

# ATLAS

Making the UK's cohorts discoverable

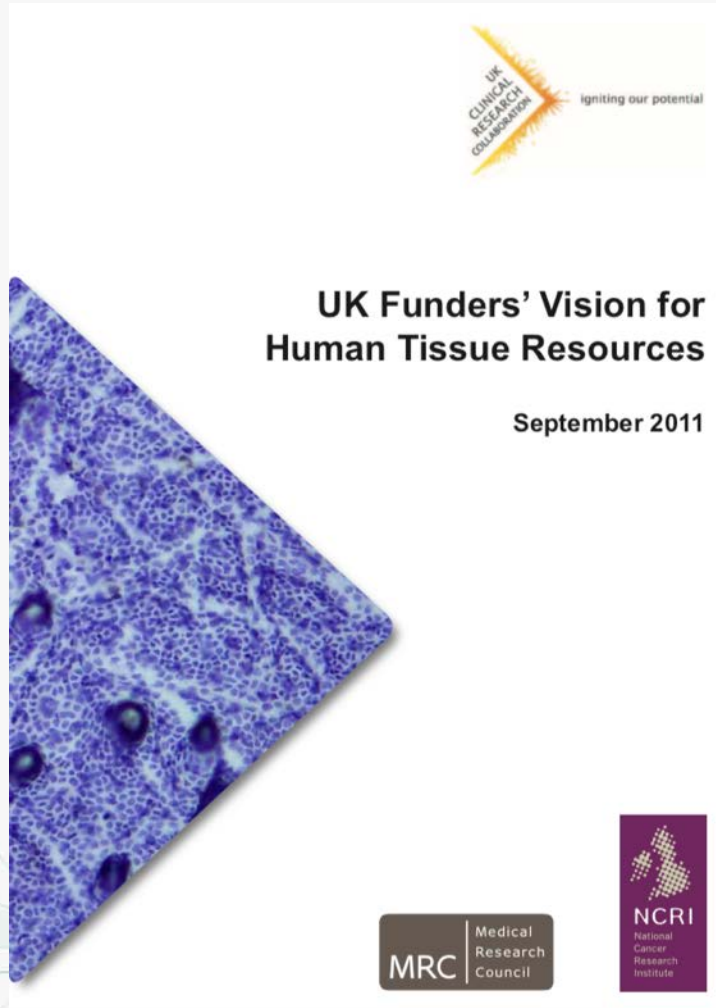
13/10/2020

Phil Quinlan



## What is the UKCRC Tissue Directory and Coordination Centre?

- <https://biobankinguk.org>



- ‘...**maximise the value** of human tissue samples and resources while **minimising duplication** of effort. This requires better characterisation of tissue samples...and increased linkage to accurate clinical data. Sample collections must then be made more **easily discoverable and accessible** for use in high quality, ethical research’

