University *of* Leicester

Data Sharing:
Progress by improving data ‘control’ ?

Anthony J Brookes

TMF Data Integration/Sharing Workshop
12-13th July 2016

DATA ARE ‘IMPORTANT’ and 'VALUABLE‘

and so

MANY OTHERS WANT YOUR DATA

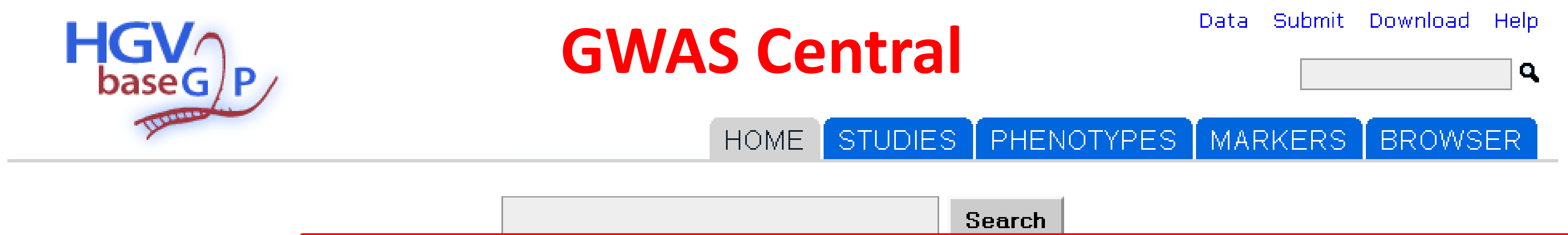
therefore

GIVE ALL YOUR DATA AWAY

Quo Vadis ?

Issues that restrict sharing data

- **OUGHT NOT: Data owners may not be allowed to share data (e.g., ethical, legal, institutional)**
- CAN NOT: Data owners may not have time nor funding to manually submit data, and/or submission process and requirements too complicated
- WANT NOT: Data owners receive little or no recognition or reward for releasing data, risk undermining their competitive edge, and hence have little incentive to try



GWAS Central

Studies

About HGVI

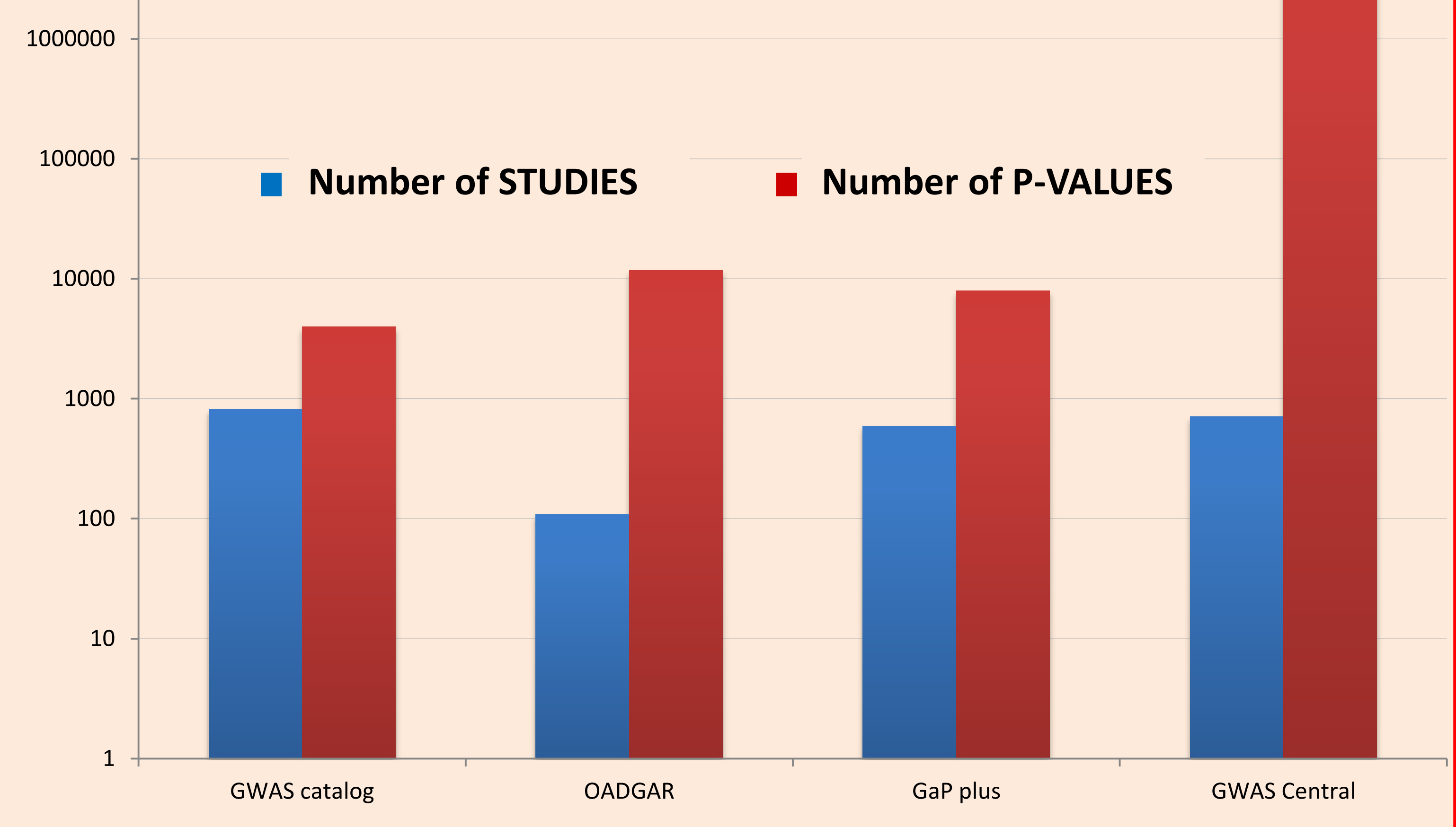
The Human Genome Vari
information (HGVbaseG2P
summary level findings fr
and small. We actively g
projects, and encourage
community. See more..

Frequently

- How is the database
- How do I find Studies
- How do I find Marker
- How do I use the Bro
- How do I submit my

Web Site Release 4.0 - Sept

- *comprehensive genetic association database*
- *aggregate data & extensive metadata*
- *links to data sources for primary data*



GWAS CENTRAL ‘Publicity Project’

March 2011

570 e-mails sent to authors of 700 studies [30 undeliverable]

19 (3.5%) positive responses (new or corrected data)

9 (1.7%) neutral or negative responses

512 (94.8%) did not reply

January 2012

505 e-mails sent to authors of 512 studies [16 undeliverable]

17 (3.5%) positive responses (new or corrected data)

38 (7.8%) neutral or negative responses

434 (88.7%) did not reply

Issues that restrict sharing data

- OUGHT NOT: Data owners may not be allowed to share data (e.g., ethical, legal, institutional)

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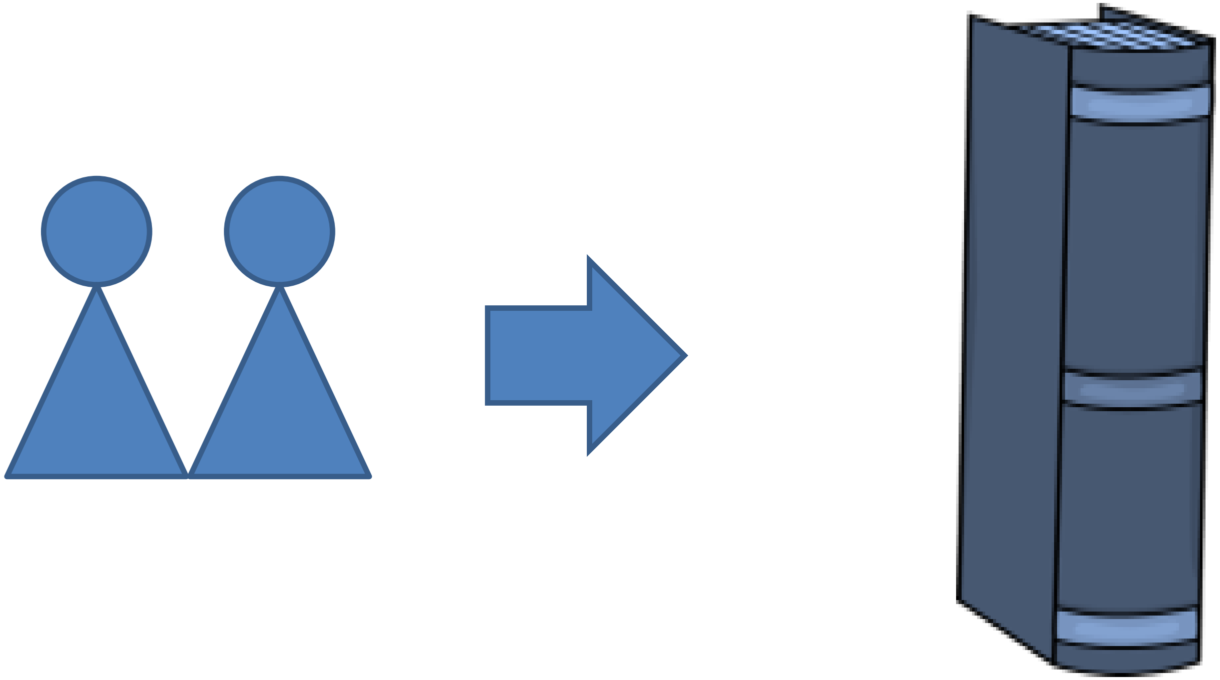
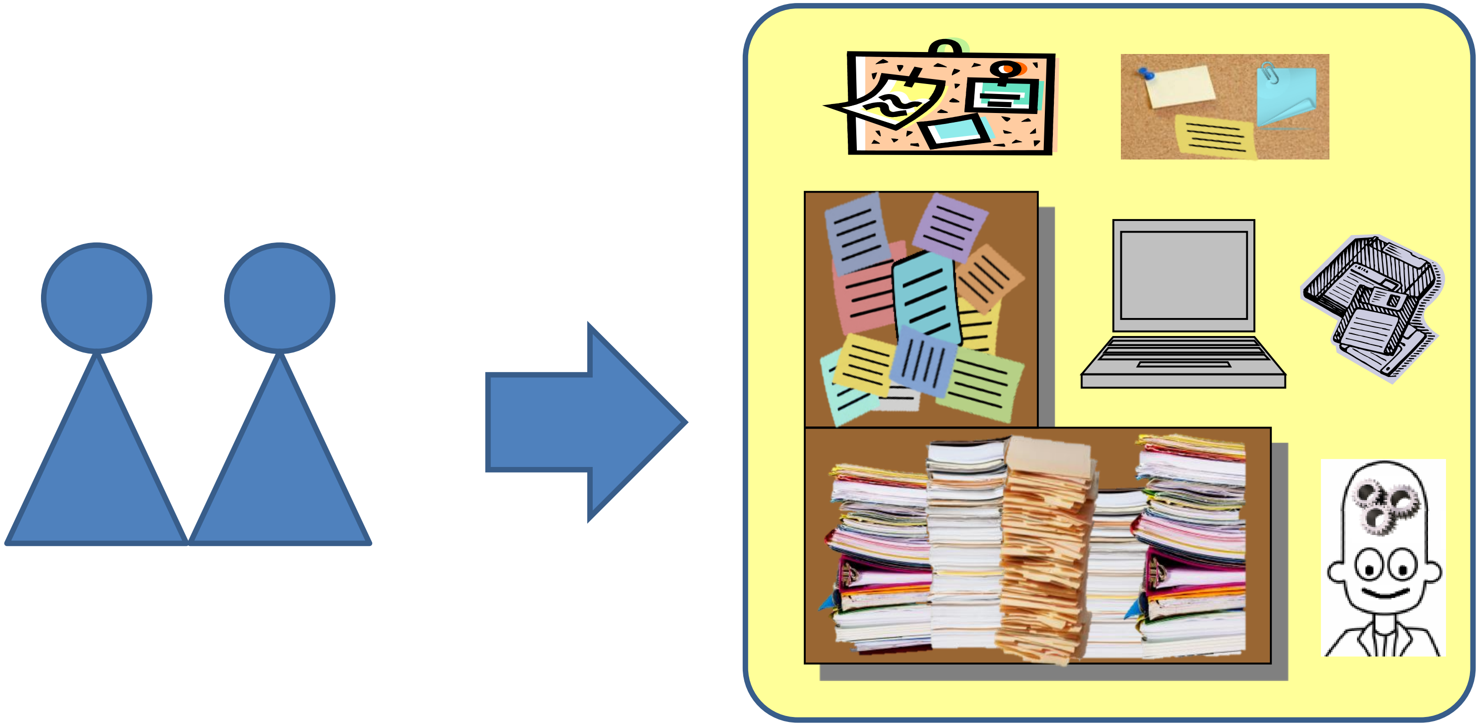
Are all data digitised, organised, structured... to make them ‘sharable’ ?



Research Team

Data

Or are data generally chaotic & unstructured ?



