stakeholders acquainted with the data formats,... [Read more](#)

Request for comm

[Repository Core Des](#)
By Johannes Reetz on 1

[RDA/WDS Publishing Recommendations](#)
By Hylke Koers

[Data Citation WG Re](#)
By Andreas Rauber

The Dataverse Project

Open source research data repository software

Researchers
Enjoy full control over your data. Receive web visibility, academic credit, and increased citation counts. A personal dataverse is easy to set up, allows you to display your data on your personal website, can be branded uniquely as your research program, makes your data more discoverable to the research community, and satisfies data management plans. [Want to set up your personal dataverse?](#)

Journals
Seamlessly manage the submission, review, and publication of data associated with published articles. Establish an unbreakable link between articles in your journal and associated data. Participate in the open data movement by using Dataverse as part of your journal data policy or list of repository recommendations. [Want to find out more about journal dataverses?](#)

Institutions
Establish a research data management solution for your community. Federate with a growing list of Dataverse repositories worldwide for increased discoverability of your community's data. Participate in the drive to set norms for sharing, preserving, citing, exploring, and analyzing research data. [Want to install a Dataverse repository?](#)

Developers
Participate in a vibrant and growing community that is helping to drive the norms for sharing, preserving, citing, exploring, and analyzing research data. Contribute code extensions, documentation, testing, and/or standards. Integrate research analysis, visualization and exploration tools, or other research and data archival systems with Dataverse. [Want to contribute?](#)

DATVERSE REPOSITORIES - A WORLD VIEW

19 Installations 1,600+ Dataverses 61,000+ Datasets 1,700,000+ Downloads

Dataverse Repositories

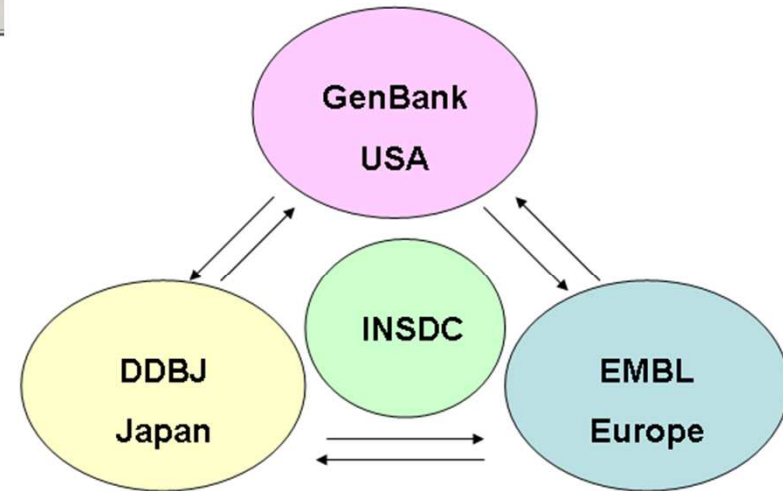
UIT The Arctic Univers...





EXAMPLES OF SUCCESSFUL DATA SHARING PROJECTS (REPOSITORIES)

The screenshot shows the NCBI website interface. The address bar displays <http://www.ncbi.nlm.nih.gov/>. The main header includes the NCBI logo and the text "National Center for Biotechnology Information", "National Library of Medicine", and "National Institutes of Health". Below the header is a navigation menu with links to "PubMed", "All Databases", "BLAST", "OMIM", "Books", "TaxBrowser", and "Structure". A search bar is present with a dropdown menu set to "All Databases" and a "Go" button. A sidebar on the left contains "SITE MAP" and "About NCBI" sections. The main content area features a "What does NCBI do?" section with a paragraph of text and a "Hot Spots" section with several links.



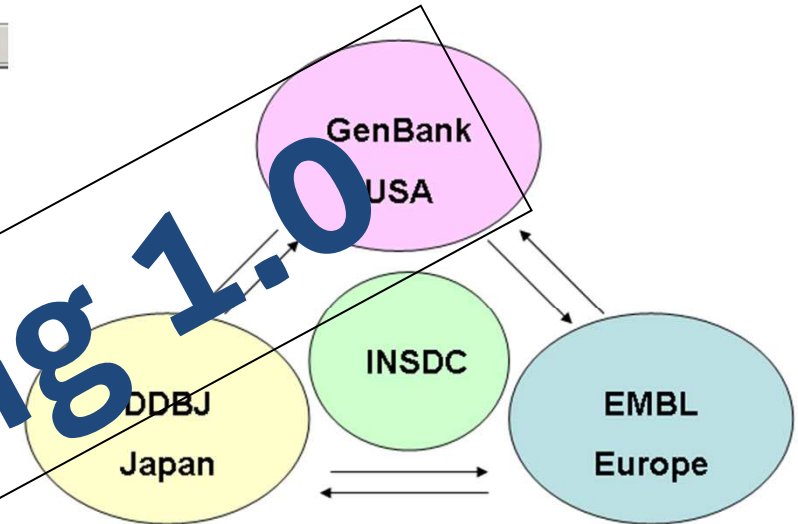
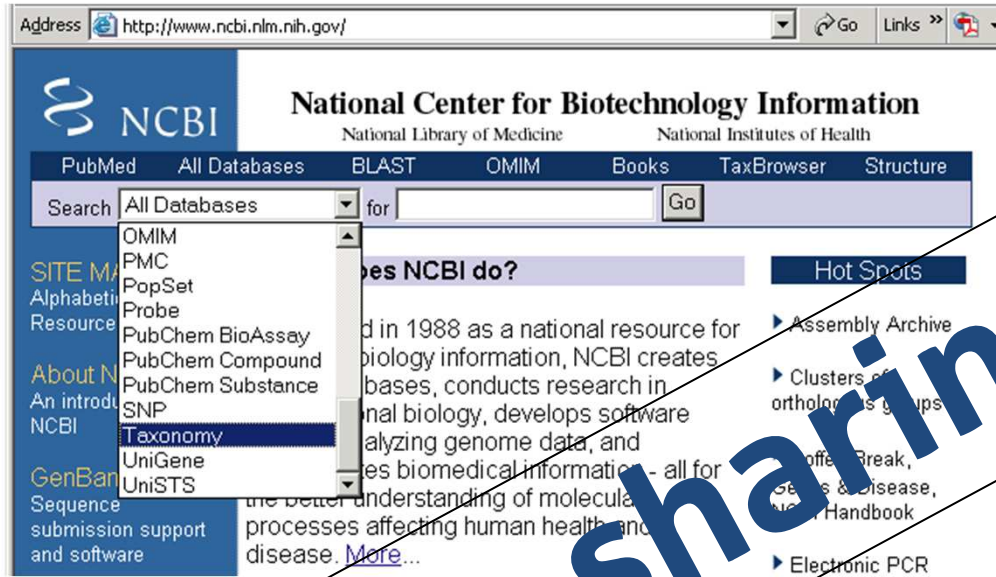
The screenshot shows the GEO website interface. The header includes the NCBI logo and the GEO logo with the text "Gene Expression Omnibus". The main content area features a "Gene Expression Omnibus" description and a "GEO navigation" section with a search bar and several buttons. A red box highlights the search bar and the "DataSets" button. The "GEO navigation" section includes "QUERY" and "BROWSE" options, with "DataSets" and "Gene profiles" highlighted. The "SUBMIT" section includes "Direct deposit / update" and "Web deposit / update" options. The right sidebar contains "Public data" statistics and "Site contents" links.

The Bioconductor logo features a stylized green DNA double helix on the left, with a white arrow pointing upwards and to the right. Below the DNA is the word "BIOCONDUCTOR" in white capital letters on a dark blue background. To the right of the logo is the "ON S" logo, and below it is the text "INSTITUTE Discover. Prevent. Cure."

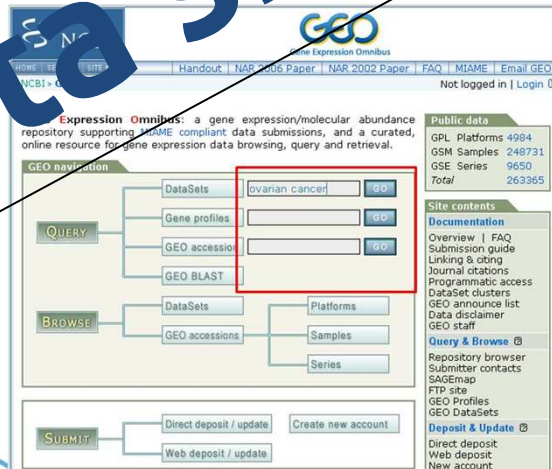




EXAMPLES OF SUCCESSFUL DATA SHARING PROJECTS (REPOSITORIES)



Data sharing 1.0





Data warehouses vs Databases

Database vs Data Warehouse

edureka!