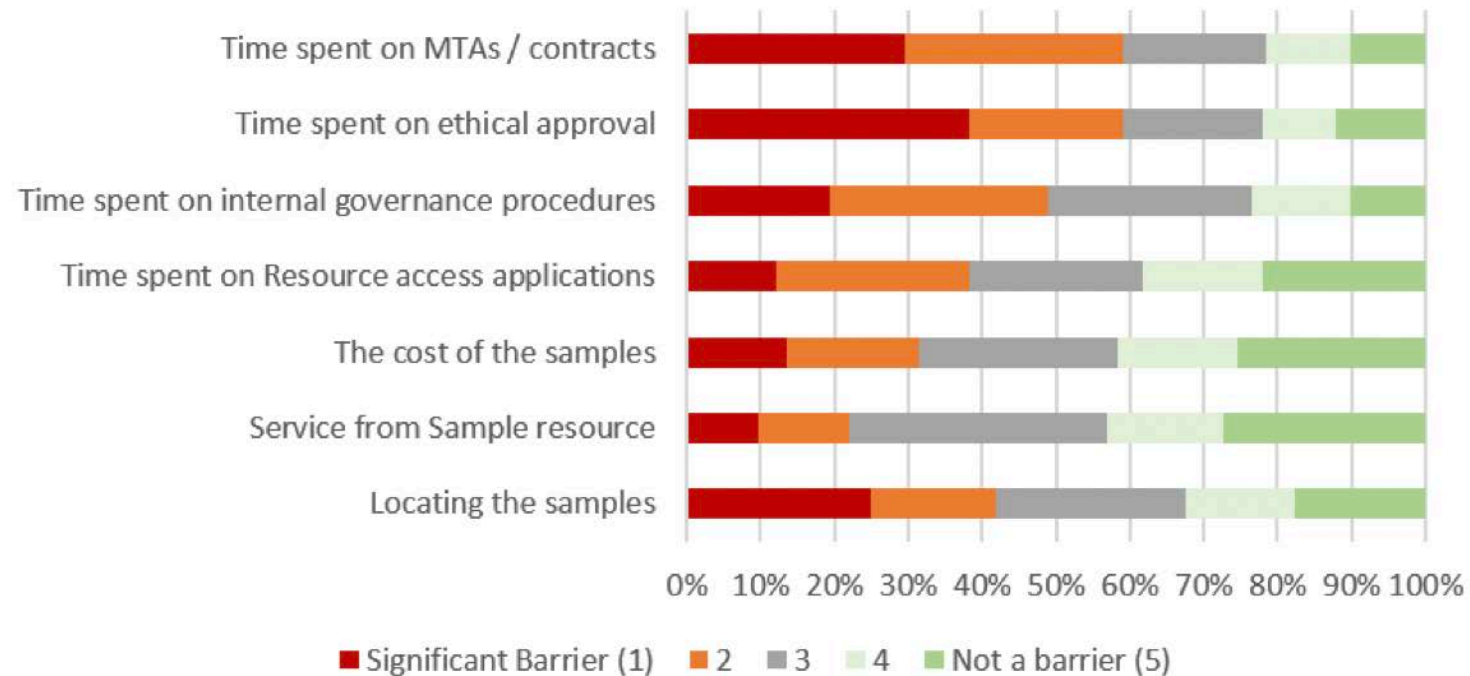
# Project deliverables



- The UK's National register for samples (and data)
- >200 registered sample resources from the UK
- Directory driven based on data available – not a sample catalogue - based on user engagement and community understanding
- Continuous improvement to respond to the needs of researchers and willingness/capabilities of biobanks
- MRC nominated representative in BBMRI-ERIC with access to a suite of open-source software tools