Research Team

Data

Issues that restrict sharing data

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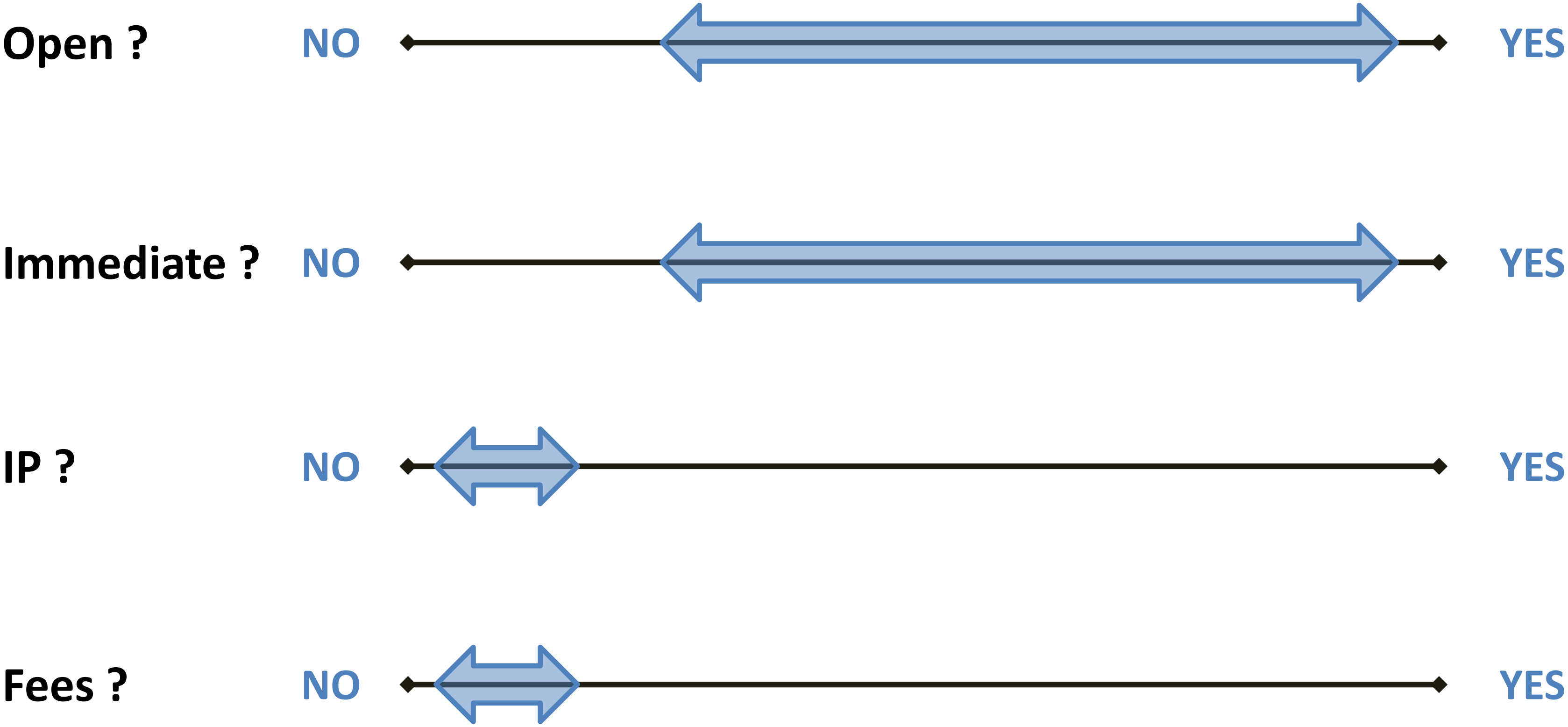
SHARING DATA



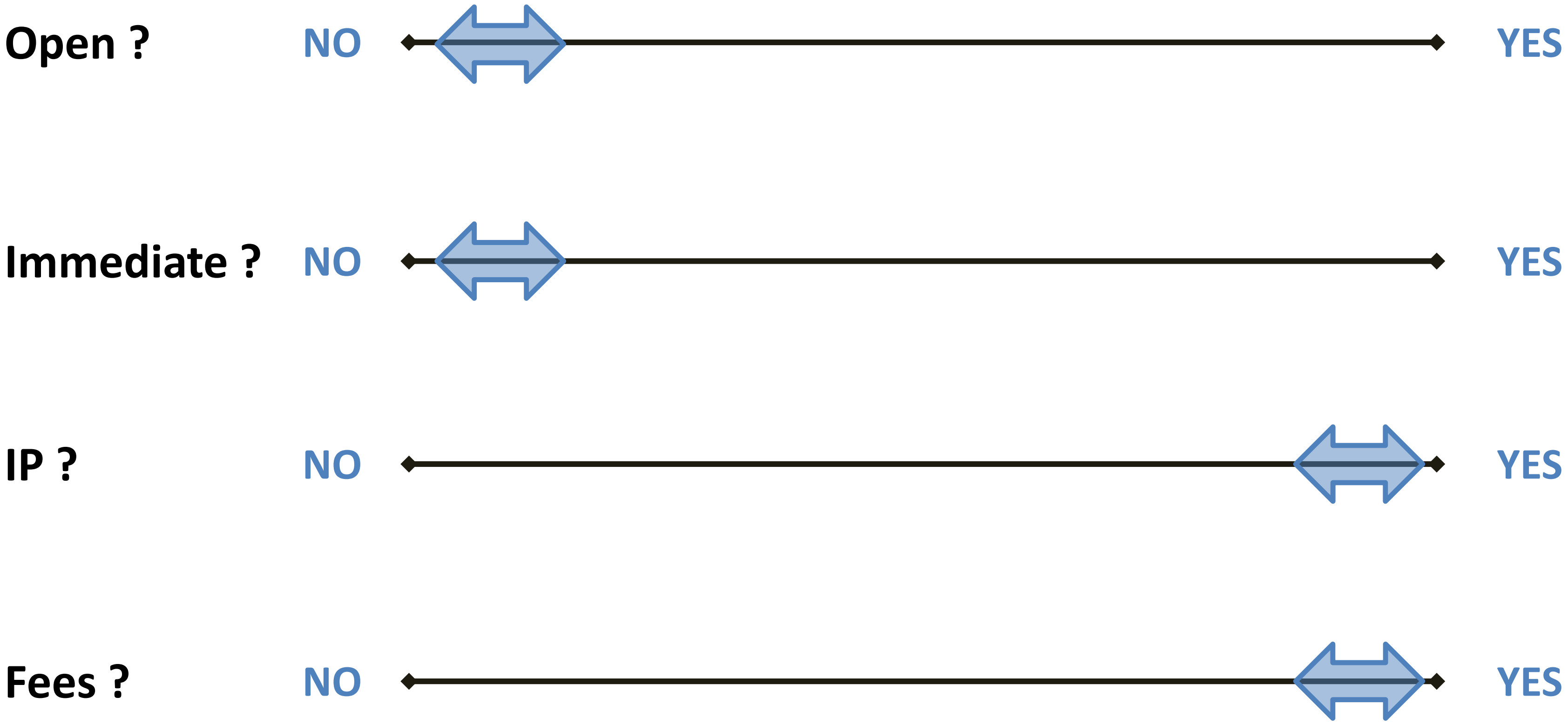
Open ? NO YES

Immediate ? NO YES

IP ? NO YES

Fees ? NO YES

SHARING NEW METHOD, BIOREAGENT, TECHNOLOGY, DRUG . . .



Open ? NO — YES

Immediate ? NO — YES

IP ? NO — YES

Fees ? NO — YES

Drazen/NEJM Editorial...

Raised general concerns about open data sharing, namely

- working separately, someone not involved in the original data collection may **misinterpret** the original data parameters or biases

- researcher "parasites" could use data of others to **unfairly compete** and/or disprove the original hypothesis

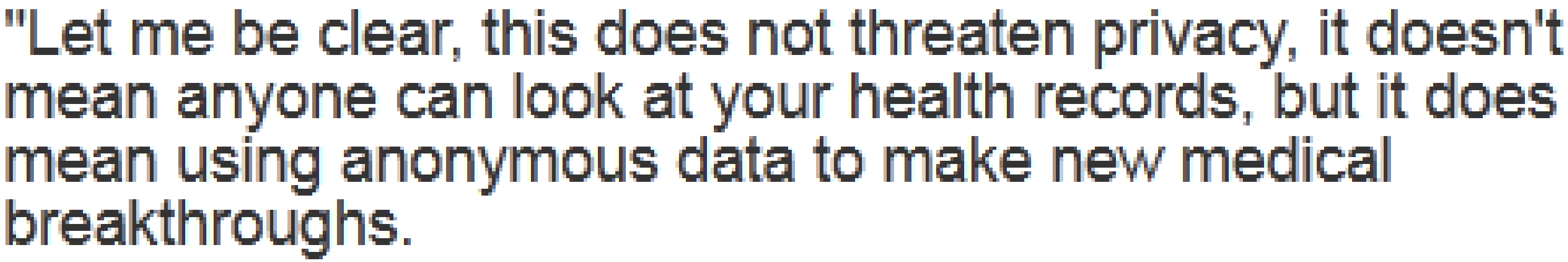
So they concluded that **data analysis should happen "symbiotically"**

Later added...
[As per ICMJE proposal] NEJM will require authors to ***make 'available' the data that underlie the reported results*** *of their work* ***within 6 months*** *of publication*

5 December 2011 Last updated at 21:22

Everyone 'to be research patient', says David Cameron

..personal data


"Let me be clear, this does not threaten privacy, it doesn't mean anyone can look at your health records, but it does mean using anonymous data to make new medical breakthroughs.

Media & Tech Network Open data economy

Google's NHS deal does not bode well for the future of data-sharing

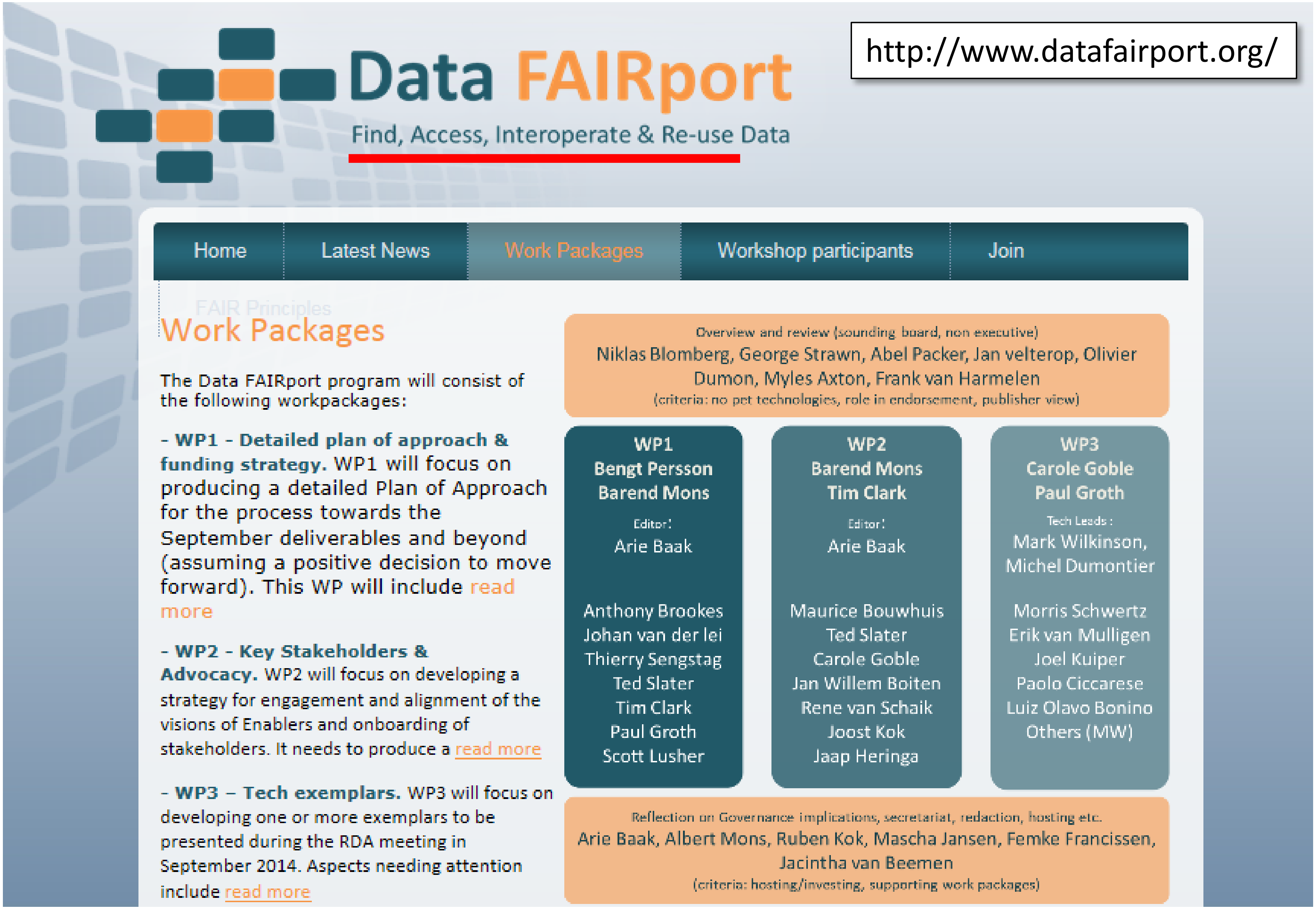
"This is people's most personal information and many will be horrified by the idea it is being shared with Google - encrypted or not"

Joy

Data protection

NHS to scrap single database of patients' medical details

Care.data scheme to close after Fiona Caldicott review calls for tougher measures to keep information confidential http://www.datafairport.org/



Data FAIRport

Find, Access, Interoperate & Re-use Data

Work Packages

The Data FAIRport program will consist of the following workpackages:

- **WP1 - Detailed plan of approach & funding strategy.** WP1 will focus on producing a detailed Plan of Approach for the process towards the September deliverables and beyond (assuming a positive decision to move forward). This WP will include read more

- **WP2 - Key Stakeholders & Advocacy.** WP2 will focus on developing a strategy for engagement and alignment of the visions of Enablers and onboarding of stakeholders. It needs to produce a read more

- **WP3 – Tech exemplars.** WP3 will focus on developing one or more exemplars to be presented during the RDA meeting in September 2014. Aspects needing attention include read more

Overview and review (sounding board, non executive)
Niklas Blomberg, George Strawn, Abel Packer, Jan velterop, Olivier Dumon, Myles Axton, Frank van Harmelen
(criteria: no pet technologies, role in endorsement, publisher view)

WP1	WP2	WP3
Bengt Persson **Barend Mons**	**Barend Mons** **Tim Clark**	**Carole Goble** **Paul Groth**
Editor: Arie Baak	Editor: Arie Baak	Tech Leads : Mark Wilkinson, Michel Dumontier
Anthony Brookes Johan van der lei Thierry Sengstag Ted Slater Tim Clark Paul Groth Scott Lusher	Maurice Bouwhuis Ted Slater Carole Goble Jan Willem Boiten Rene van Schaik Joost Kok Jaap Heringa	Morris Schwertz Erik van Mulligen Joel Kuiper Paolo Ciccarese Luiz Olavo Bonino Others (MW)

Reflection on Governance implications, secretariat, redaction, hosting etc.
Arie Baak, Albert Mons, Ruben Kok, Mascha Jansen, Femke Francissen, Jacintha van Beemen
(criteria: hosting/investing, supporting work packages)

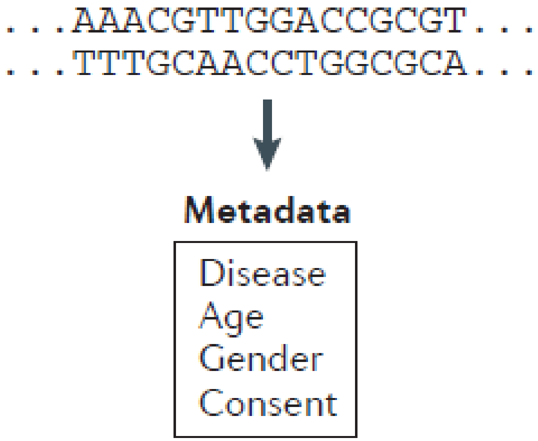
A Critical Insight / Solution... ???