	Database	Data Warehouse
Purpose	Data retrieval, updating and management	Data analysis and decision making
Application	OLTP (Online Transaction Processing)	Reporting and OLAP (Online Analytical Processing)
Format	Normalized	Denormalized
Time Frame	Current/Real-Time	Historical



Note that you can use a database as a data warehouse. It depends on, for which purpose you have design the database

www.edureka.co/data-warehousing-and-bi





Data warehouses vs Databases

"Bioinformatics issues for conducting sophisticated
multiple-pass genome sequence analysis"

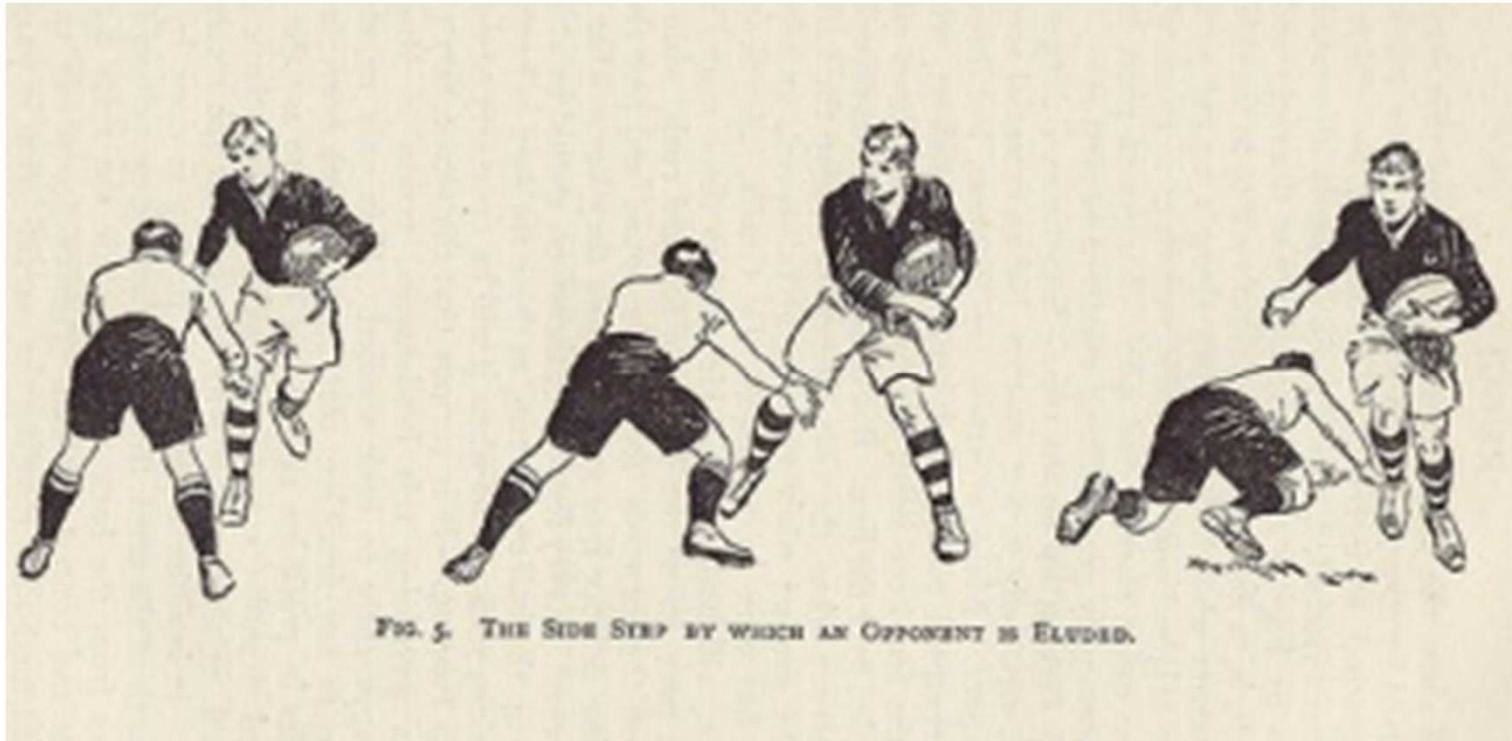
Kim W. Carter

Murdoch University, 2004.





How/WHY DID I GET INTERESTED IN DATA SHARING TECHNOLOGIES?



The International Consortium for Autism Registry Epidemiology (iCARE)



iCARE annual meeting, Sweden 2011



VISION FOR iCARE and autism research

Motivated and willing collaborators wanted to join forces to create a resource that allows for analyses that:

- cannot be performed with a single existing system**
- enhance the analytic potential of a single data system**
- allow direct comparison of findings across different data systems with eg geographic, population, or data collection variation.**





Overarching aims of iCARE

- 1. Funded (Autism Speaks 2009-2013) to setup a multi-national virtual data set for the study of pre- and perinatal risk factors for autism.**
 - Establish a minimal database requirement.
 - Establish and conduct data preparation protocols across registries.
 - Enable and test centralized data access protocols to multiple registries.
 - Establish a collaborative framework and guidelines for a working relationship among sites/investigators.

- 2. Demonstrate the utility of the resource**





How did I get involved with iCARE?

Setup a multi-national virtual data set for the study of pre- and perinatal risk factors for autism.

The group had funding and ethics approval for virtual pooling but the original IT group had to withdraw





iCARE CONSORTIUM CHARACTERISTICS

Site	Population Size	Birth Years	Births/Year	Coverage	Health Care Provision
Denmark	5.5 million	1980-2007	62,000	National	Public
Finland	5.4 million	1987-2008	60,000	National	Public
Israel	7.6 million	1987-2006	86,000	National	Public
Norway	4.8 million	1980-2005	55,000	National	Public
Sweden	9.4 million	1980-2008	107,000	National	Public
Western Australia	1.9 million	1983-1999	24,000	State	Public and private

Population-based registries → Large samples, unbiased, prospective, with ability to link with other population databases





Data DICTIONARY AND HARMONISATION

Critical to the success of the project (and any data sharing project) is making data comparable across sites

Challenge

Diverse data availability and formats, over time and by site

Solution: Harmonisation

generic term for procedures that create comparability between data derived from different sources





Data DICTIONARY and HARMONISATION



Data dictionary V1 (Sep 2010) – 48 variables

Data dictionary V2 (Mar 2011) – 52 variables

Data dictionary V3 (Mar 2013) – 58 variables





Recap: So WHY DO WE WANT TO SHARE RESEARCH DATA?

Benefits

- Increased power, leading to subgroup analyses and interactions
- Ability to compare outcomes and validate models across sites

Pitfalls

- Cost of harmonisation – time and \$
- Difficult to validate/error check when anonymous
- Potentially more complex analysis
- Ethico-legal issues with privacy & consent
- Requires strong collaborations





**Are there electronic methods that
facilitate data sharing and analysis
together?**



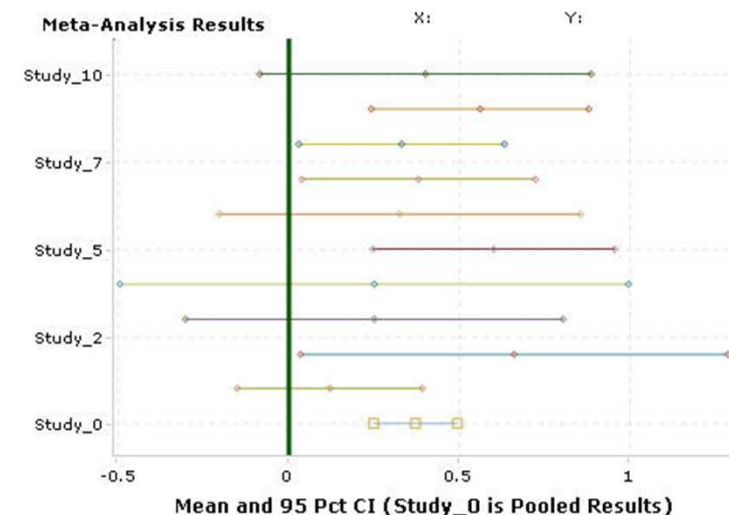


METHODS FOR SHARING and ANALYSING Research Data

1. Traditional Meta Analysis

Combining existing results of analyses on similar outcomes and predictors using similar methodology

- needs published data on similar outcomes and predictors using similar methodology
- can suffer from “resolution”
As individual level data may not be used





METHODS FOR SHARING and ANALYSING Research Data (cont)

2. Manual Data Pooling

Analysis of harmonised pooled data from multiple sites, sent to a single analysis site

- (manually) unified methodology
- needs harmonised data
- consent and ethics for sharing
- significant effort for a single analysis centre
- requires strong collaboration

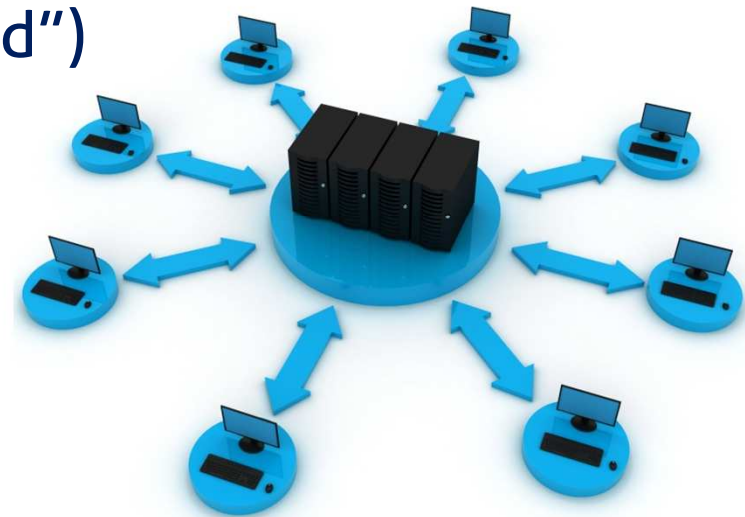




METHODS FOR SHARING and ANALYSING Research Data (cont)

3. Automated Data Pooling (federation)

Analysis of harmonised pooled data automatically from multiple sites (pooling in the “cloud”)



- unified methodology
- needs harmonised data
- consent and ethics for sharing
- strong collaboration
- requires informatics infrastructure to enable the federation process
- Requires some infrastructure at all data-contributing sites



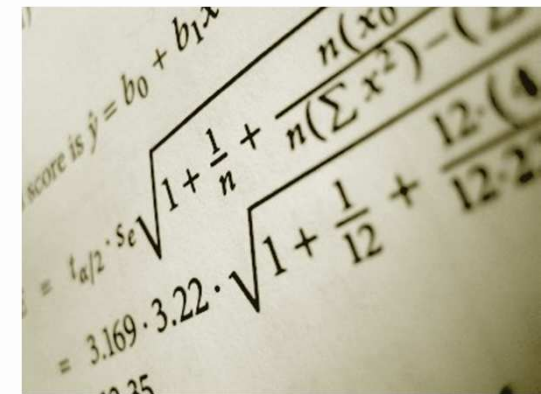


METHODS FOR SHARING and ANALYSING Research Data (cont)