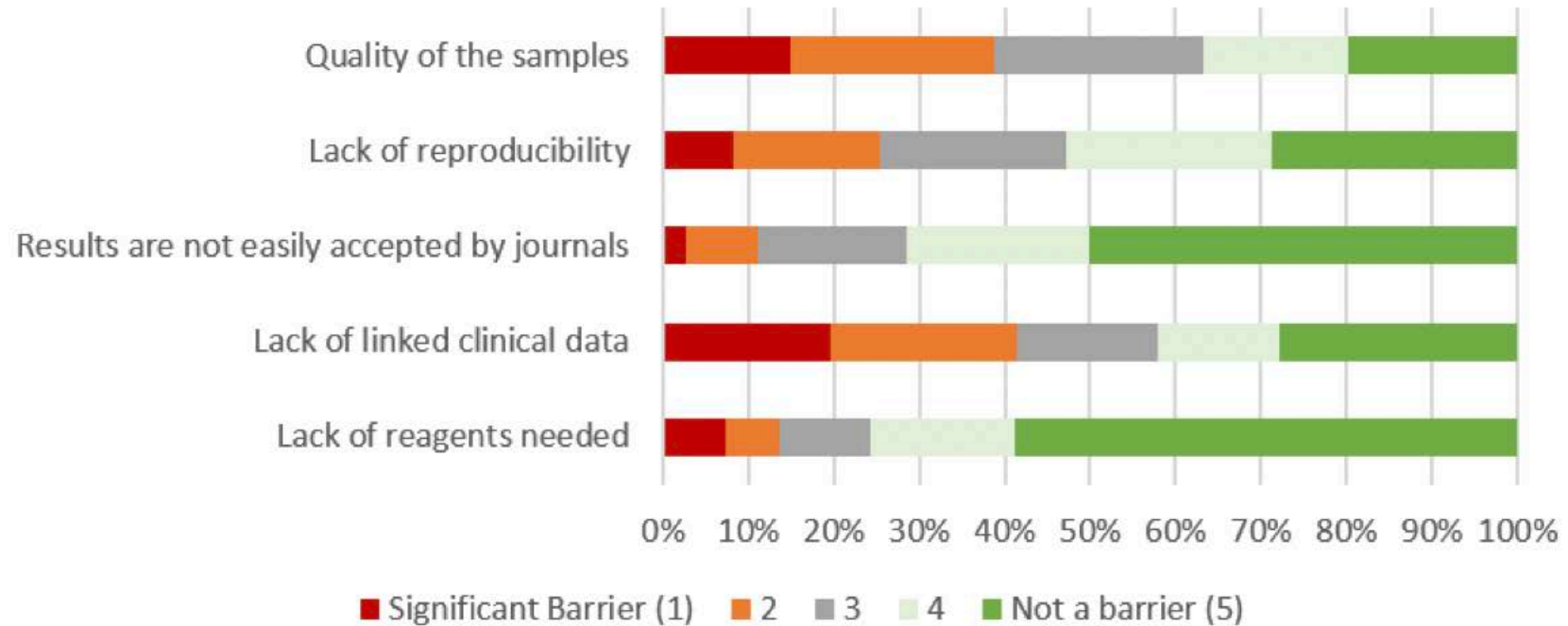
# User Engagement

On a scale of 1-5 how do you rate the following as barriers to you accessing human samples for your research?



# User Engagement

On a scale of 1-5 how do the following act as barriers to you using human samples for your research?



# What is the least reported mis-use?



## Non-use of samples is a mis-use

- Many reasons can be found why not to make samples available, very few are compatible with the consent taken from the patient
- Lack of data is one of largest reasons for samples not being used and linking data is still one of the largest challenges for biobanks
- Only 15% of samples are used!

# What is discovery?



- To allow researchers to find **new** resources that they may not have considered before
- To allow researchers to **cross domains** so that communities can reach out and form collaborations
- It is the stage before the use and analysis of data