Possession → **Control**

(not sharing) (power & opportunity)

So, we need to disconnect possession and control, so that data can be released (in whole or in part) whilst not undermining the data owner's reasonable control of the data

(1) Alternative Forms of data

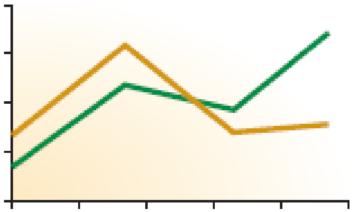


...AAACGTTGGACCGCGT...
...TTTGCAACCTGGCGCA...

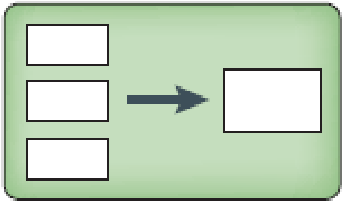
Metadata

Disease
Age
Gender
Consent

Graphics

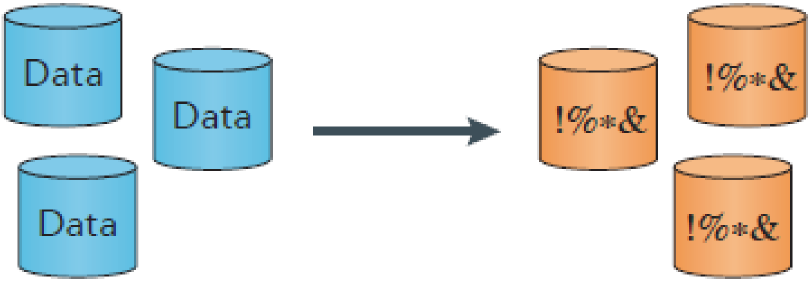


Aggregates

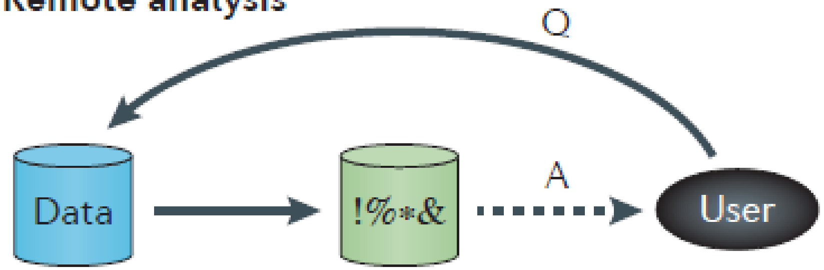


(2) Encryption based solutions

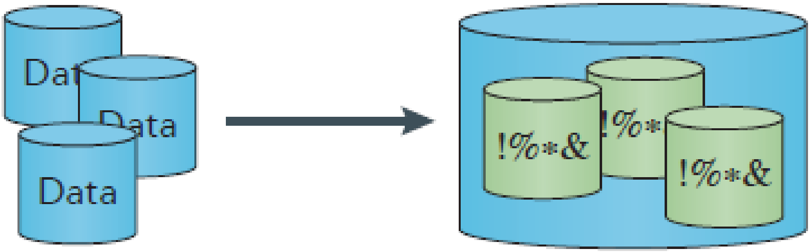
Encryption



Remote analysis



Pooling



(3) Automatable Discovery and Access Matrix (ADA-M) v1.0

- ‘Atomic’ – smallest sensible, standardised concepts which can be combined into a data use conditions profile, encompassing
  - Mode of Sharing
  - Permissions
  - Terms
  - Meta-conditions
- Various cross-mapping exercises completed, e.g., to datasets managed by EGA (Jordi Rambla De Argila), Consent Codes (S. Dyke), DUOS (Anthony Philippakis, Gregory Rushton), and a database of consent clauses (E. Forbes)
- Alpha testing by many teams after broad email notification Jan 2016, enabling stepwise feedback and refinement (now v1.0)
- Various collaboration opportunities identified and being developed

(3) Potential applications

1. As a descriptor

   ADA-M used to communicate the use conditions profile of a dataset

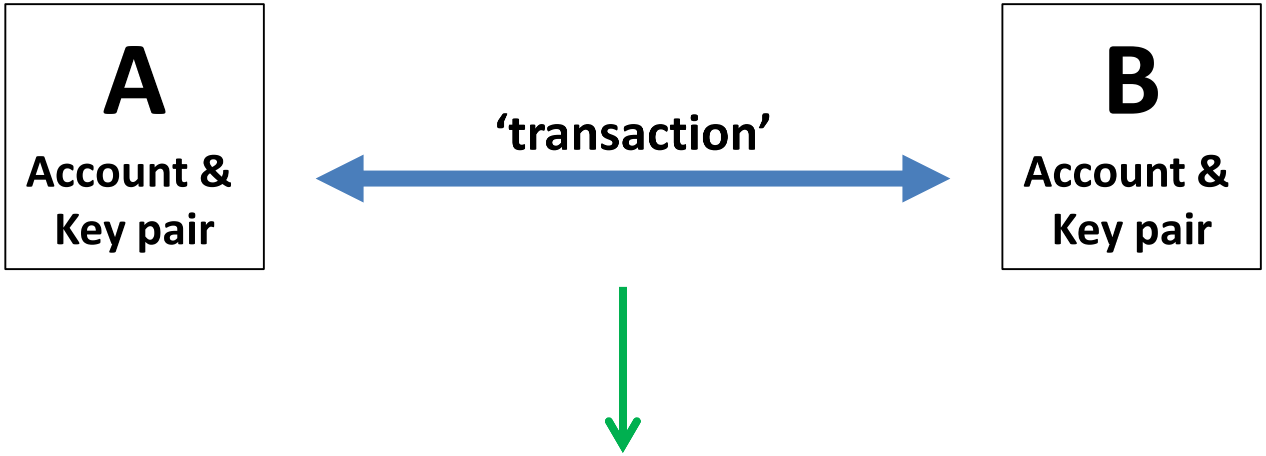
2. Enhance discovery

   provide extra level of information to underpin ‘discovery’ queries

3. Automated data sharing:
   align access requests to ADA-M profiles, and share if conditions are met

(3) ADA-M

Permissions:	
use within countries/locations	"Unrestricted" or "Limited"
within specified countries/locations	Free text list, with optional suffix "[Obligatory]" after each list entry
use by organisations	"Unrestricted" or "Limited"
for specified categories of organisation	Free text list, with optional suffix "[Obligatory]" after each list entry
use by non-profit organisations	"Unrestricted" or "Unrestricted[Obligatory]" or "Limited" or "Limited[Obligatory]" or "Forbidden"
by specified non-profit organisations	Free text list, with optional suffix "[Obligatory]" after each list entry
use by profit organisations	"Unrestricted" or "Unrestricted[Obligatory]" or "Limited" or "Limited[Obligatory]" or "Forbidden"
by specified profit organisations	Free text list, with optional suffix "[Obligatory]" after each list entry
use by categories of person	"Unrestricted" or "Limited"
for specified categories of person	Free text list, with optional suffix "[Obligatory]" after each list entry
use by academic professional	"Unrestricted" or "Unrestricted[Obligatory]" or "Limited" or "Limited[Obligatory]" or "Forbidden"
by specified categories of academic professional	Free text list, with optional suffix "[Obligatory]" after each list entry
use by clinical professional	"Unrestricted" or "Unrestricted[Obligatory]" or "Limited" or "Limited[Obligatory]" or "Forbidden"
by specified categories of clinical professional	Free text list, with optional suffix "[Obligatory]" after each list entry
use by profit-making professional	"Unrestricted" or "Unrestricted[Obligatory]" or "Limited" or "Limited[Obligatory]" or "Forbidden"
by specified categories of profit-making professional	Free text list, with optional suffix "[Obligatory]" after each list entry
use by non-professional	"Unrestricted" or "Unrestricted[Obligatory]" or "Limited" or "Limited[Obligatory]" or "Forbidden"
by specified categories of non-professional	Free text list, with optional suffix "[Obligatory]" after each list entry
use for non-profit purpose	"Unrestricted" or "Unrestricted[Obligatory]" or "Limited" or "Limited[Obligatory]" or "Forbidden"
for specified non-profit purposes	Free text list, with optional suffix "[Obligatory]" after each list entry
Terms:	
There are no requirements for any formal approval, contract or review conditions to be satisfied	"True" or "Untrue"
Formal approval, contract or review conditions are to be met, as specified	Free text list
There are no requirements regarding publication of results, or included references or acknowledgements	"True" or "Untrue"
Publication or disclosure of derived results is subject to restrictions, as specified	Free text list
Meta-Conditions:	
Interpretation rule if multiple Obligatory permissions are specified	"Meet all Obligatory permissions" or "Meet at least one Obligatory permission"
There are no other use restrictions/limitations in force which are not herein specified	"True" or "Untrue"
Other permissions/limitations may apply as specified	Free text list
No special evaluation required for access requests involving sensitive/restricted populations	"True" or "Untrue"



A

Account & Key pair

‘transaction’

B

Account & Key pair

‘A’ agrees a debt returnable to ‘B’ (IOU)

‘A’ pays money to ‘B’ (cheque)

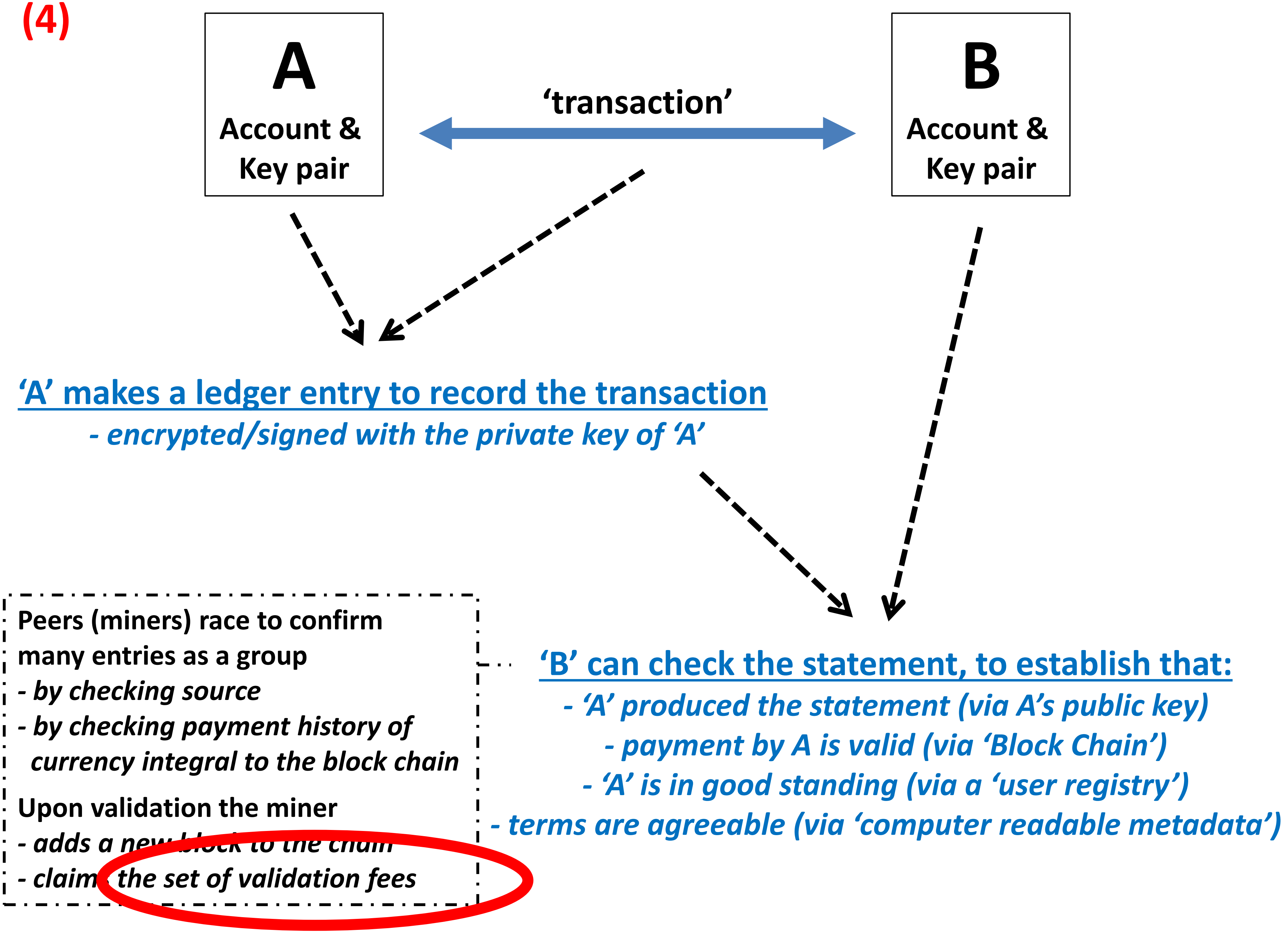
‘A’ receives/accesses an item from ‘B’ (receipt)

‘A’ receives/accesses data (token) from ‘B’, intended for use XYZ

(4) BLOCK-CHAIN

- **A fully transparent, public ledger, of transactions**
- **Eliminates the ‘middle man’, and makes terms of all interactions visible**

(4)



A

Account & Key pair

'transaction'

B

Account & Key pair

'A' makes a ledger entry to record the transaction

- encrypted/signed with the private key of 'A'

'B' can check the statement, to establish that:

- 'A' produced the statement (via A's public key)

- payment by A is valid (via 'Block Chain')

- 'A' is in good standing (via a 'user registry')

- terms are agreeable (via 'computer readable metadata')