4. Automated decentralised analysis – eg DataSHIELD

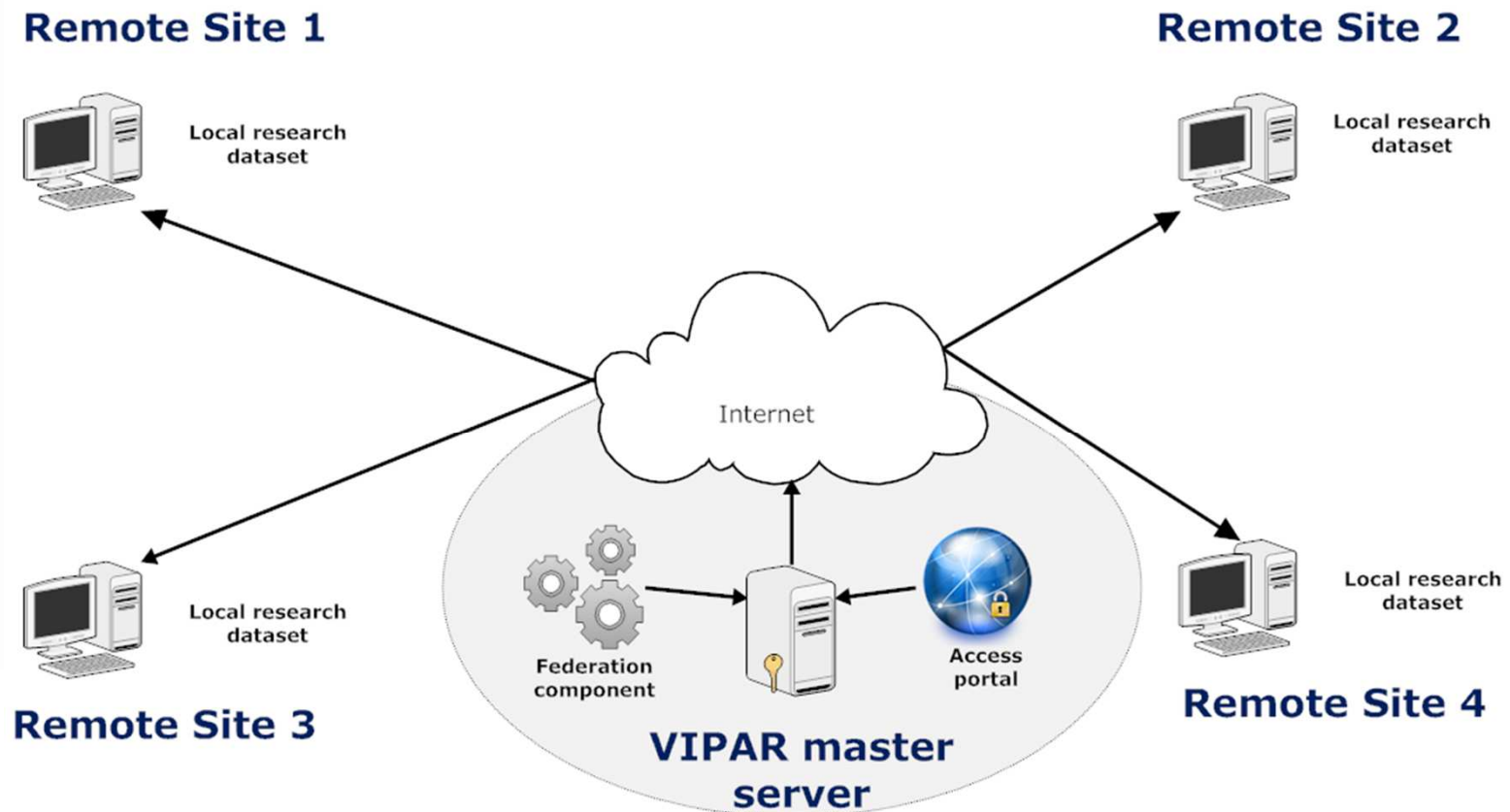
Analysis of harmonised data automatically from multiple sites by pooling statistics (ie no data transfer)

- unified methodology
- needs harmonised data
- may need consent and ethics for sharing
- potentially limited types of analysis
- Requires significant informatics infrastructure at all data-contributing sites



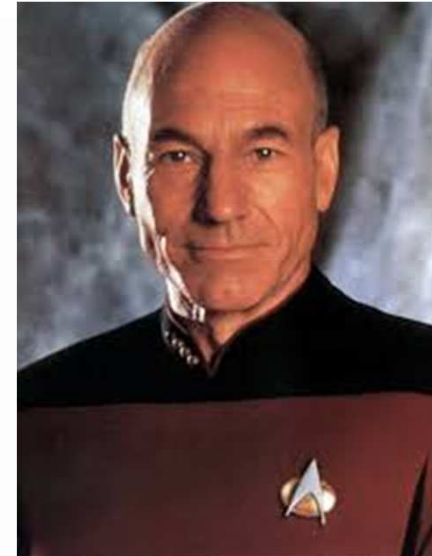
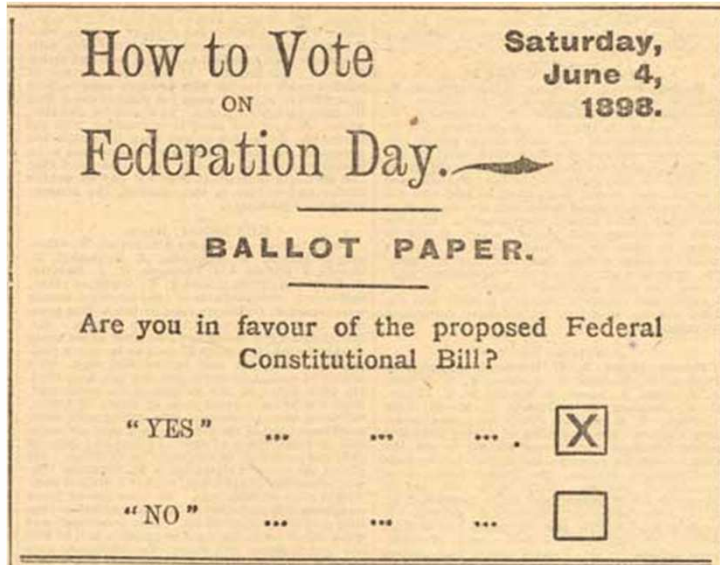


VIPAR: VIRTUAL INFRASTRUCTURE FOR POOLING AND ANALYSIS OF RESEARCH DATA



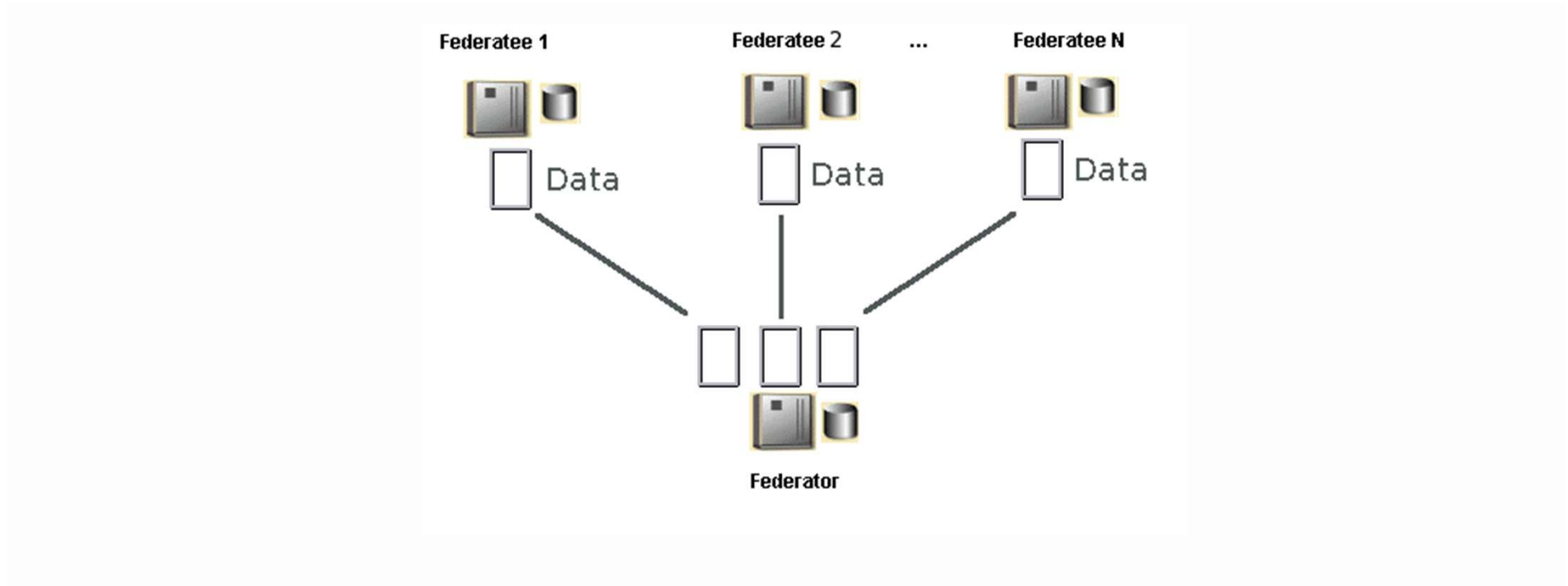


What is Federation?





WHAT IS DATABASE FEDERATION?