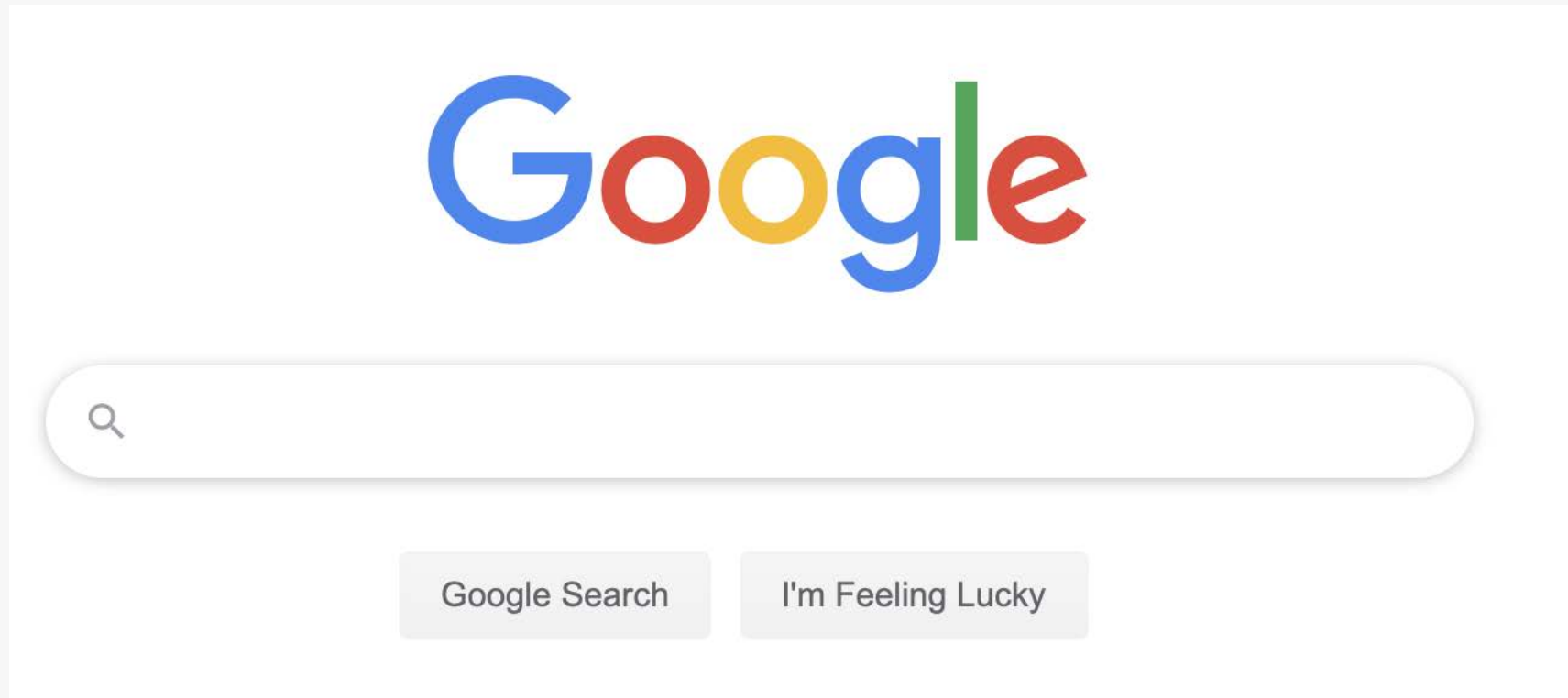
## The current search environment

- Concerns over access procedures
- Concerns over governance
- Finding a new resource will just take time...
- There isn't even what I need, quality concerns and lack of data
- We have a very skeptical shopper!





# Do you need harmonisation for discovery?



```
<HTML>  
  <Head></Head>  
  <Body></Body>  
</HTML>
```

## What we have been working on....

- Use existing standards – OMOP
- Look for ‘obvious’ harmonisation
  - First instance this is simply word matches
- Allow the interface to reveal the options (‘Asthma’, ‘Ever had asthma’)
- Log the searches (and combinations) made
- Direct future harmonization based on user searches



# The New Einsteins Will Be Scientists Who Share

From cancer to cosmology, researchers could race ahead by working together—online and in the open

*By Michael Nielsen*

October 29, 2011

## Academia

University of Nottingham  
University College London  
University of Bristol

## Research Infrastructures

UKCRC Tissue Directory  
Health Data Research UK  
ALSPAC  
Generation Scotland  
NIHR BioResource  
BREATHE HDR UK Hub

## Industry

BC Platforms

## ATLAS approach

- Harmonisation takes about 1 day of effort
- Researchers can perform 'live' harmonisation
- Immediate impact
- Allows alignment with longer term harmonisation and data standards development work

Q asthma

Condition Demographics Measurement Observation Procedure Questionnaire

Asthma

A14: Ever had asthma

A15a: Asthma medication is a reliever inhaler

A15b: Asthma medication is a preventor inhaler

A15c1: Frequency steroid tablets taken as asthma medication

A15c: Asthma medication is steroid tablets

**We have some exciting news**

A professional studio lighting setup. The scene is dominated by a large, bright octagonal light fixture hanging from a rig in the center. Above it, a complex rig of lights and equipment is visible, with some lights numbered 10, 11, 21, 22, 23, 24, 25, 26, and 27. To the left and right of the central light are two large black softboxes on stands. The background is a plain white wall with a door on the left and a window on the right. The floor is dark with red and white striped safety lines. In the foreground, there are some pieces of equipment, including a black bag and some small containers.

ATLAS  
is  
live!

# Search across thousands of data points

Condition	Demographics	Measurement	Observation
Abnormal behavior	Gender	Body height	Abnormal platelet
Abnormal menstrual cycle	<input type="radio"/> Female <input type="radio"/> Male	Body weight	Absolute CD3 count
Allergic rhinitis	Race	BP diastolic	Alcohol units consumed per week
Alopecia		BP systolic	Allergy to bee venom
Alzheimer's disease	The year of birth of the person	Diastolic blood pressure	Allergy to cat dander
Apnea		Forced expiratory flow rate between 25+75% of vital capacity	Allergy to fruit
Asthma		Forced expired volume	Allergy to nut
Asthma disturbs sleep weekly		Forced expired volume in one second/forced vital capacity ratio	Allergy to penicillin
Asthma never disturbs sleep		Forced vital capacity	Allergy to pollen
Autoimmune thrombocytopenia			Baked beans

# The rules

- It is open to everyone with a need, no separation between academics and industry
- An account is required to access
- Go to [biobankinguk.org/atlas](https://biobankinguk.org/atlas) to create an account
- Can only be used for discovery, not research, permission for research must be sought from the biobanks and cohorts



# Summary

- Over 200 biobanks registered with the national directory, containing data on disease, gender, age and samples available.
- New from today, search thousands of variables on four leading UK cohorts
- Access the discovery for free, and we need to get more samples and data used for the benefit of those who have donated.
- **“There is a responsibility for those holding information to do something with it, because nobody wants to give their data, or their samples, and then nothing happen with it”** *Patient Advocate, use MY data.*

**HDRUK**  
Health Data Research UK



**Thank you!**

13/10/2020 |