Peers (miners) race to confirm many entries as a group

- by checking source

- by checking payment history of currency integral to the block chain

Upon validation the miner

- adds a new block to the chain

- claims the set of validation fees

(5) DISCOVERY

= a distinct discipline

Share the ‘existence’
rather than the ‘substance’
of the data
or knowledge
or sample
or subject
or resource
or standard...

nature REVIEWS GENETICS

nature.com ▸ journal home ▸ advance online publication ▸ review ▸ abstract

NATURE REVIEWS GENETICS | REVIEW

ARTICLE SERIES: **Computational tools**

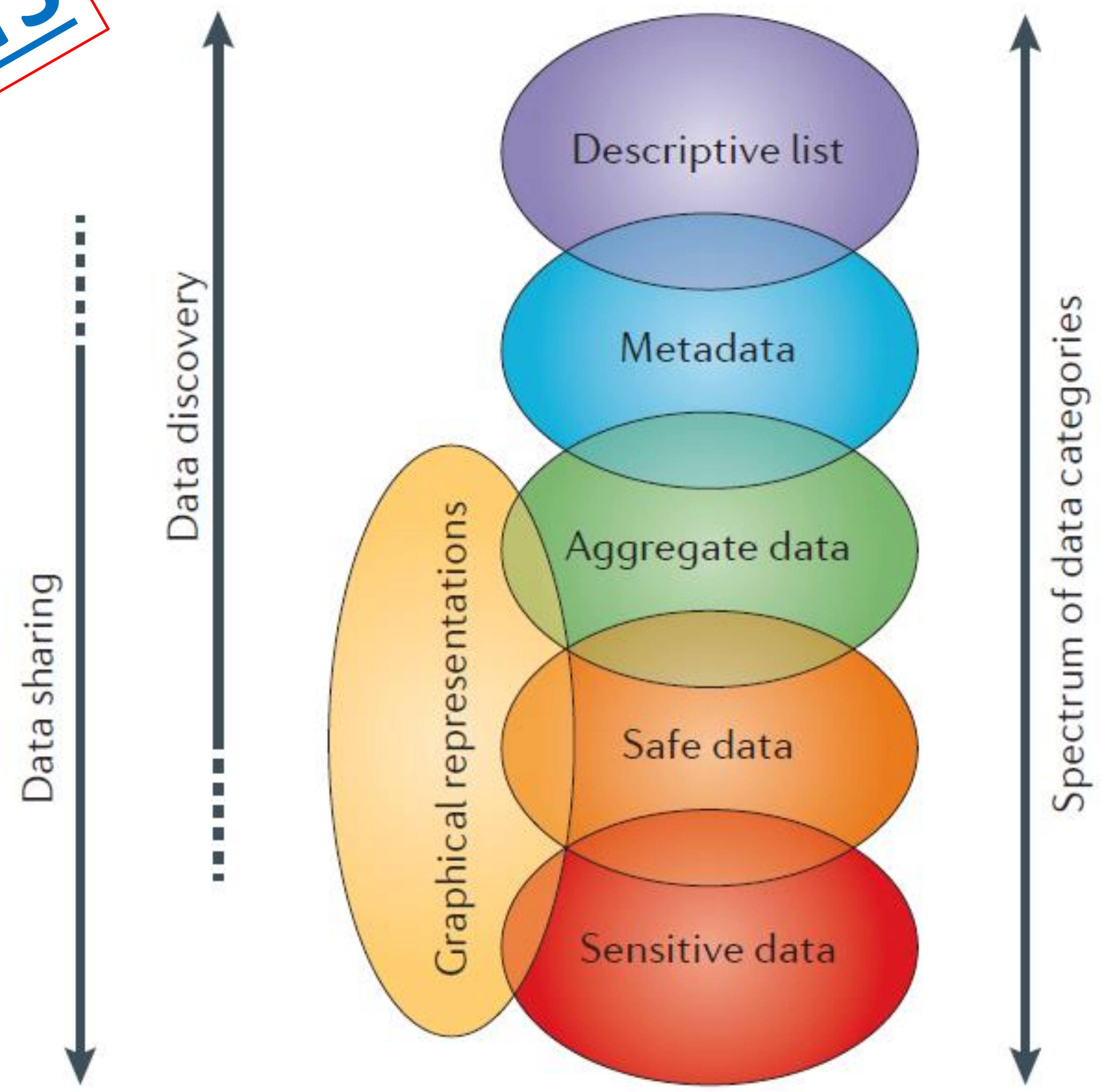
Human genotype–phenotype databases: aims, challenges and opportunities

Anthony J. Brookes & Peter N. Robinson

Affiliations | **Corresponding author**

Nature Reviews Genetics (2015) | doi:10.1038/nrg3932

TARGETS


Data sharing

Data discovery

Graphical representations

Descriptive list

Metadata

Aggregate data

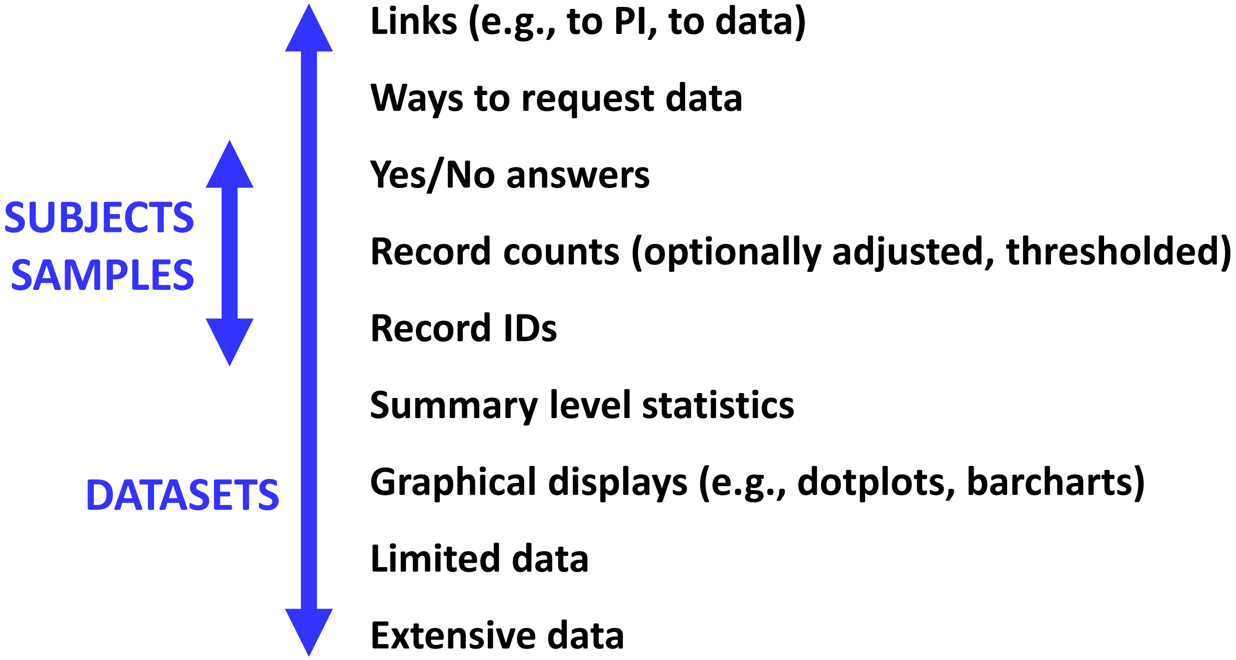
Safe data

Sensitive data

Spectrum of data categories

Nature Reviews | Genetics

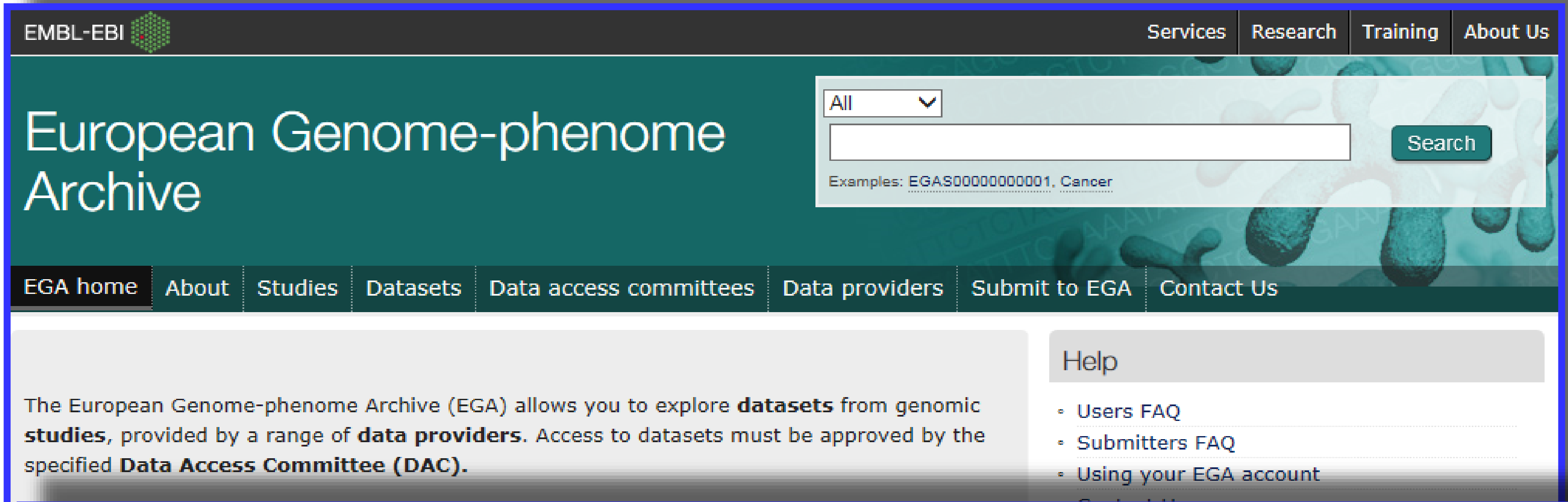
OUTPUTS



SUBJECTS
SAMPLES

DATASETS

- Links (e.g., to PI, to data)
- Ways to request data
- Yes/No answers
- Record counts (optionally adjusted, thresholded)
- Record IDs
- Summary level statistics
- Graphical displays (e.g., dotplots, barcharts)
- Limited data
- Extensive data

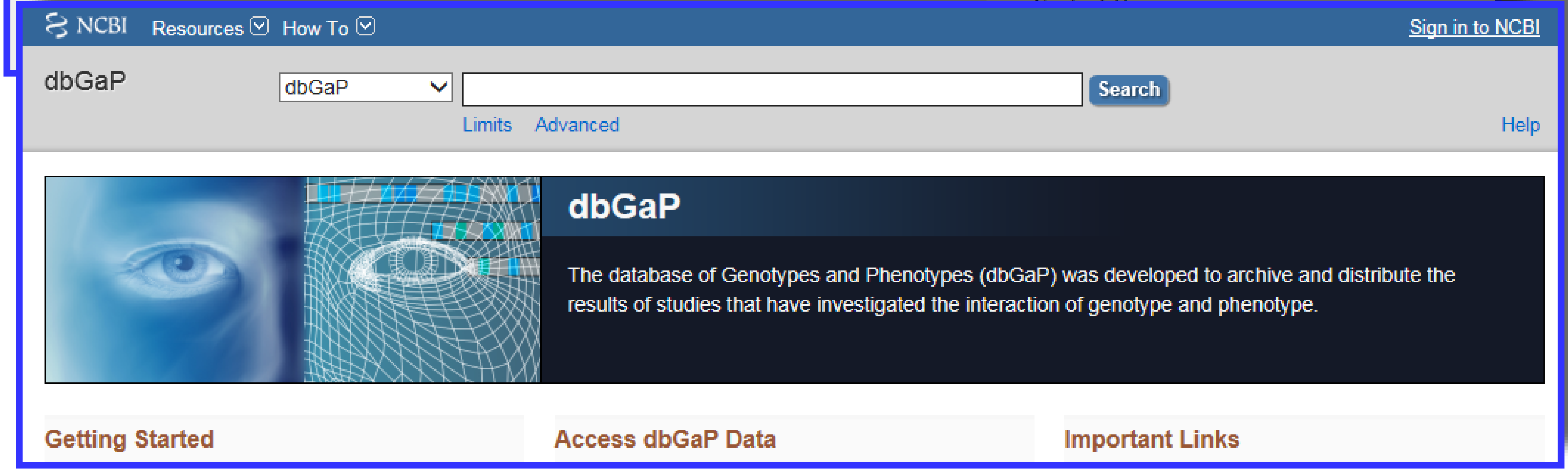


European Genome-phenome Archive

The European Genome-phenome Archive (EGA) allows you to explore **datasets** from genomic **studies**, provided by a range of **data providers**. Access to datasets must be approved by the specified **Data Access Committee (DAC).**

Help

- Users FAQ
- Submitters FAQ
- Using your EGA account



dbGaP

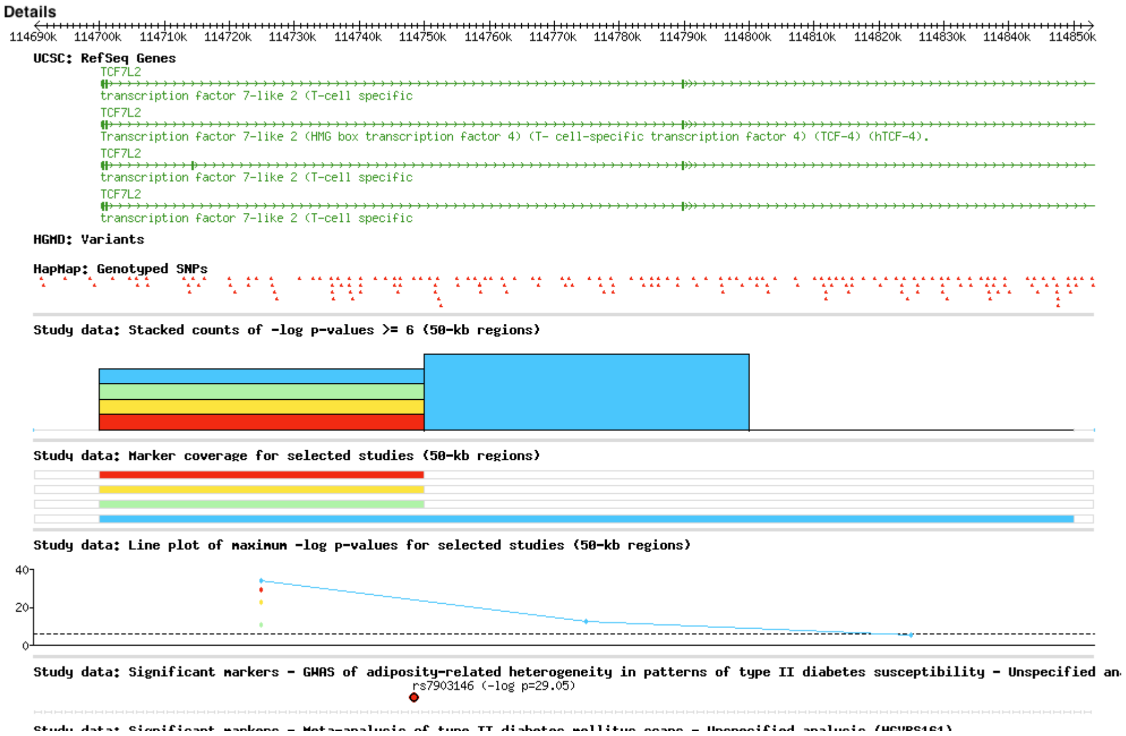
The database of Genotypes and Phenotypes (dbGaP) was developed to archive and distribute the results of studies that have investigated the interaction of genotype and phenotype.