Tools that transparently integrates multiple autonomous databases into a single virtual entity





FEDERATION WITHIN RDMS

Site 1

First Name	Last Name	Address	City	Age
Mickey	Mouse	123 Fantasy Way	Anaheim	73
Bat	Man	321 Cavern Ave	Gotham	54
Wonder	Woman	987 Truth Way	Paradise	39
Donald	Duck	555 Quack Street	Mallard	65
Bugs	Bunny	567 Carrot Street	Rascal	58
Wiley	Coyote	999 Acme Way	Canyon	61
Cat	Woman	234 Purrfect Street	Hairball	32
Tweety	Bird	543	Itottaw	28

Site 2

First Name	Last Name	Address	City	Age
Mickey	Mouse	123 Fantasy Way	Anaheim	73
Bat	Man	321 Cavern Ave	Gotham	54
Wonder	Woman	987 Truth Way	Paradise	39
Donald	Duck	555 Quack Street	Mallard	65
Bugs	Bunny	567 Carrot Street	Rascal	58
Wiley	Coyote	999 Acme Way	Canyon	61
Cat	Woman	234 Purrfect Street	Hairball	32
Tweety	Bird	543	Itottaw	28

RDMS federated table

First Name	Last Name	Address	City	Age
Mickey	Mouse	123 Fantasy Way	Anaheim	73
Bat	Man	321 Cavern Ave	Gotham	54
Wonder	Woman	987 Truth Way	Paradise	39
Donald	Duck	555 Quack Street	Mallard	65
Bugs	Bunny	567 Carrot Street	Rascal	58
Wiley	Coyote	999 Acme Way	Canyon	61
Cat	Woman	234 Purrfect Street	Hairball	32
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Mickey	Mouse	123 Fantasy Way	Anaheim	73
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Wiley	Coyote	999 Acme Way	Canyon	61
Cat	Woman	234 Purrfect Street	Hairball	32
Tweety	Bird	543	Itottaw	28





FEDERATION WITHIN RDMS (cont)



PostgreSQL



RDMS federated table

First Name	Last Name	Address	City	Age
Mickey	Mouse	123 Fantasy Way	Anaheim	73
Bat	Man	321 Cavern Ave	Gotham	54
Wonder	Woman	987 Truth Way	Paradise	39
Donald	Duck	555 Quack Street	Mallard	65
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Cat	Woman	234 Purrfect Street	Hairball	32
Tweety	Bird	543	Itotltaw	28

Select firstname, age
from table

First Name	Last Name	Address	City	Age
Hicky	Mouse	123 Fantasy Way	Anaheim	73
Bat	Man	321 Cavern Ave	Gotham	54
Wonder	Woman	987 Truth Way	Paradise	39
Donald	Duck	555 Quack Street	Mallard	65
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Wiley	Coyote	999 Acme Way	Canyon	61
Cat	Woman	234 Purrfect Street	Hairball	32
Tweety	Bird	543	Itotltaw	28

First Name	Age
Mickey	73
Bat	54
Wonder	39
Donald	65
Bugs	58
Wiley	61
Cat	32
Tweety	28



FEDERATION WITHIN RDMS (cont)



PostgreSQL



RDMS federated table

First Name	Last Name	Address	City	Age
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Select firstname, age from table

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First Name	Age
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Bat	54
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Cat	32
Tweety	28



FEDERATION WITHIN RDMS (cont)

Select firstname,age
from table

RDMS federated table

First Name	Last Name	Address	City	Age
Mickey	Mouse	123 Fantasy Way	Anaheim	73
Bat	Man	321 Cavern Ave	Gotham	54
Wonder	Woman	987 Truth Way	Paradise	39
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First Name	Age
Mickey	73
Bat	54
Wonder	39
Donald	65
Bugs	58
Wiley	61
Cat	32
Tweety	28

Intermediate copy of entire database tables
made on the fly at the central site





FEDERATION WITHIN RDMS (cont)

RDMS federated table



First Name	Last Name	Address	City	Age
Mickey	Mouse	123 Fantasy Way	Anaheim	73
Bat	Man	321 Cavern Ave	Gotham	54
Wonder	Woman	987 Truth Way	Paradise	39
Donald	Duck	555 Quack Street	Mallard	65
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Bat	Man	321 Cavern Ave	Gotham	54
Wonder	Woman	987 Truth Way	Paradise	39
Donald	Duck	555 Quack Street	Mallard	65
Bugs	Bunny	567 Carrot Street	Rascal	58
Wiley	Coyote	999 Acme Way	Canyon	61
Cat	Woman	234 Purrfect Street	Hairball	32
Tweety	Bird	543	Itotltaw	28

Federation engines in MySQL and Postgres appear to be poorly implemented:

- * suitable for LAN only
- * suitable for smallish datasets

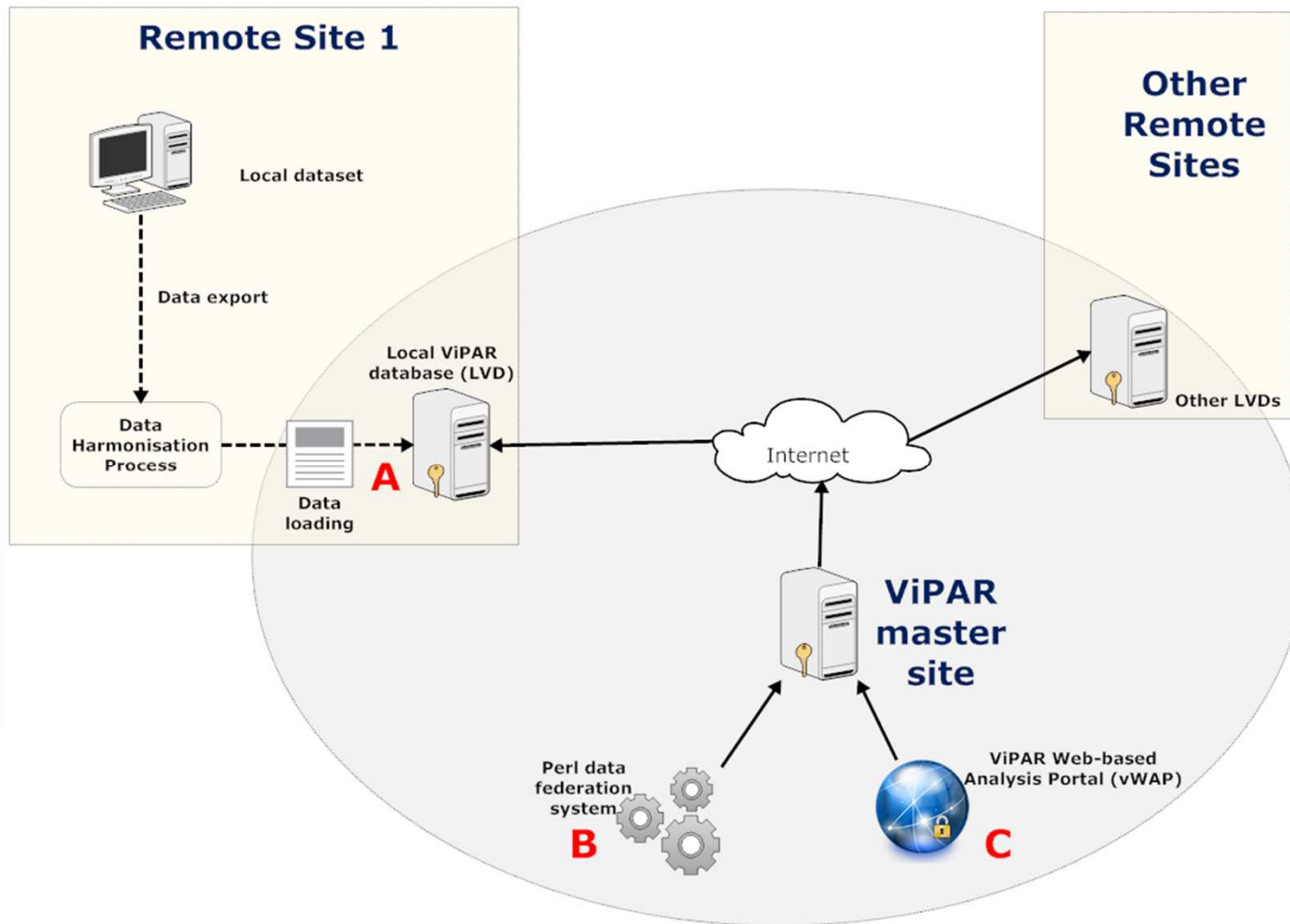
Problem: needs to work securely over Internet with large datasets

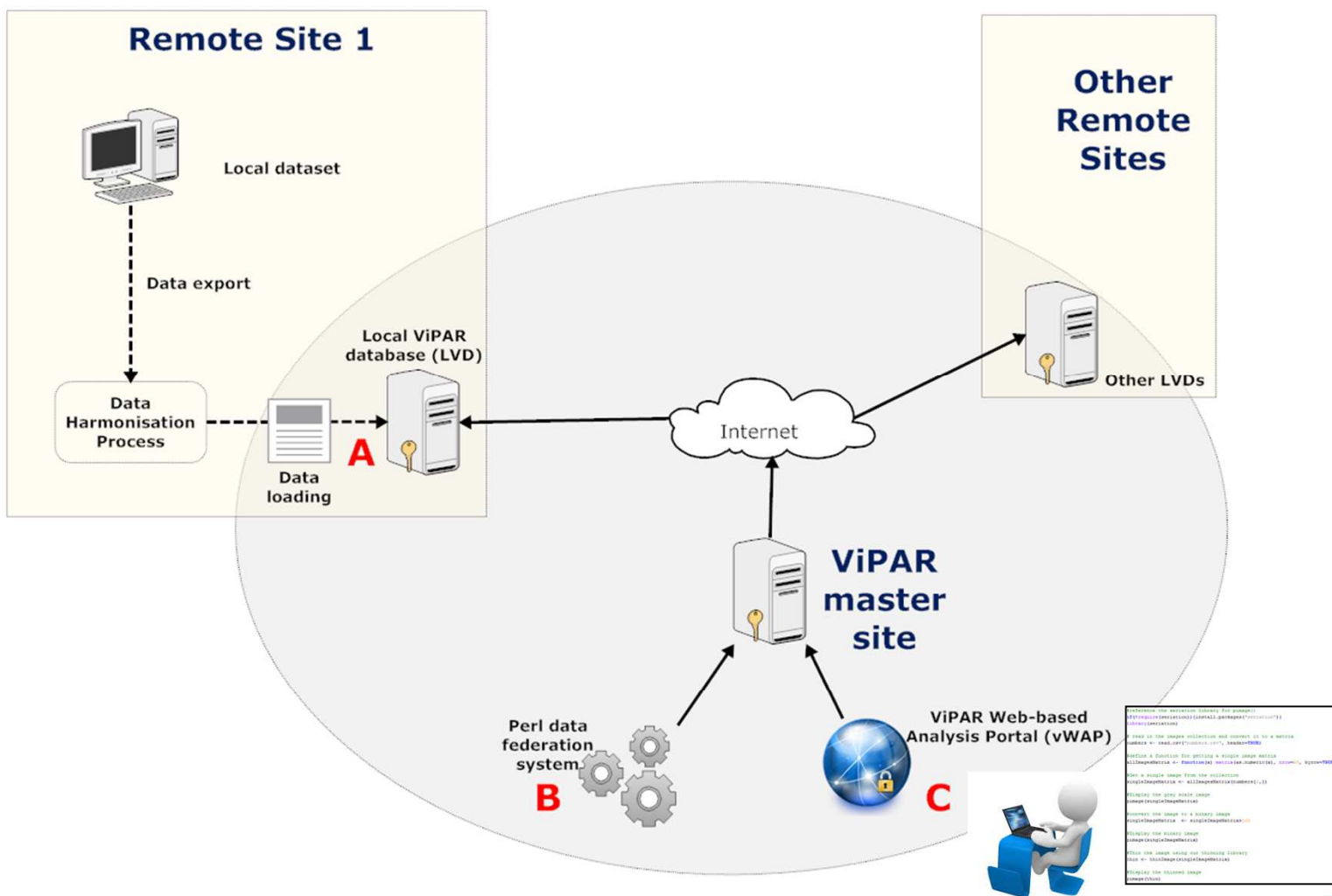


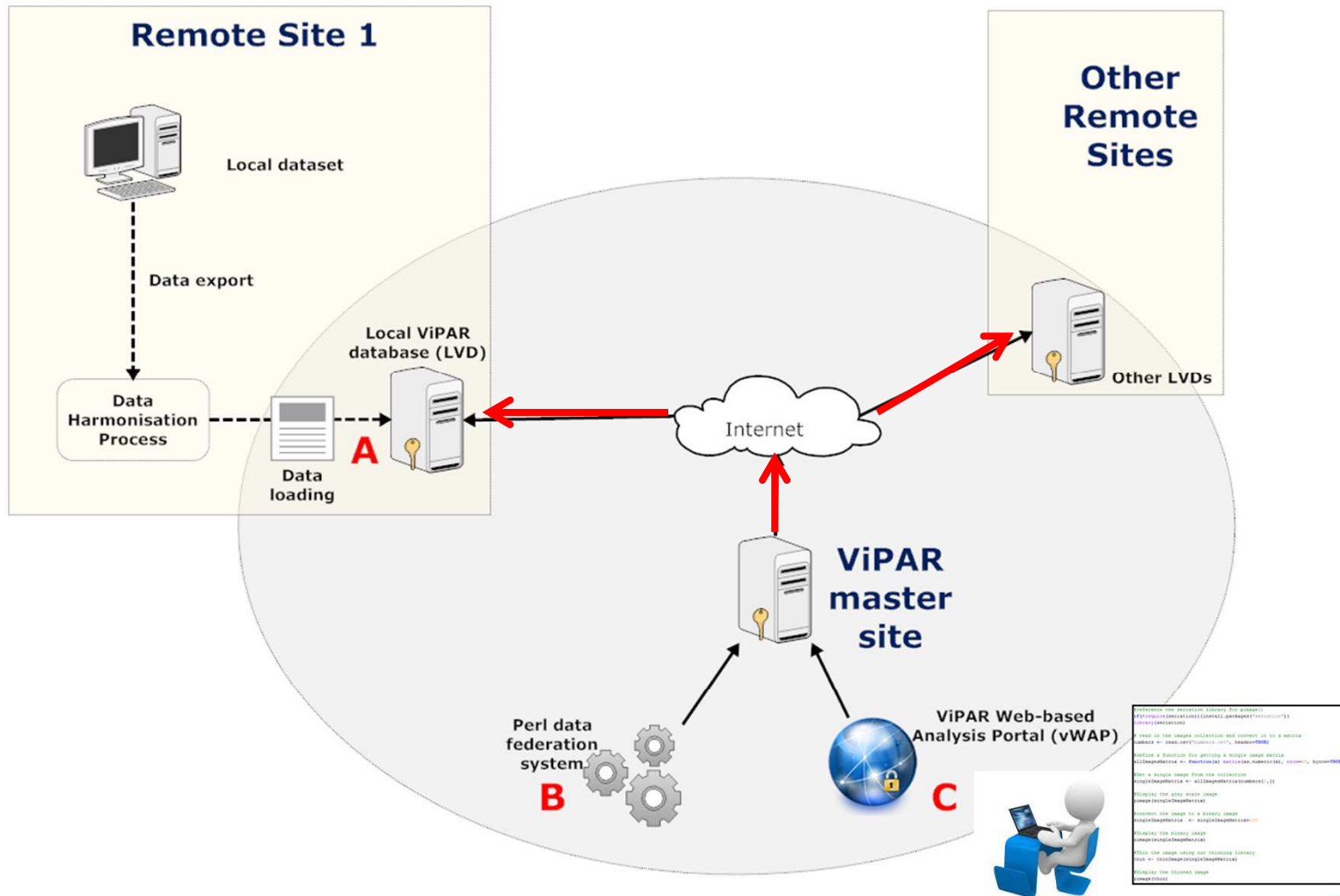


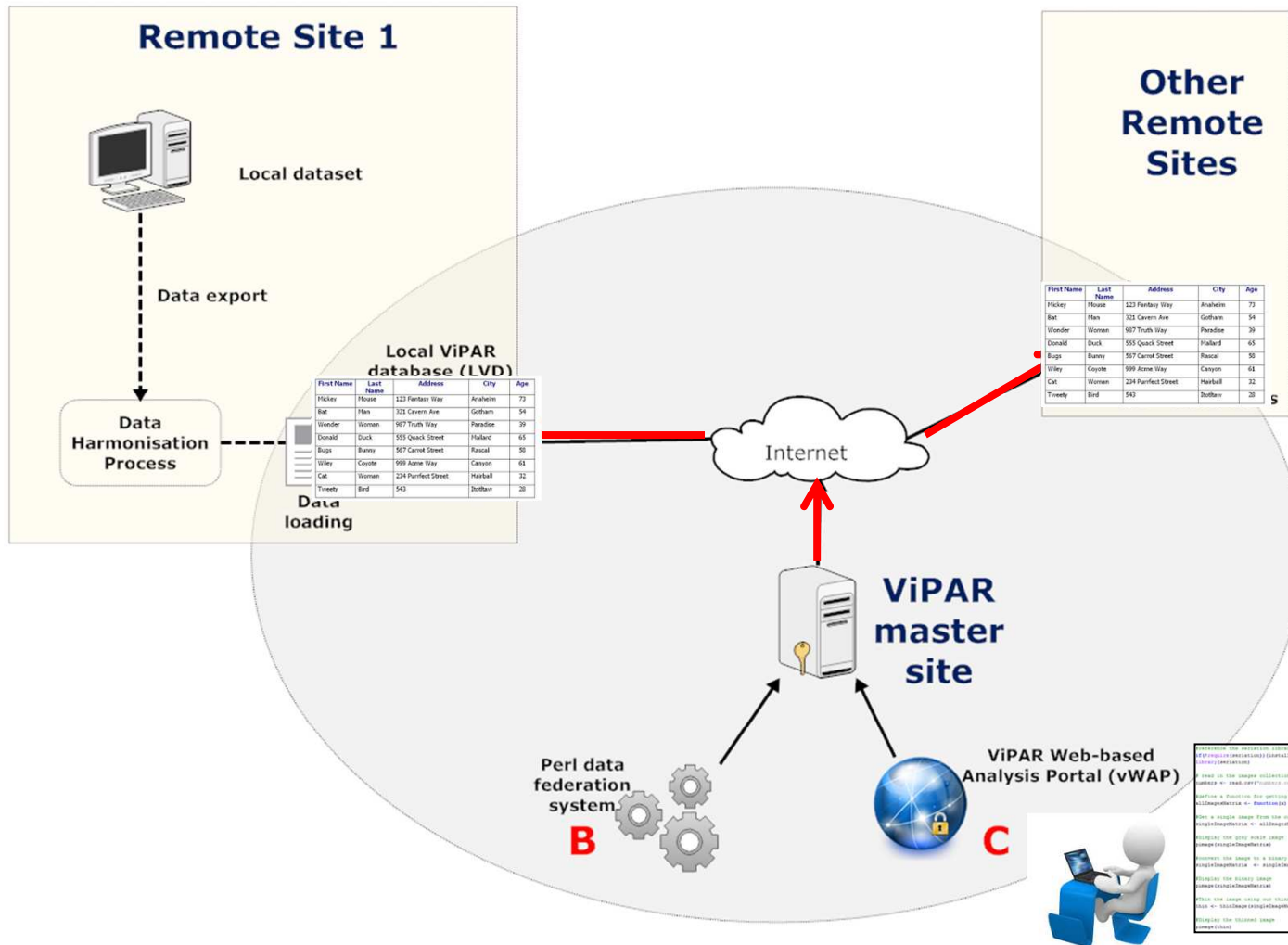


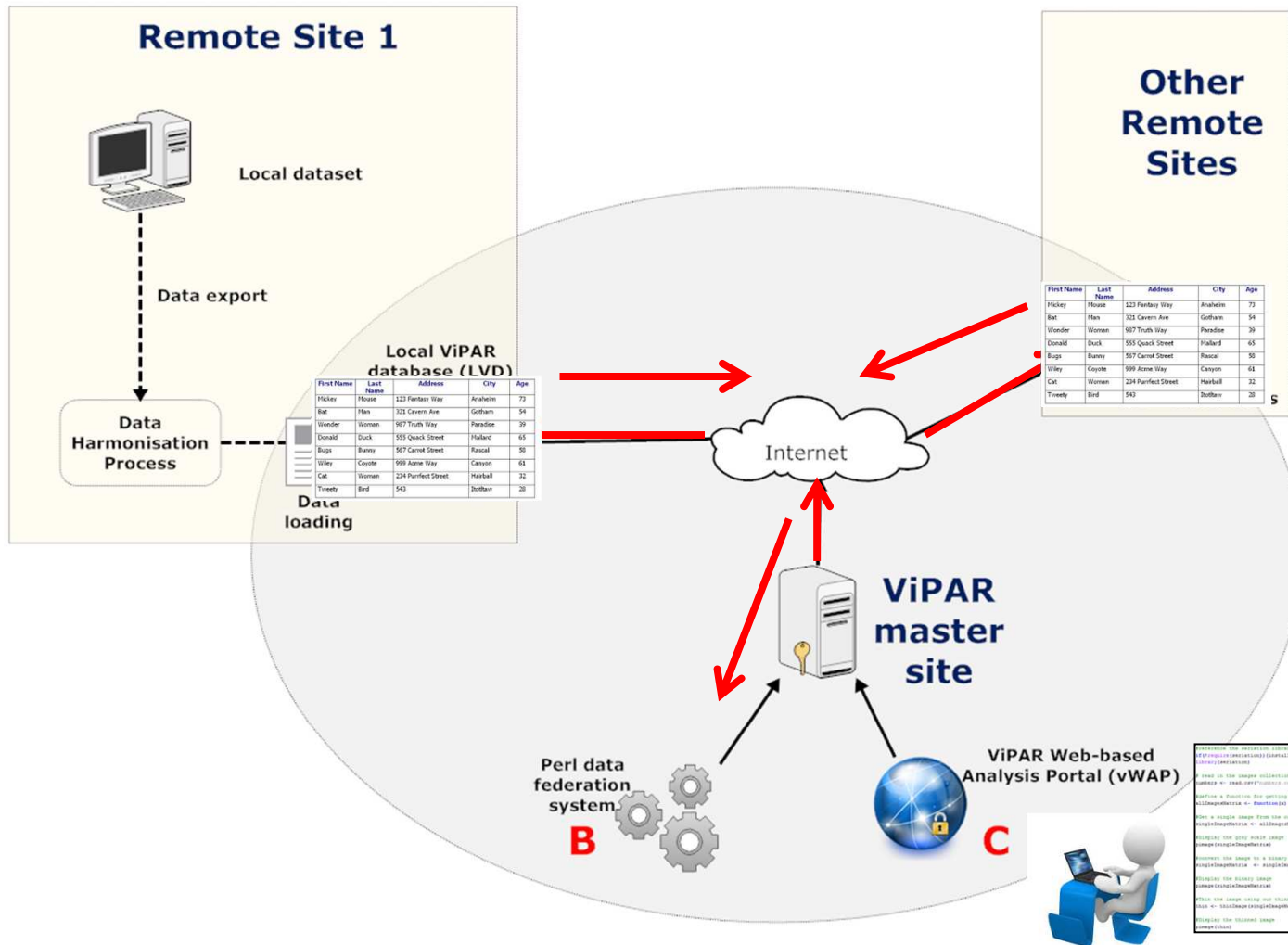
ViPAR: overview

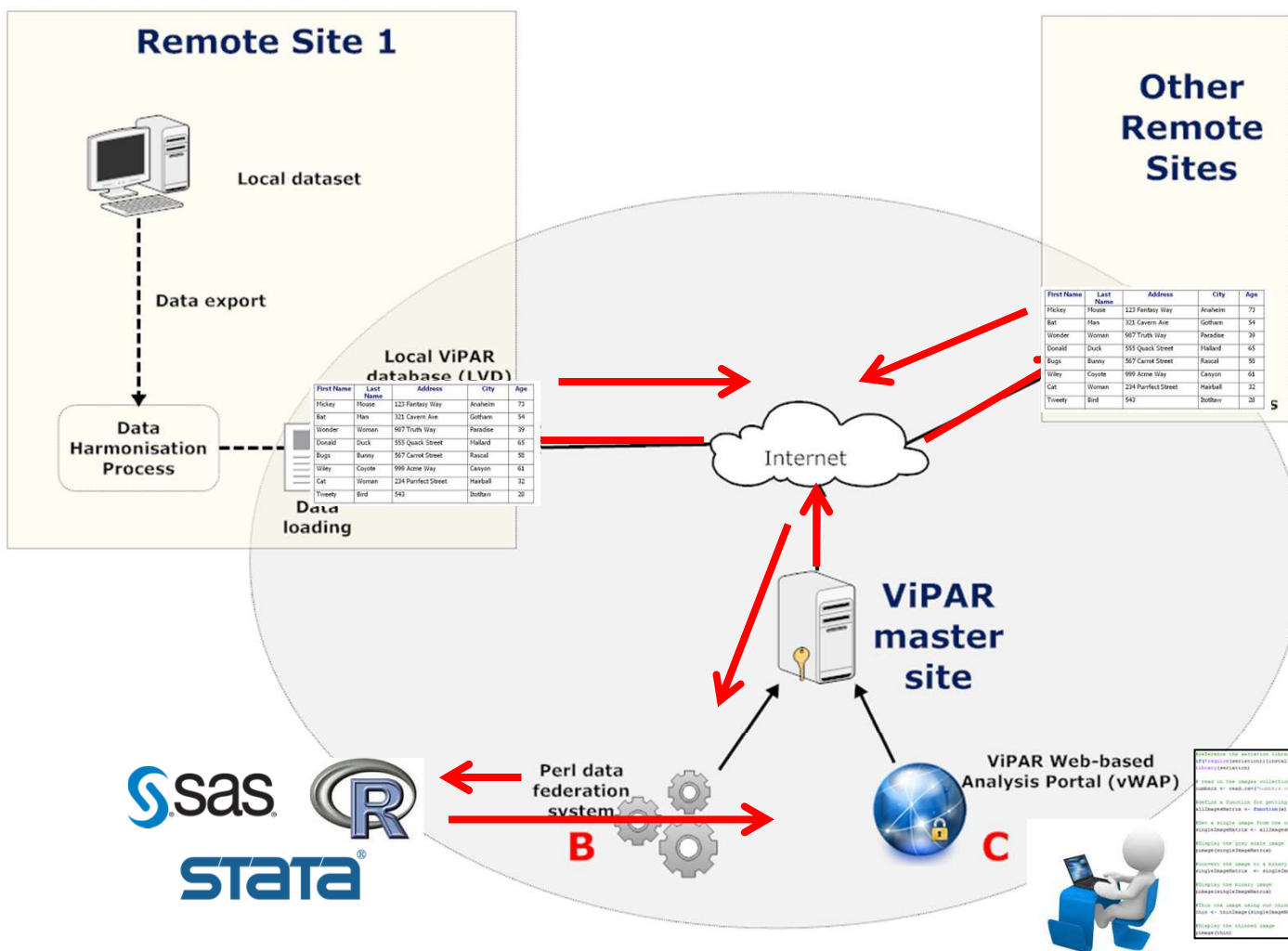












B

C





ViPAR – a CUSTOM DATA FEDERATION PLATFORM

Open-source stack – Linux, Apache, Mysql, OpenSSL
Available as a pre-built VM images for easy access

<http://bioinformatics.childhealthresearch.org.au/software/vipar/>
(pre-built VM images for easy use – Vbox and Vmware)

<https://gitlab.com/kim.carter/ViPAR> (source code)

<https://groups.google.com/forum/#!forum/vipar> (support forum)

ViPAR Daemon – 1500 lines of Perl code

- Handles multiple clients simultaneously, and can perform eg parallel data retrieval (all sites at the same time)
- Implements its own federation (and analysis) engine

VWAP – (ViPAR Web-based Analysis Portal)

- 8000 lines of Perl code
- 1200 lines of Javascript





BEHIND THE SCENES





BEHIND THE SCENES

MySQL

Open-source database management system, with powerful features including database federation

Widely used, especially for large databases

SSH

Powerful, free solution to securely exchange data between 2 networked devices over an insecure channel (such as the Internet)

Enterprise reliability and security

“tunnels” allow us to transfer of programs services between remote computers dynamically

SSL

Client-side and Server-side SSL certificates used (along with user accounts and roles) to provide layered, strong security model





Data model

Study

Overarching conglomeration of analysis projects, data resources, data dictionary and variables and users

Data dictionary

A version controlled set of Variables and Missing data fields

Variable

A data field of a given type (eg continuous, categorical, date) with a missing data type

Sites, Servers and Resources

A site is a nominal geo-location housing a ViPAR LVD server accessible on a specified SSH port, with one or more (certified) harmonised dataset resources on the server





Data model (cont)

Analysis “projects”

Defined research question(s) (eg agreed by AOC)

- Specified list of Resources to be included
- Specified list of Variables available for analysis
- Specified list of Users with access @ analyst or guest level (read-only)
- Results/outputs can be tagged as “sharing” accessible to enable non-project users within ViPAR to see specific results