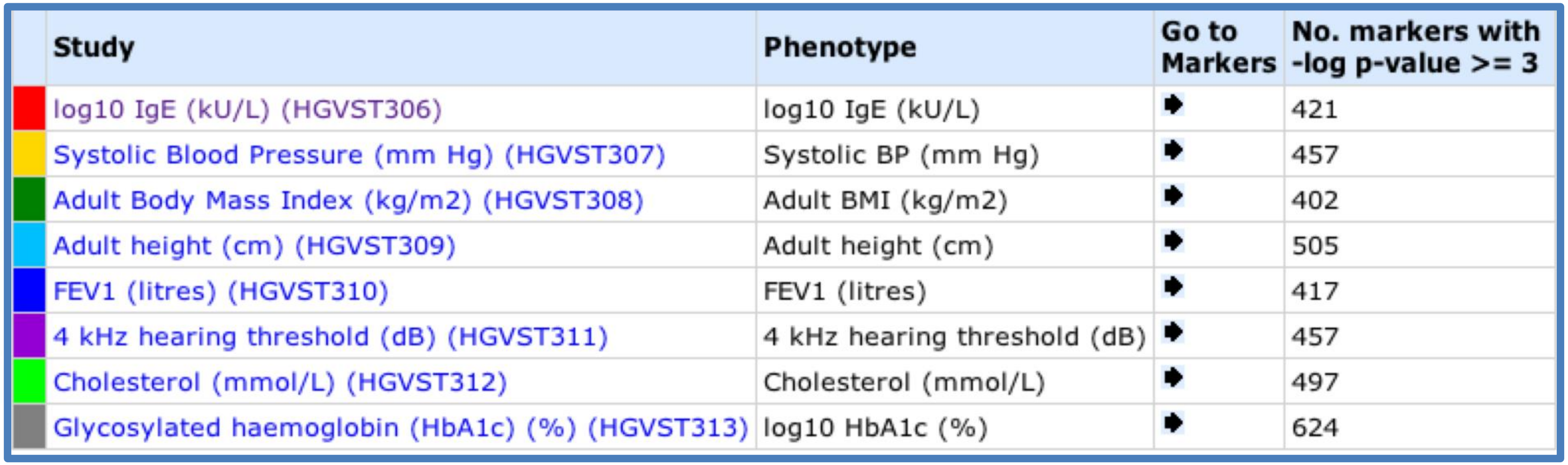
Getting Started

Access dbGaP Data

Important Links

GWAS Central (www.gwascentral.org)



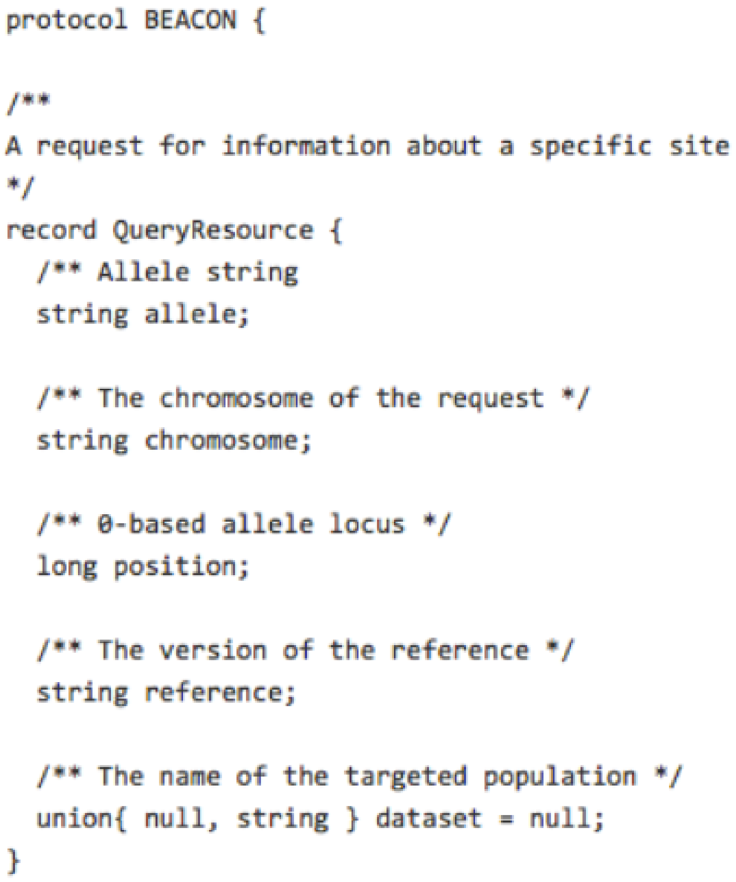


	Study	Phenotype	Go to Markers	No. markers with -log p-value >= 3
🟥	log10 IgE (kU/L) (HGVST306)	log10 IgE (kU/L)	➡	421
🟨	Systolic Blood Pressure (mm Hg) (HGVST307)	Systolic BP (mm Hg)	➡	457
🟩	Adult Body Mass Index (kg/m2) (HGVST308)	Adult BMI (kg/m2)	➡	402
🟦	Adult height (cm) (HGVST309)	Adult height (cm)	➡	505
🟦	FEV1 (litres) (HGVST310)	FEV1 (litres)	➡	417
🟪	4 kHz hearing threshold (dB) (HGVST311)	4 kHz hearing threshold (dB)	➡	457
🟩	Cholesterol (mmol/L) (HGVST312)	Cholesterol (mmol/L)	➡	497
⬛	Glycosylated haemoglobin (HbA1c) (%) (HGVST313)	log10 HbA1c (%)	➡	624

Beacon Project (*GA4GH)*

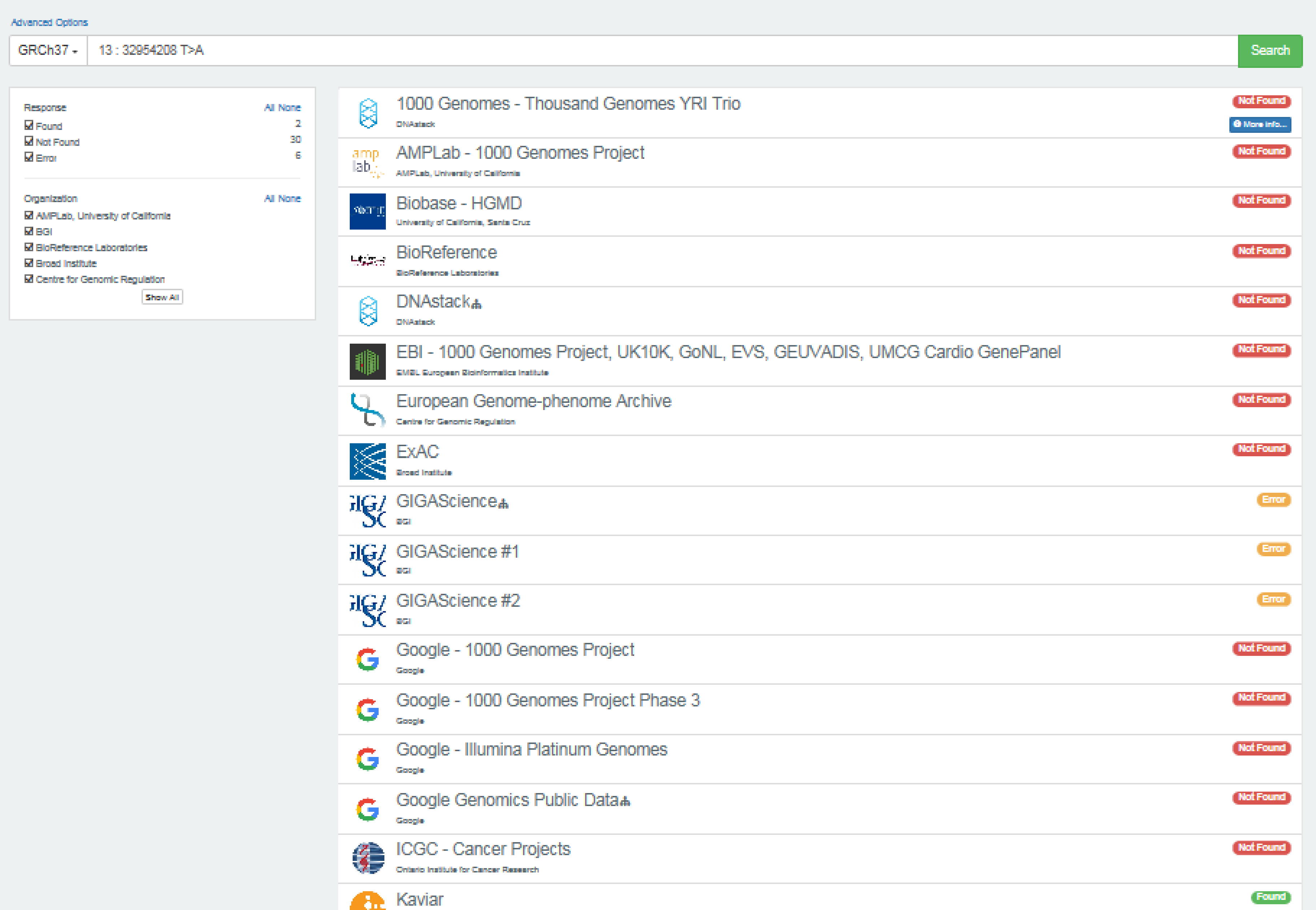
Lead - Marc Fiume

- a beacon answers the question, have you observed this allele?
- the 0.2 Beacon query is shown on the right



```
protocol BEACON {

/**
A request for information about a specific site
*/
record QueryResource {
  /** Allele string
  string allele;

  /** The chromosome of the request */
  string chromosome;

  /** 0-based allele locus */
  long position;

  /** The version of the reference */
  string reference;

  /** The name of the targeted population */
  union{ null, string } dataset = null;
}
```

Beacon-of-Beacons (*GA4GH, DNASTACK)*



Advanced Options

GRCh37 - | 13 : 32954208 T>A | Search

Response — All None
- ☑ Found 2
- ☑ Not Found 30
- ☑ Error 6

Organization — All None
- ☑ AMPLab, University of California
- ☑ BGI
- ☑ BioReference Laboratories
- ☑ Broad Institute
- ☑ Centre for Genomic Regulation

Show All

1000 Genomes - Thousand Genomes YRI Trio	DNAstack	Not Found More info...
AMPLab - 1000 Genomes Project	AMPLab, University of California	Not Found
Biobase - HGMD	University of California, Santa Cruz	Not Found
BioReference	BioReference Laboratories	Not Found
DNAstack	DNAstack	Not Found
EBI - 1000 Genomes Project, UK10K, GoNL, EVS, GEUVADIS, UMCG Cardio GenePanel	EMBL European Bioinformatics Institute	Not Found
European Genome-phenome Archive	Centre for Genomic Regulation	Not Found
ExAC	Broad Institute	Not Found
GIGAScience	BGI	Error
GIGAScience #1	BGI	Error
GIGAScience #2	BGI	Error
Google - 1000 Genomes Project	Google	Not Found
Google - 1000 Genomes Project Phase 3	Google	Not Found
Google - Illumina Platinum Genomes	Google	Not Found
Google Genomics Public Data	Google	Not Found
ICGC - Cancer Projects	Ontario Institute for Cancer Research	Not Found
Kaviar		Found

Plus…

- Biobank catalogs (e.g., BBMRI, UKCRC-TDC)
- Health data discovery (e.g., EMIF, Jerboa, PopMedNet, i2b2, OHDSI)
- Research data (e.g., MME, NGS-Logistics, Orphanet, VarWatch)
- Patient data (e.g., PEER, RD-Connect, PatientsLikeMe)

Cafe Variome

Informatics

FREE

Cafe Variome: General-Purpose Software for Making Genotype–Phenotype Data Discoverable in Restricted or Open Access Contexts

Owen Lancaster[1], Tim Beck[1], David Atlan[2], Morris Swertz[3], Dhiwagaran Thangavelu[1], Colin Veal[1], Raymond Dalgleish[1] and Anthony J Brookes[1,*]

DOI: 10.1002/humu.22841

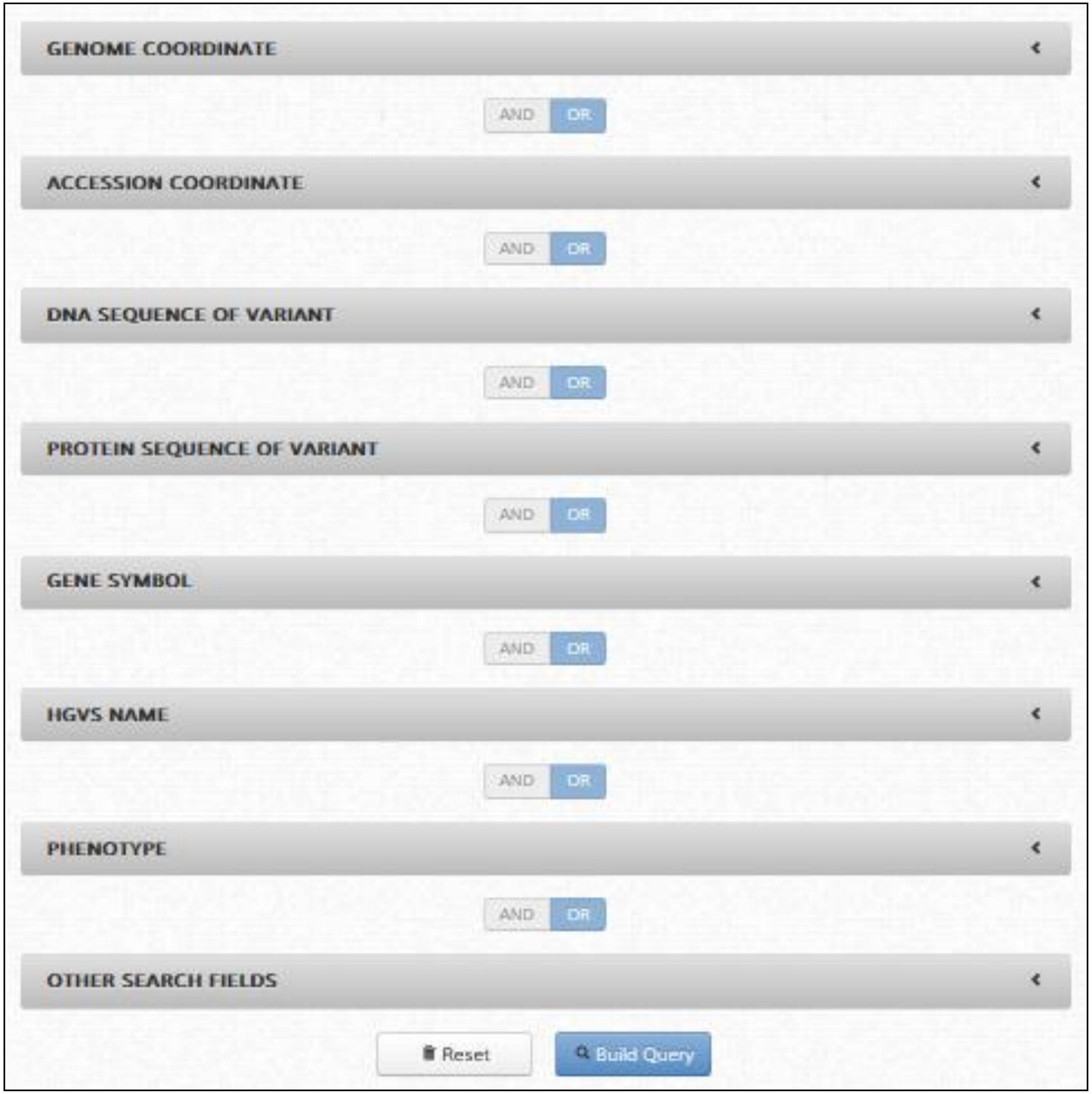
Issue

Human Mutation

Special Issue: The Matchmaker Exchange

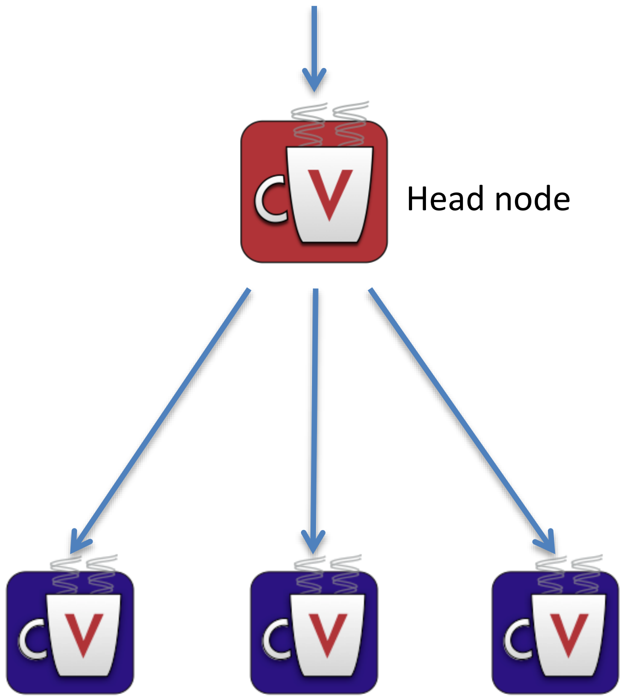
Volume 36, Issue 10, pages 957–964, October 2015

Query Builder Interface



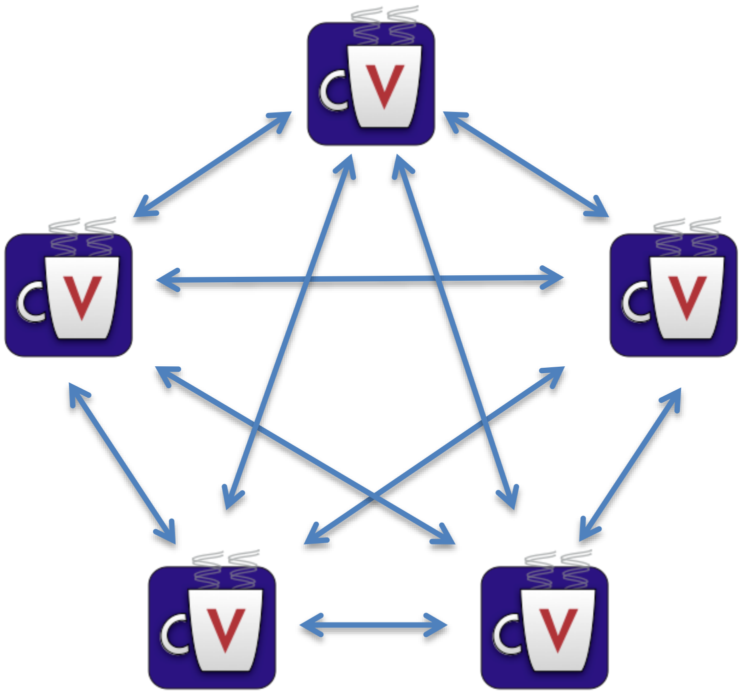
Node Search Options

External searches

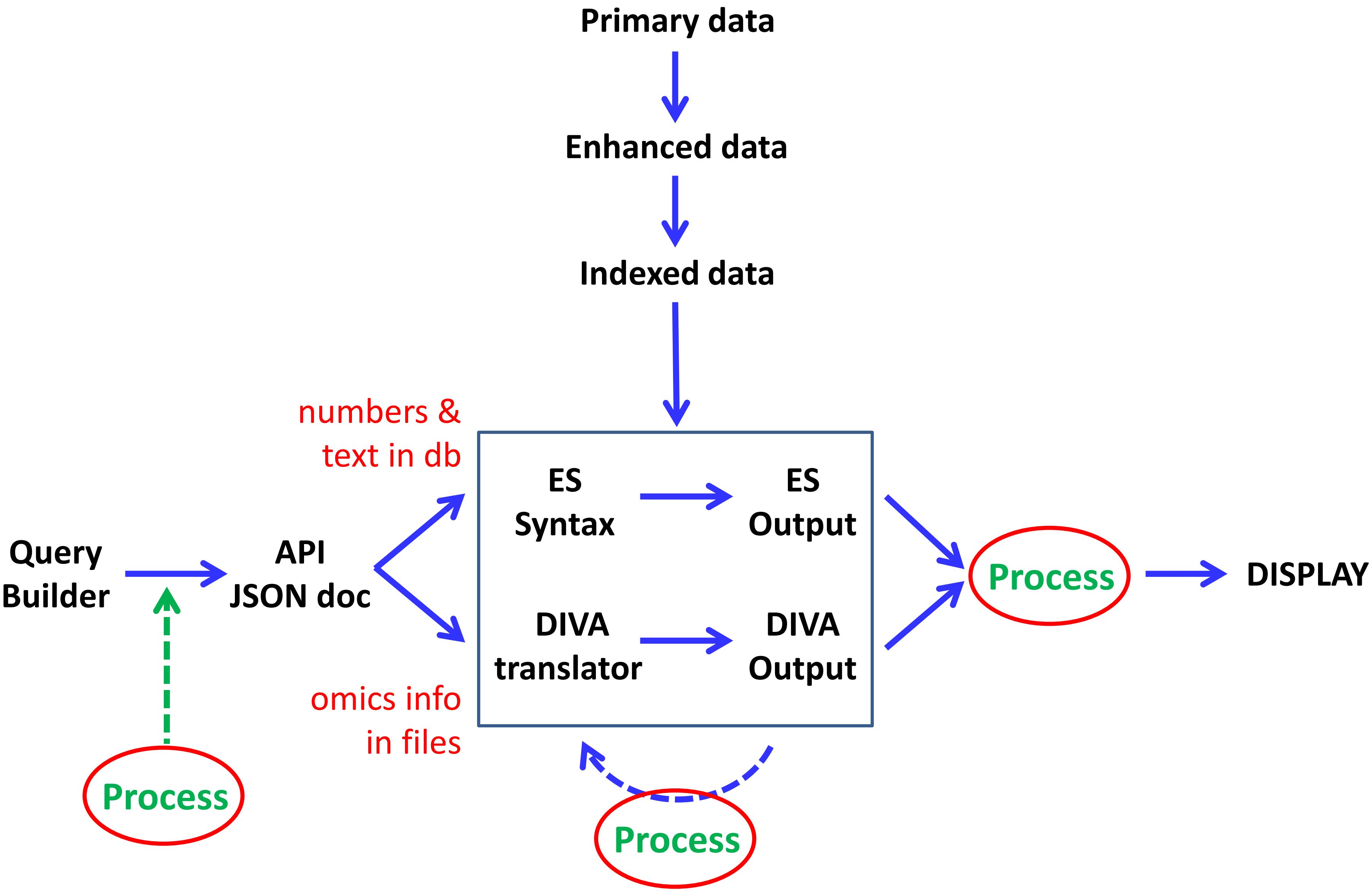


- Searches are performed through one nominated head node

Internal searches



- Searches can be performed from any node in the network



Primary data

Enhanced data

Indexed data

numbers &
text in db

ES
Syntax

ES
Output

Query
Builder

API
JSON doc

Process

DISPLAY

DIVA
translator

DIVA
Output

omics info
in files

Process

Process

Geno-Pheno Query-by-Method API

Anthony Brookes
Morris Swertz
(Isaac Kohane)
(Marc Fiume)
(Johan van der Lei)

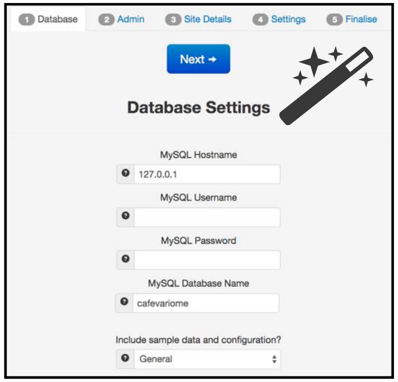
```
"query" : {
   "gender" : [
   {
      "querySegmentID" : "",
      "operator" : "",
      "gender" : {
         "ontologyGender" : {"id" : "<ontology term code>",
                             "term" : "<ontology term string>",
                             "source" : "<ontology source name>"},
         "cursiveGender" : {"term" : "FEMALE|MALE", "source" : ""}
      }
   },
   ...
   ]
   "sex" : [
   {
      "querySegmentID" : "",
      "operator" : "",
      "sex" : {
         "ontologySex" : {"id" : "<ontolog
                          "term" : "<ontol
                          "source" : "<ont
         "cursiveSex" : {"term" : "FEMALE
      }
   },
   ...
   ]
   "age" : [
   {
      "querySegmentID" : "",
      "operator" : "",
      "age" : {"value" : "", "units" : ""
   },
   ...
   ]
   "inheritanceMode" : [
   {
      "querySegmentID" : "",
      "operator" : "",
      "inheritanceMode" : {
         "ontologyInheritanceMode" : {"id"
                                      "ter
                                      "sou

         "cursiveInheritanceMode" : {"ter
      }
   },
   ...
   ]
   "diseaseFeature" : [
   {
```

```
   "geneRegion" : [
   {
      "querySegmentID" : "",
      "operator" : "",
      "geneRegion" : {
         "ontologyGeneRegion" : {"id" : "<ontology term code>",
                                 "term" : "<ontology term string>",
                                 "source" : "<ontology source name>"},
         "cursiveGeneRegion" : {"term" : "", "source" : ""}
      }
   },
   ...
   ]
   "geneConsequence" : [
   {
      "querySegmentID" : "",
      "operator" : "",
      "geneConsequence" : {
         "ontologyGeneConsequence" : {"id" : "<ontology term code>",
                                      "term" : "<ontology term string>",
                                      "source" : "<ontology source name>"},
         "cursiveGeneConsequence" : {"term" : "", "source" : ""}
      }
   },
   ...
   ]
   "pathogenicityClass" : [
   {
      "querySegmentID" : "",
      "operator" : "",
      "pathogenicityClass" : {"class" : "", "source" : ""}
   },
   ...
   ]
   "queryStatement" : "(1 AND 2) OR 3"
}
```

Phenotype Semantics

- Allow phenotypes to be described using **public ontologies**
  - Many terms from many ontologies can be associated with one entity
- Allow phenotypes to be described using a **local vocabulary or list**
- Enable hierarchical viewing and querying of the phenotype ontology data

Multiple Admin Options



Database Settings

MySQL Hostname: 127.0.0.1

MySQL Username:

MySQL Password:

MySQL Database Name: cafevariome

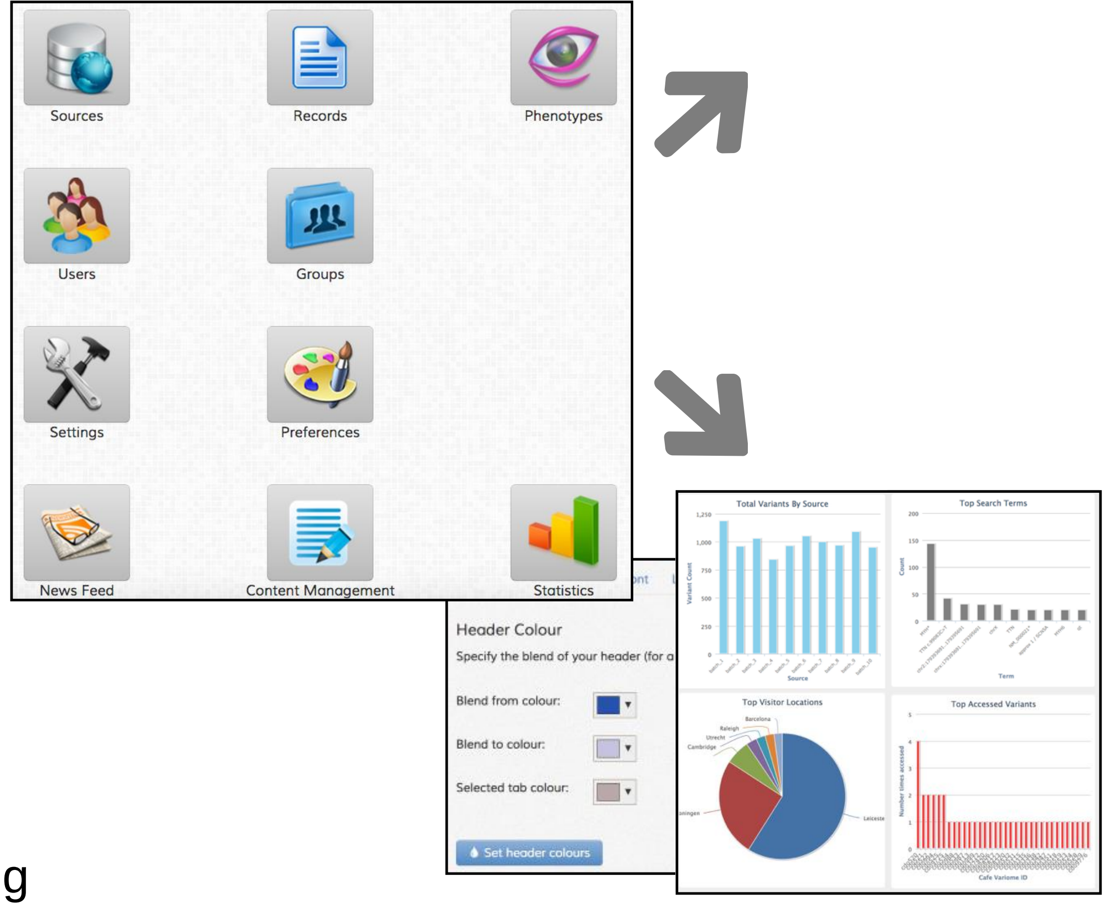
Include sample data and configuration? General

Installation wizard

User, group and record access control management

Core system settings, defining displayed and searchable fields, bulk import template configuration

Record and source management



Header Colour

Specify the blend of your header (for a

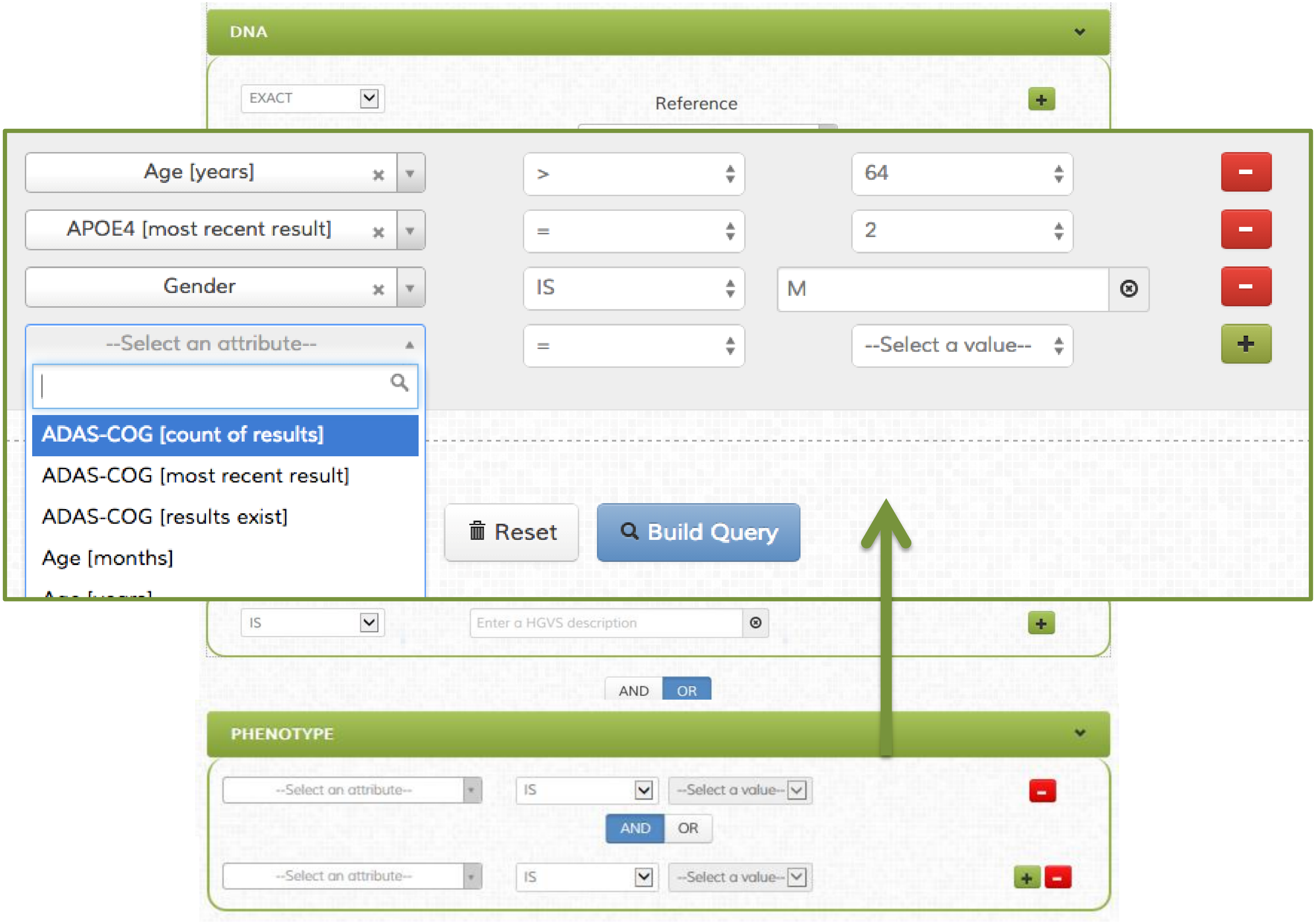
Blend from colour:

Blend to colour:

Selected tab colour:

Appearance preferences, content management system and statistics reporting

Query Builder in action

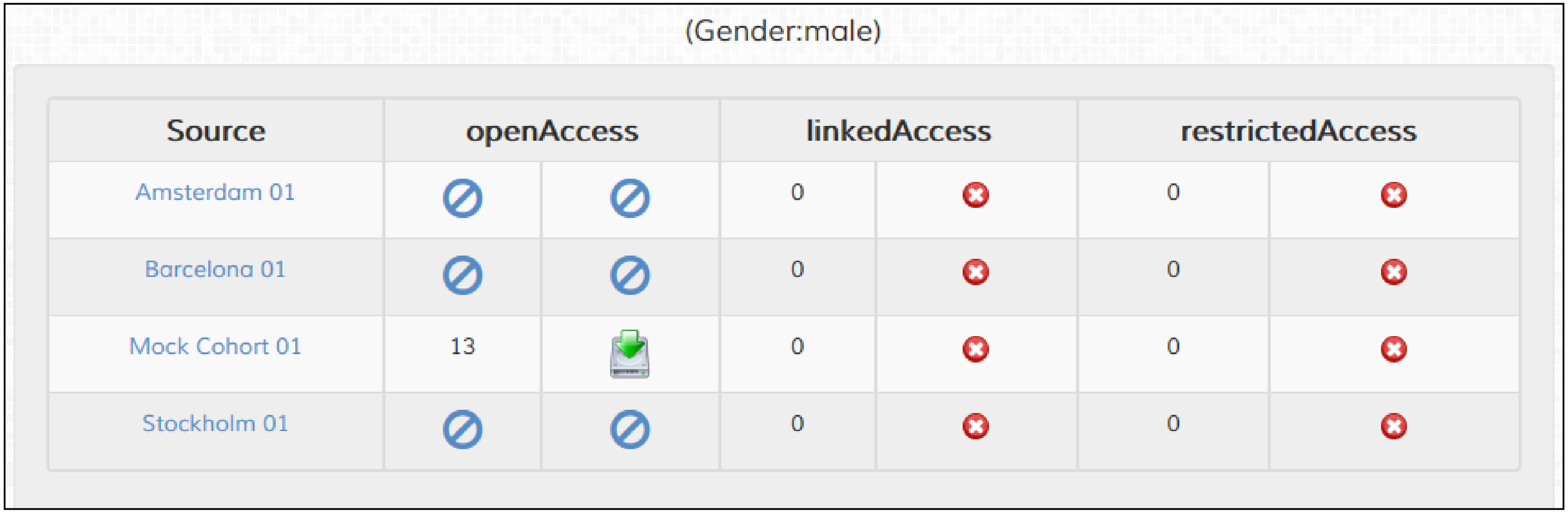


Age [years] > 64

APOE4 [most recent result] = 2

Gender IS M

Controlled Display of Matched Record Counts & Data (if permitted)

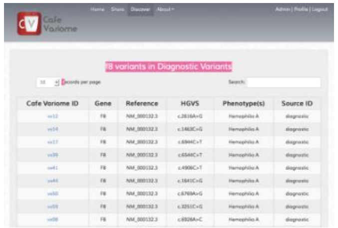


(Gender:male)

Source	openAccess		linkedAccess		restrictedAccess	
Amsterdam 01	⊘	⊘	0	⊗	0	⊗
Barcelona 01	⊘	⊘	0	⊗	0	⊗
Mock Cohort 01	13	⬇	0	⊗	0	⊗
Stockholm 01	⊘	⊘	0	⊗	0	⊗