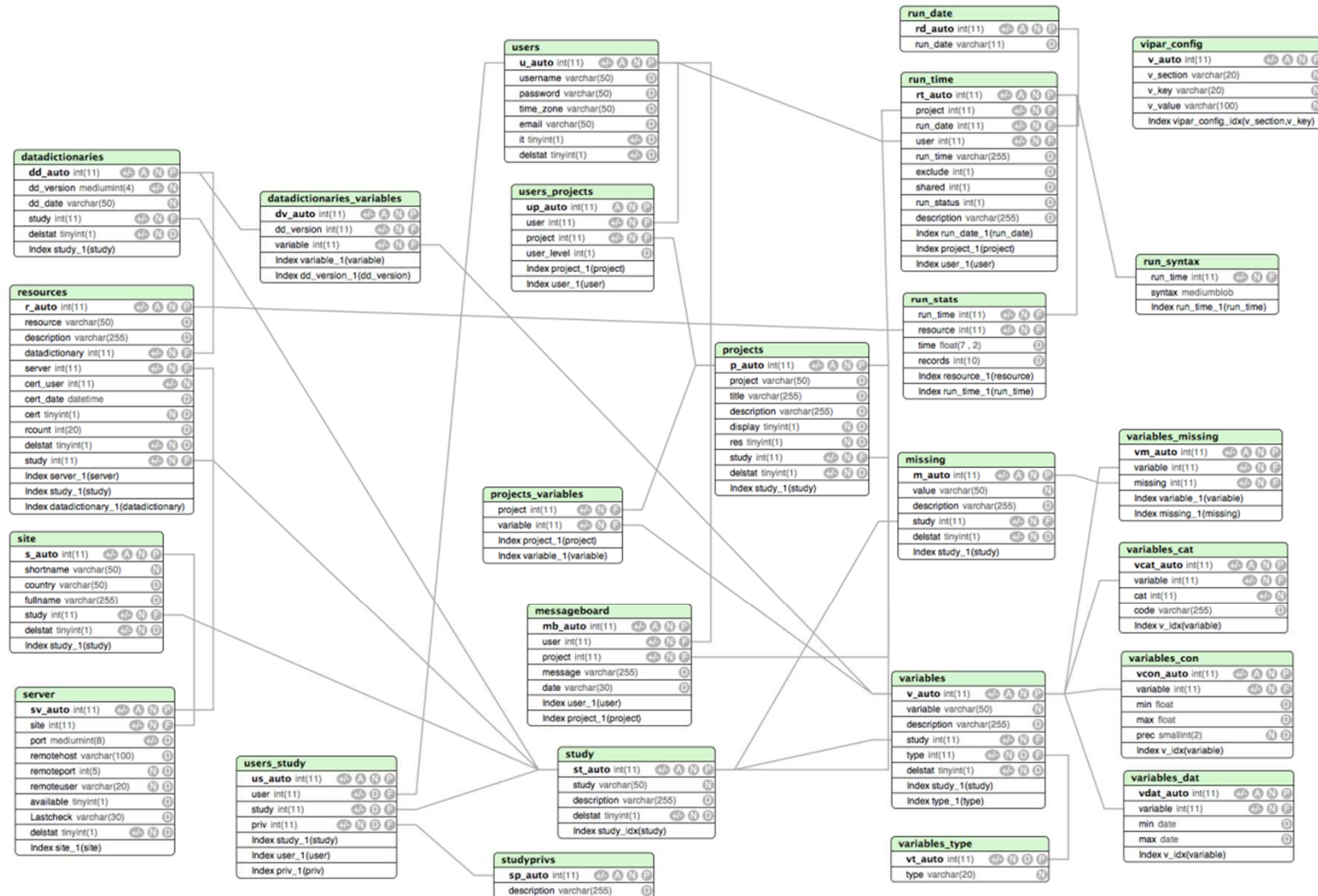
Users

- Can be designated as “Admin” (see all projects and get extra admin menu options”
- Can be member of multiple analysis projects
- Unique user/pass, along with client SSL certificate (recommended)





BEHIND THE SCENES: DATA MODEL





How does ViPAR PROTECT MY DATA?

Network level

- Private, encrypted network connecting each data site (LVD) to the master site (VMS). Protected by hardware & software firewalls
- Only the VMS can initiate connections to the LVDs
- Sites maintain their own data (in the LVD) – no data is saved at the VMS

User-level

- Unique user pass & cert combo (with client SSL certificates) – you can't get to the site login page without
- Only users who run code get to “pool” the data (within a defined project)
- Implicit “trust” to give max flexibility in analysis -> that users won't try to access individual data

Portal-level

- Everything is logged, all run code, all interactions including “deletions”.
- No direct access to the data

Data-level design

- Design your dictionary to minimise potentially identifying fields





VIPAR PORTAL (FOR ICARE)

The screenshot shows a web browser window with the following content:

- Browser Address Bar:** https://www.icareautism.org/cgi-bin/iwap_projman.cgi
- Page Title:** iCARE Web based Analysis Port...
- Left Sidebar:**
 - Welcome Kim!**
 - Home
 - New Project
 - Your projects
 - IMFAR2011_v1
 - IMFAR2011_v2
 - advpatmatage
 - australia_v1
 - australia_v2
 - denmark_v1
 - denmark_v2
 - norway_v1
 - norway_v2
 - sweden_v1
 - sweden_v2
 - testproj

- Main Content Area:**
- The iCARE Web-based Analysis Portal** kim [Logout]
- Welcome to the ICARE Web-based Analysis Portal (IWAP).
- Browse the ongoing and completed projects below as well as the official Data Dictionary releases for each version of the database. If you have any ongoing projects you should see them on the left. The status of each ICARE site can be seen below.
- If you have problems or suggestion please contact us
- Project Summary**

advpatmatage	Advancing Paternal and Advancing Maternal Age and Risk For Autism	Advancing Paternal and Advancing Maternal Age and Risk For Autism
--------------	---	---
- Data Dictionaries**
 - Version 1 - September 2010
 - Version 2 - March 2011
- Site Status:** Mon May 9 13:01 2011 Perth
- Country Indicators:** Australia, Denmark, Finland, Israel, Norway, Sweden

Done

FoxyProxy: Patterns



Running an analysis

The screenshot shows the iCARE Web based Analysis Portal - Project Manager interface. The browser window title is "iCARE Web based Analysis Portal - Project Manager - Chromium" and the URL is "https://www.icareautism.org/cgi-bin/iwap_projman.cgi".

Welcome Helen!
Home
Your Projects
australia_v1
australia_v2
obs_comp
simdata_v1
Other Projects
2012_preterm
advpatmatage
bwASD
seasonality

helen [Logout]

New Run View Files Manage Code Libraries

Choose a title for this analysis (40 char max)
This is a test analysis (note: use letters, numbers, hyphen and underscore)

Enter a description for this analysis (optional)
Example analysis tabulating a variable

Select the data dictionary version for this project
Version 1 - September 2010

Choose iCARE resources
 Select all
 icare_israel_v1_sim icare_denmark_v1_sim icare_norway_v1_sim
 icare_finland_v1_sim icare_sweden_v1_sim icare_australia_v1_sim

Choose iCARE analysis variables
 Select all
 iBWz iCOUNT iBW iSITE

Choose analysis package
R

Type your syntax
table(icaredata\$iBW)

Analyse Reset





ACCESSING OUTPUTS

Project Name: simdata_v1
User level: Analyst
Project Title: Simulated test data v1 Data Dictionary

helen [Logout]

Your Projects

- australia_v1
- australia_v2
- obs_comp
- simdata_v1

Other Projects

- 2012_preterm
- advpatmatage
- bwASD
- seasonality

Actions: New Run, View Files, Manage Code Libraries

Search:

21_23_02_rich_test	13_Feb_2012	richard	<input type="checkbox"/>	Sharing <input type="checkbox"/>
--------------------	-------------	---------	--------------------------	----------------------------------

runlog.txt	21:23:06	799.00b
errors.txt	21:23:06	64.00b
output.txt	21:23:06	42.00b
<u>iCARE simdata v1 13 Feb 2012 21 23 02 rich test.zip</u>	21:23:06	775.00b
user_syntax.txt	21:23:04	320.00b

Upload a file to attach to this run

No file chosen

https://www.icareautism.org/cgi-bin/iwap_download.cgi?p...



Management

iCARE Web based Analysis Portal - Project Manager - Chromium

https://www.icareautism.org/cgi-bin/iwap_projman.cgi

Arrow Classic R... Other Bookmarks

Welcome Kim! kim
[Logout]

Home

- Manage
 - Users
 - Studies
 - Variables and DataDictionaries
 - Resources
 - Projects
 - Certification

Your Projects

- 2012_preterm
- advpatmatage
- australia_v1
- australia_v2
- bwASD
- denmark_v1
- denmark_v2
- finland_v2
- israel_v2
- norway_v1
- norway_v2
- obs_comp
- seasonality
- simdata_v1
- sweden_v1
- sweden_v2

Other Projects

Add New User

Username

IT member

Generate a password

Email address

Timezone
Australia/Perth

Update User

Username
-- Select username --

Remove User

Username
-- Select username --





Has ViPAR been successful?

Currently:

- 7 remote sites (Nor,Fin,Den,Swe,Isr,US,WA), containing approx 9million records across 60 harmonised fields
- Passed multiple ethics approvals (at each site)
- Data retrieval with ViPAR: approx 2minutes in serial (one site at a time); approx 30-40 seconds in parallel

J Autism Dev Disord. 2013 Nov;43(11):2650-63. doi: 10.1007/s10803-013-1815-x.

The International Collaboration for Autism Registry Epidemiology (iCARE): multinational registry-based investigations of autism risk factors and t

Mol Psychiatry. 2015 Jun 9. doi: 10.1038/mp.2015.70. [Epub ahead of print]

Schendel DE¹, Bresnahan M, Carter K, Parner ET, Reichenberg A, Sandin S, :

Autism risk associated with parental age and with increasing difference in age between the parents.

Sandin S¹, Schendel D², Magnusson P³, Hultman C³, Surén P⁴, Susser E⁵, Grønberg T⁶, Gissler M⁷, Gunnes N⁴, Gross R⁸, Henning M⁹, Bresnahan M⁵, Sourander A¹⁰, Hornig M¹¹, Carter K¹², Francis R¹², Parner E⁶, Leonard H¹², Rosanoff M¹³, Stoltenberg C¹⁴, Reichenberg A¹⁵.

Author information

Author information

Open/close author information list

Abstract

The International Collaboration for iCARE devised solutions to challenge existing national or state analyses are performed using data from an unprecedented resource in autism research.

Abstract

Advancing paternal and maternal age have both been associated with risk for autism spectrum disorders (ASD). However, the shape of the association remains unclear, and results on the joint associations is lacking. This study tests if advancing paternal and maternal ages are independently associated with ASD risk and estimates the functional form of the associations. In a population-based cohort study from five countries (Denmark, Israel, Norway, Sweden and Western Australia) comprising 5 766 794 children born 1985-2004 and followed up to the end of 2004-2009, the relative risk (RR) of ASD was estimated by using logistic regression and splines. Our analyses included 30 902 cases of ASD. Advancing paternal and maternal age were each associated with increased RR of ASD after adjusting for confounding and the other parent's age (mothers 40-49 years vs 20-29 years, RR=1.15 (95% confidence interval (CI): 1.06-1.24), P-value<0.001; fathers ≥50 years vs 20-29 years, RR=1.66 (95% CI: 1.49-1.85), P-value<0.001). Younger maternal age was also associated with increased risk for ASD (mothers <20 years vs 20-29 years, RR=1.18 (95% CI: 1.08-1.29), P-value<0.001). There was a joint effect of maternal and paternal age with increasing risk of ASD for couples with increasing differences in parental ages. We did not find any support for a modifying effect by the sex of the offspring. In conclusion, as shown in multiple geographic regions, increases in ASD was not only limited to advancing paternal or maternal age alone but also to differences parental age including younger or older similarly aged parents as well as disparately aged parents. Molecular Psychiatry advance online publication, 9 June 2015; doi:10.1038/mp.2015.70.

Centrepiece of a successful NIH grant bid (2013-2017) \$5.5M





FOR MORE INFORMATION

Int. J. Epidemiol. Advance Access published October 8, 2015



International Journal of Epidemiology, 2015, 1–9

doi: 10.1093/ije/dyv193

Original article



Original article

ViPAR: a software platform for the Virtual Pooling and Analysis of Research Data

Kim W. Carter,^{*†} Richard W. Francis[†] and the International Collaboration for Autism Registry Epidemiology

Telethon Kids Institute, Centre for Child Health Research, University of Western Australia, Perth, WA, Australia

^{*}Corresponding author. Telethon Kids Institute, The University of Western Australia, 100 Roberts Road, Subiaco, Perth, Western Australia, 6008. E-mail: Kim.Carter@telethonkids.org.au

[†]These authors contributed equally.

A full list of authors and affiliations appears at the end of the paper.

Accepted 3 September 2015

Abstract

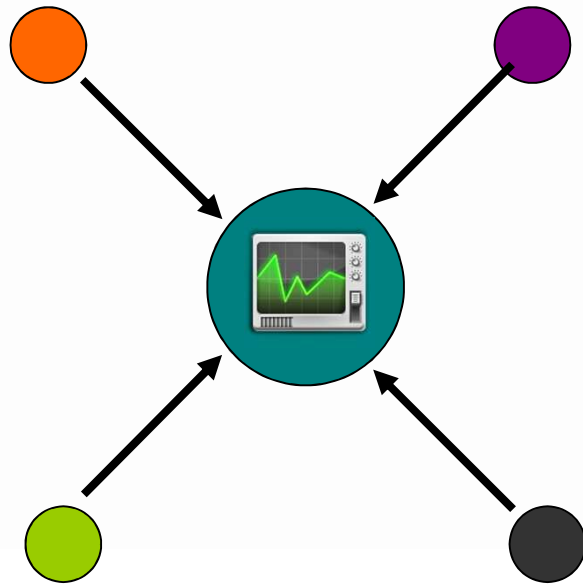
Background: Research studies exploring the determinants of disease require sufficient statistical power to detect meaningful effects. Sample size is often increased through centralized pooling of disparately located datasets, though ethical, privacy and data ownership issues can often hamper this process. Methods that facilitate the sharing of research data that are sympathetic with these issues and which allow flexible and detailed statistical analyses are therefore in critical need. We have created a software platform for the Virtual Pooling and Analysis of Research data (ViPAR) which employs free and open

Int J Epi 2015; doi: 10.1093/ije/dyv193

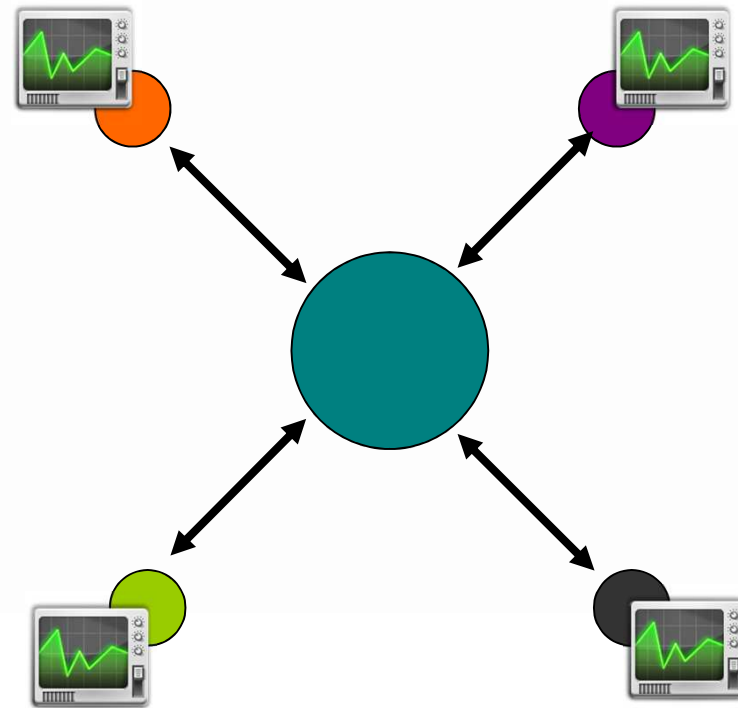


ViPAR vs DataSHIELD

ViPAR



DataSHIELD





ViPAR vs DataSHIELD

- Data remains at study site
 - Harmonisation is required before copies of data are sent 'to the cloud'
 - Generation of pooled dataset occurs 'in the cloud'
 - Results generated from a combined virtual dataset
 - Pooled virtual dataset not saved/stored – only exists while analysis is running
 - Straightforward analysis syntax in multiple languages
- Data remains at the study site
 - Harmonisation is required before sending
 - No data is sent anywhere
 - No pooled dataset is generated
 - Statistical methods sent to each study site, where methods are run locally
 - Results are pooled back at analysis centre, to produce final result
 - Requires specific analysis syntax and software (R) to make this happen





FUTURE DIRECTIONS

- Transparent integration of ViPAR with other complementary techniques eg DataSHIELD
- Web 2.0 interface
- Building capabilities to handle complex and large data types eg imaging data, whole genome seq
 - NoSQL, Object and other DBs
- Further security enhancements
 - on the fly privacy checks
 - using containers (Docker) for running analyses for greater separation





ACKNOWLEDGEMENTS

- Richard Francis, TKI



- Becca Wilson, Univ of Bristol
- Paul Burton, Univ. of Bristol





A QUICK PLUG

METHODS ARTICLE

Front. Neurosci. | doi: 10.3389/fnins.2016.00365

COINSTAC: A privacy enabled model and prototype for leveraging and processing decentralized brain imaging data

Sergey M. Plis^{1*}, Anand Sarwate², Dylan Wood¹, Christopher Dieringer¹, Drew Landis¹, Cory Reed¹, Sandeep R. Panta¹, Jessica A. Turner^{1,3}, Jody Shoemaker¹, Kim Carter⁴, Paul Thompson⁵, Kent Hutchinson⁶ and Vince D. Calhoun^{1,7}

¹The Mind Research Network, USA

²Dept. of Electrical and Computer Engineering, Rutgers, The State University of New Jersey, USA

³Dept. of Psychology and Neuroscience Institute, Georgia State University, USA

⁴Telethon Kids Institute, the University of Western Australia, Australia

⁵Imaging Genetics Center, ENIGMA Center for Worldwide Medicine, Imaging, and Genomics, Departments of Neurology, Psychiatry, Engineering, Radiology, and Pediatrics, University of Southern California, USA

⁶Department of Psychology and Neuroscience, University of Colorado Boulder, USA

⁷Dept. of Electrical and Computer Engineering, University of New Mexico, USA

The field of neuroimaging has embraced the need for sharing and collaboration. Data sharing mandates from public funding agencies and major journal publishers have spurred the development of data repositories and neuroinformatics consortia.

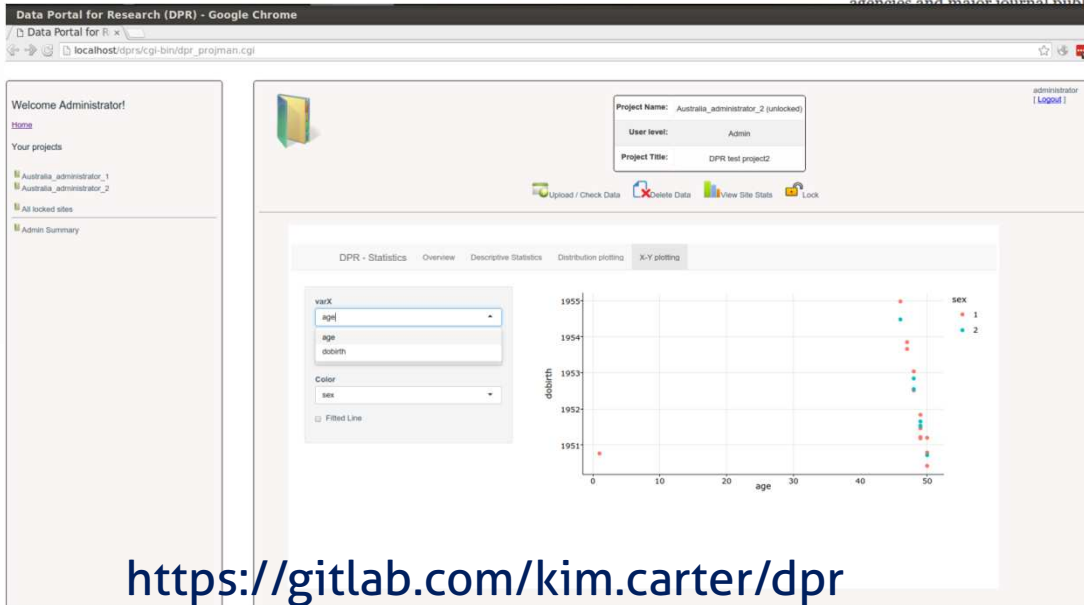
Data sharing still faces several hurdles. For example, open data sharing is on the rise but is not easily shared, such as genetics. Current approaches can be cumbersome (such as negotiating

There are also significant data transfer, organization and computational challenges. Centralized the issues. We propose a dynamic, decentralized platform for large scale analyses called the roimaging Suite Toolkit for Anonymous Computation (COINSTAC). The COINSTAC solution ral repositories, allows pooling of both open and "closed" repositories by developing privacy-algorithms, and incorporates the tools within an easy-to-use platform enabling distributed prototype system which we demonstrate on two multi-site data sets, without aggregating the ss sites, the COINSTAC model enables meta-analytic solutions to converge to "pooled-data" vere in hand). More advanced approaches such as feature generation, matrix factorization incorporated into such a model. In sum, COINSTAC enables access to the many currently ly privacy enabled interface for decentralized analysis, and a powerful solution that ; solutions.

Privacy, brain imaging, data sharing, Decentralized algorithms

Dieringer C, Landis D, Reed C, Panta SR, Turner JA, Shoemaker J, Carter K, Thompson P, Hutchinson K and y enabled model and prototype for leveraging and processing decentralized brain imaging data. *Front.* 16.00365

11.1 2016



<https://gitlab.com/kim.carter/dpr>





Questions & Demo time?



<http://xkcd.com/257/>