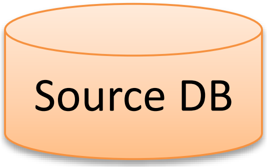
Open Access

Data provided



Linked Access

No data provided,
only link to data source

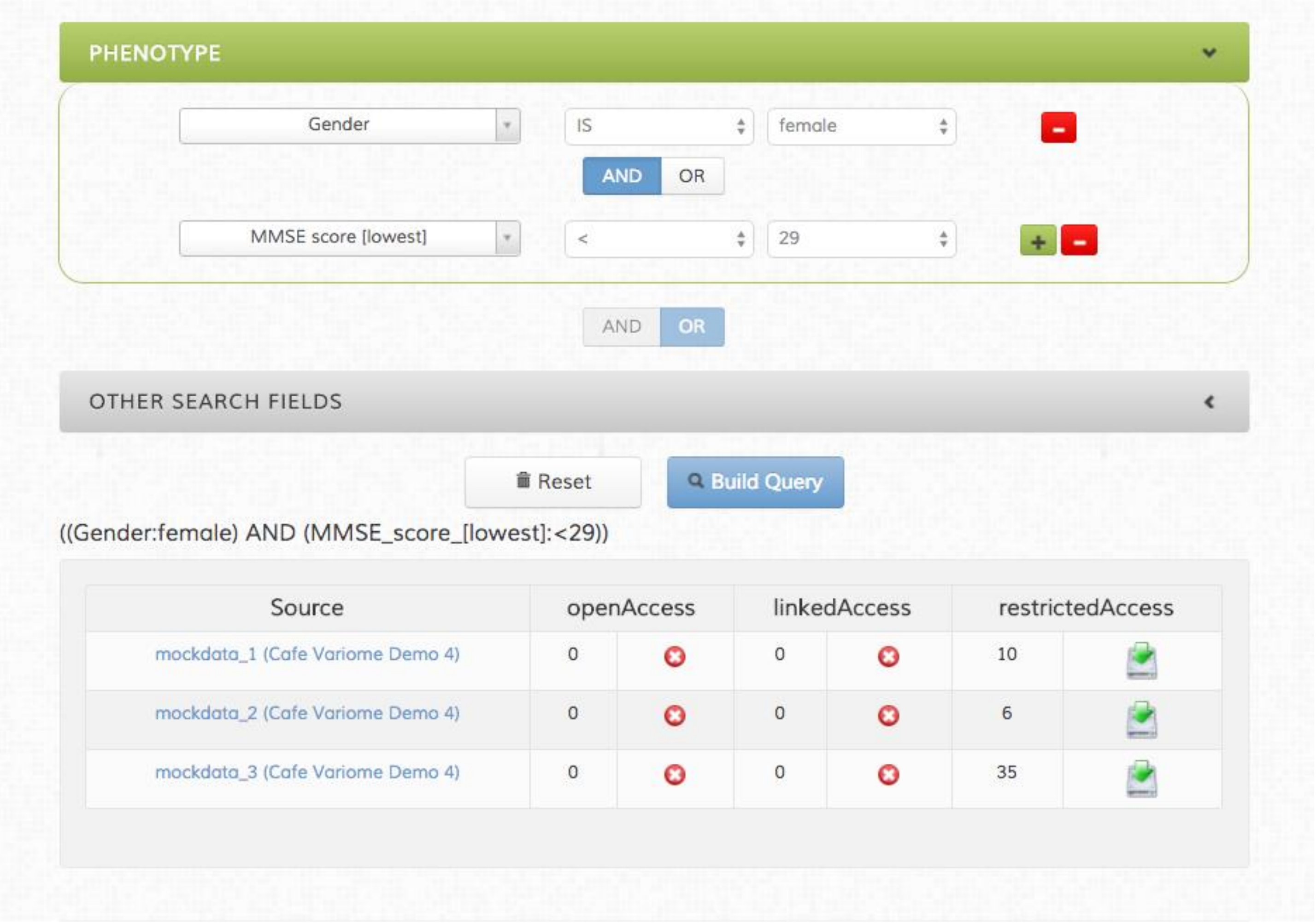


Restricted Access

You may request
pre-approval
for these data

CafeVariome Discovery

Coordinator has access to all counts, but no access to data itself



Gender IS female

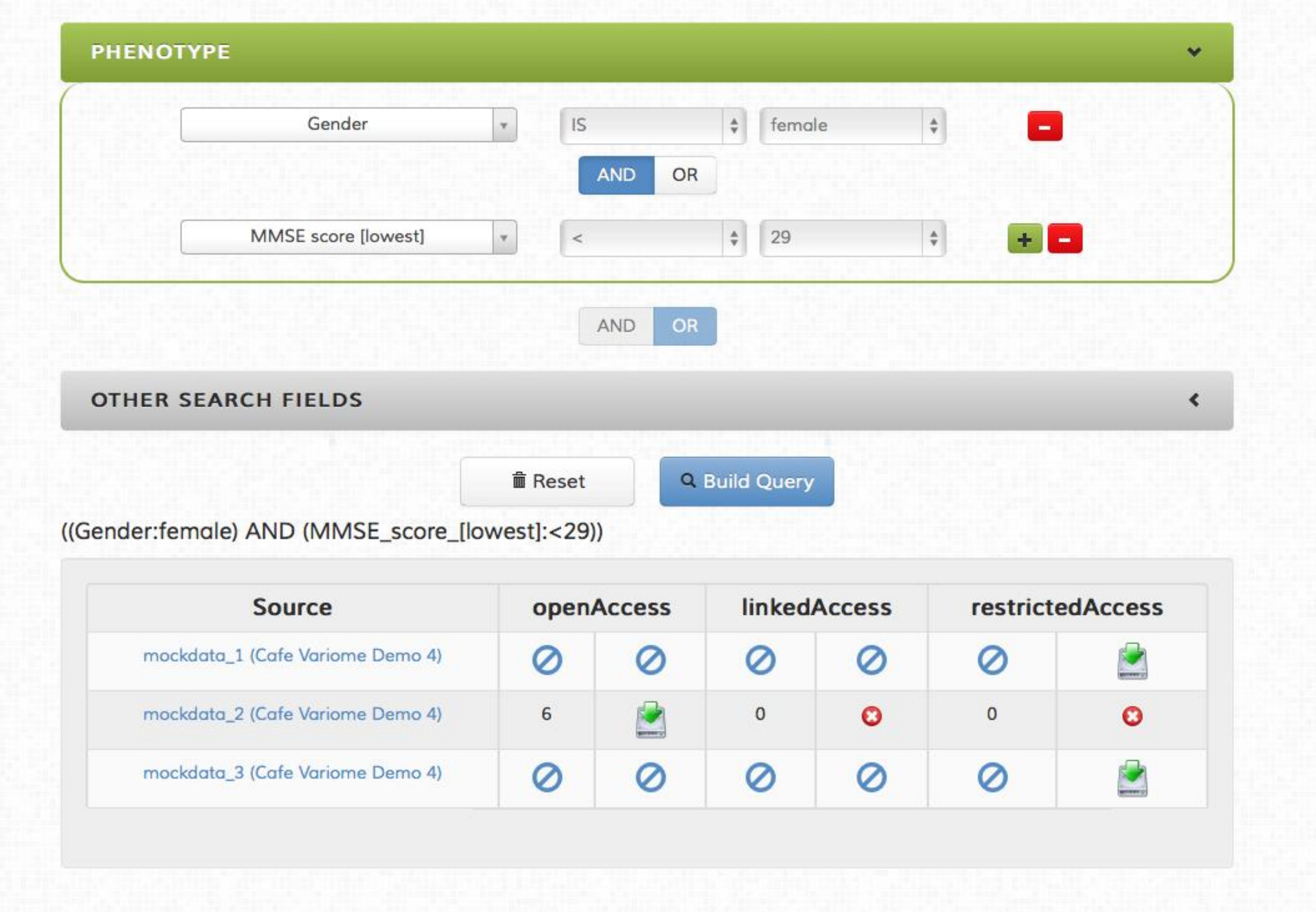
MMSE score [lowest] < 29

((Gender:female) AND (MMSE_score_[lowest]:<29))

Source	openAccess		linkedAccess		restrictedAccess	
mockdata_1 (Cafe Variome Demo 4)	0	⊗	0	⊗	10	⬇
mockdata_2 (Cafe Variome Demo 4)	0	⊗	0	⊗	6	⬇
mockdata_3 (Cafe Variome Demo 4)	0	⊗	0	⊗	35	⬇

CafeVariome Discovery

User 2 has full access to own data,
but no access to counts or data from other datasets



Gender IS female
AND [✓ AND] OR
MMSE score [lowest] < 29

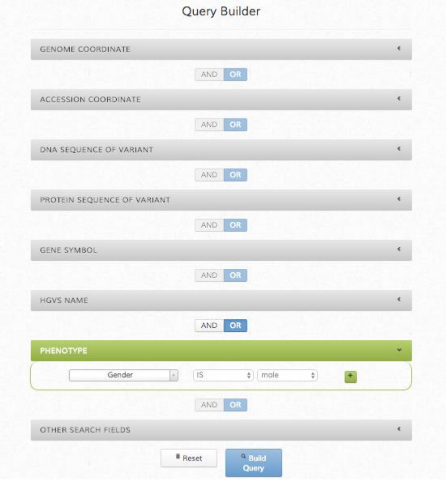
AND OR

((Gender:female) AND (MMSE_score_[lowest]:<29))

Source	openAccess		linkedAccess		restrictedAccess	
mockdata_1 (Cafe Variome Demo 4)	⊘	⊘	⊘	⊘	⊘	⬇
mockdata_2 (Cafe Variome Demo 4)	6	⬇	0	✖	0	✖
mockdata_3 (Cafe Variome Demo 4)	⊘	⊘	⊘	⊘	⊘	⬇

Café Variome: Overview

Query Builder



Query Builder

GENOME COORDINATE

AND OR

ACCESSION COORDINATE

AND OR

DNA SEQUENCE OF VARIANT

AND OR

PROTEIN SEQUENCE OF VARIANT

AND OR

GENE SYMBOL

AND OR

HGVS NAME

AND OR

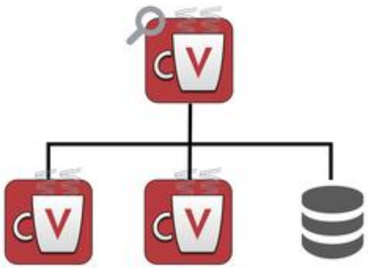
PHENOTYPE

Gender IS male

AND OR

OTHER SEARCH FIELDS

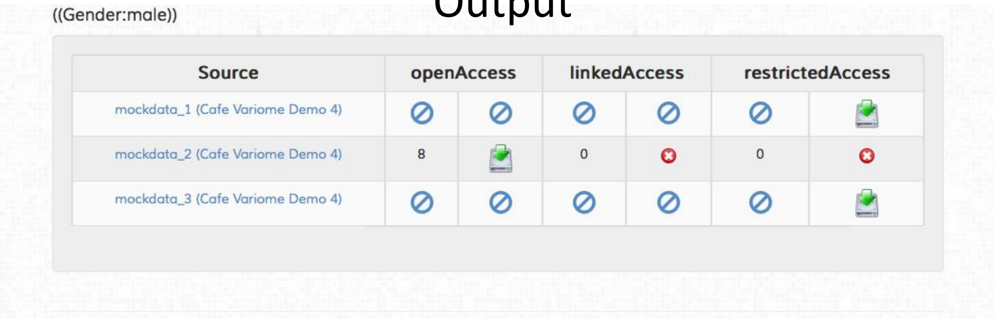
Café Variome Federated



Access Control

User, group and record access control management

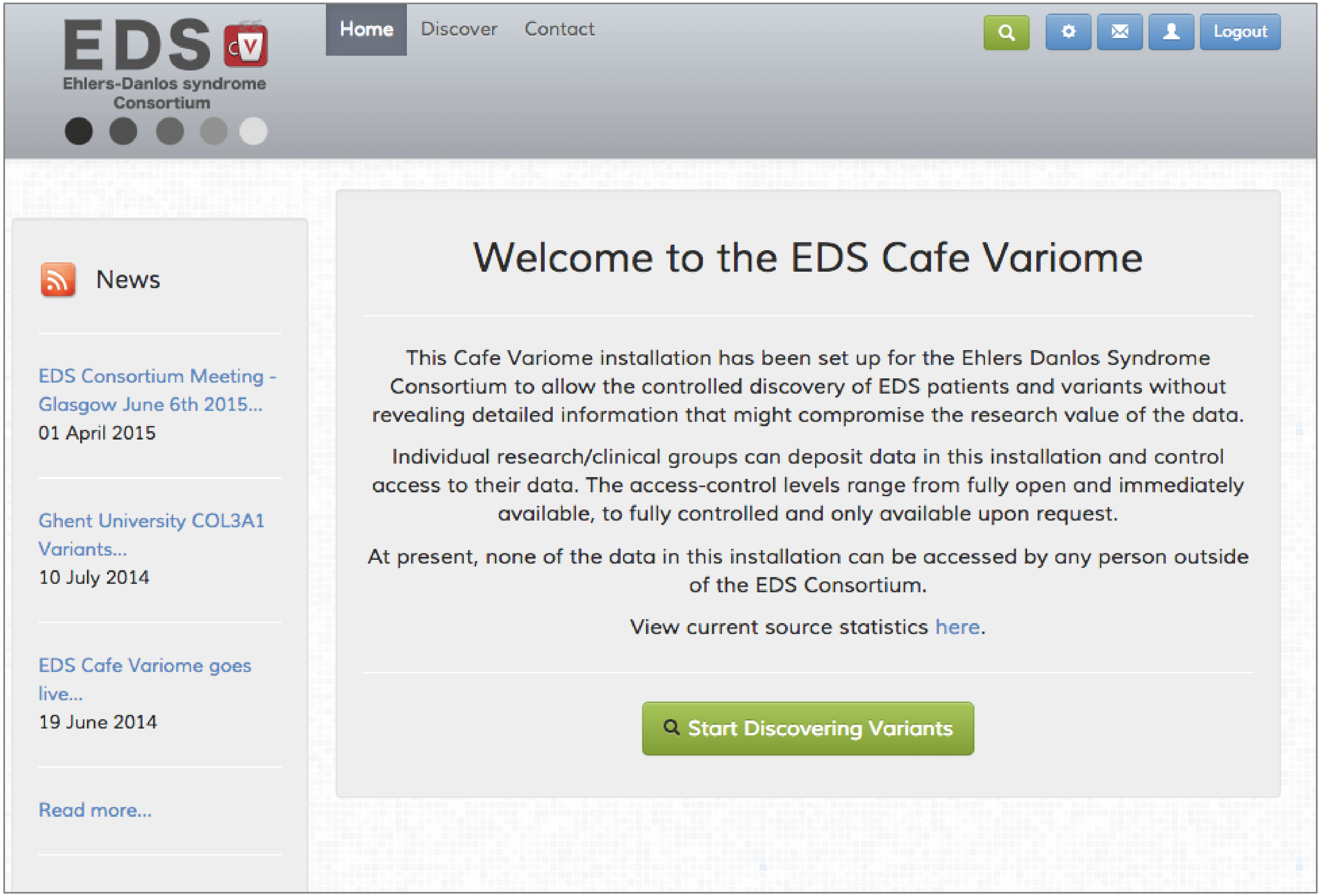
Output



((Gender:male))

Source	openAccess		linkedAccess		restrictedAccess	
mockdata_1 (Cafe Variome Demo 4)	⊘	⊘	⊘	⊘	⊘	⬇
mockdata_2 (Cafe Variome Demo 4)	8	⬇	0	✖	0	✖
mockdata_3 (Cafe Variome Demo 4)	⊘	⊘	⊘	⊘	⊘	⬇

EDS Consortium Cafe Variome



EDS Consortium Meeting - Glasgow June 6th 2015...

01 April 2015

Ghent University COL3A1 Variants...

10 July 2014

EDS Cafe Variome goes live...

19 June 2014

Read more...

Welcome to the EDS Cafe Variome

This Cafe Variome installation has been set up for the Ehlers Danlos Syndrome Consortium to allow the controlled discovery of EDS patients and variants without revealing detailed information that might compromise the research value of the data.

Individual research/clinical groups can deposit data in this installation and control access to their data. The access-control levels range from fully open and immediately available, to fully controlled and only available upon request.

At present, none of the data in this installation can be accessed by any person outside of the EDS Consortium.

View current source statistics here.

http://eds.cafevariome.org

COL3A1: Six Data-match Discoveries

- Two examples:
- c.812G>A p.(Arg271Gln)
  - Site #1: two EDS entries: both “Probably Pathogenic”
  - Site #2: (no phenotype specified) VUS
- c.3938A>G p.(Lys1313Arg)
  - Site #1: two EDS entries: one “Pathogenic” & the other “Probably Pathogenic”
  - Site #2: (no phenotype specified) VUS
  - Site #3: “Pathogenic”

List of Café Variome adopters (July2016)

Café EDS	EDS Mendelian mutations	private network
Café HCV	HCV bio-samples	[public]
PREPAD	population & dementia cohorts	private network
Café REQUITE	Radiotherapy toxicity data	[public]
Café Cardiokit	CVD mutation frequencies	public
LCBRU Biobank	CVD Biobank + Omics data	[public]
Café eTOX	Drug company toxicity data	[public]
Café IPSI	GP Clinic data	private

SUMMARY

- **DATA POSSESSION ≠ DATA CONTROL**
- **EXPLOIT THIS INSIGHTS, e.g.,**

  - Stress synergistic/collaborative use of data

  - Share alternative forms of data

  - Make greater use of encrypted data

  - Metadata standards, e.g., for data use conditions (ADA-M)

  - Public ledger of data sharing deals & terms (Blockchain, fees)

  - Create a universal 'Data Discovery Lattice'

  [stress interoperability standards, e.g., query API, metadata, consents]

Acknowledgements

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- *BBMRI(.uk), ELIXIR (EGA), GA4GH, IRDiRC, FAIRport*

- *The community of Café Variome adopters*

- ***Colin Veal***
  Tim Beck
  Charalambos Chrysostomou
  Adam Webb
  Vagelis Ladas
  Dhiwagaran Thangavelu
  Peter Freman
  Raymond Dalgleish

  Owen Lancaster
  Robert Hastings
  Robert Free

efpia

imi innovative medicines initiative

EPAD
European Prevention of
Alzheimer's Dementia Con

eTOX

EMIF

BBMRI.uk
Biobanking and
BioMolecular resources
Research Infrastructure
United Kingdom

UK Clinical Research Collaboration
Tissue Directory and
Coordination Centre