

# Data Access & Discovery

- HDR Innovation Gateway  
Interactive Feedback Workshop

11:00 - 12:00

Thursday, 11 August 2022

**HDRUK**  
Health Data Research UK

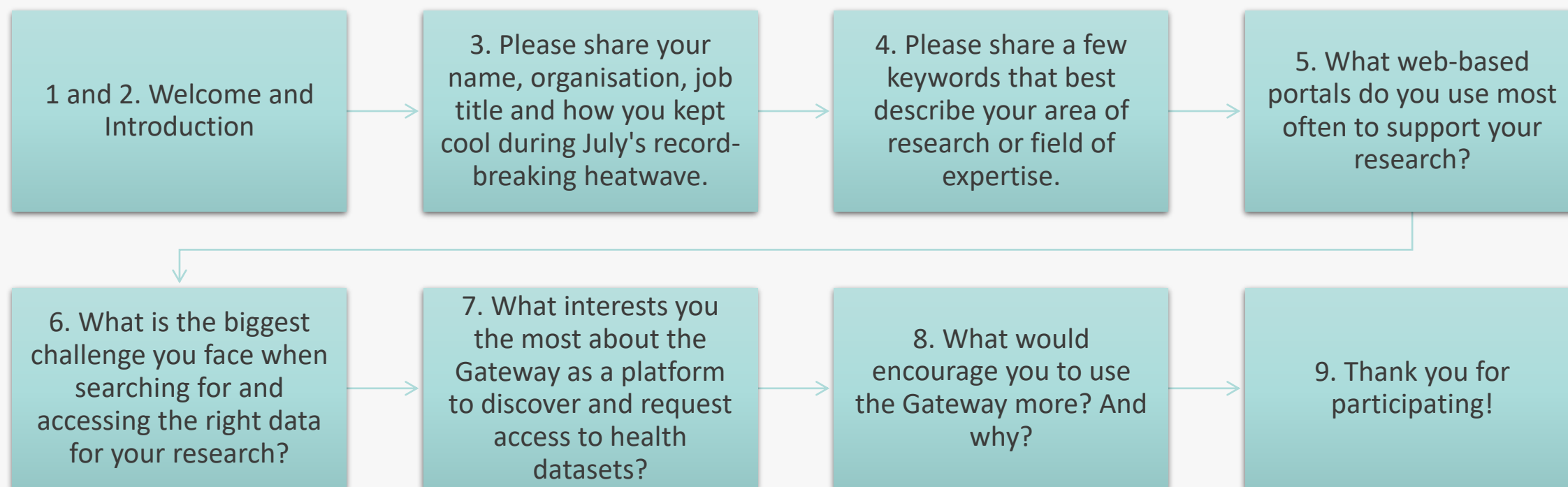
Health Data Research  
Innovation Gateway



**#HealthDataGateway**



## Breakout Room Sessions: Jam Board Activity Pages



[Click here to view the Jam Board template](#)

## Group Findings: Page 3 and 4

3. Please share your name, organisation, job title and how you kept cool during July's record-breaking heatwave.

4. Please share a few keywords that best describe your area of research or field of expertise.

You represented:

- Research (academic and clinical)
- The public
- Research support and professional services
- Private companies (health research related)
- HDR UK staff

You had expertise in:

- Clinical health
- Life sciences
- Data science
- Other (cancer, imaging, mental health, AI)
- HDR UK staff (marketing, technology, project management)

## Group Findings: Page 5 and 6

5. What web-based portals do you use most often to support your research?

The most common categories mentioned were:

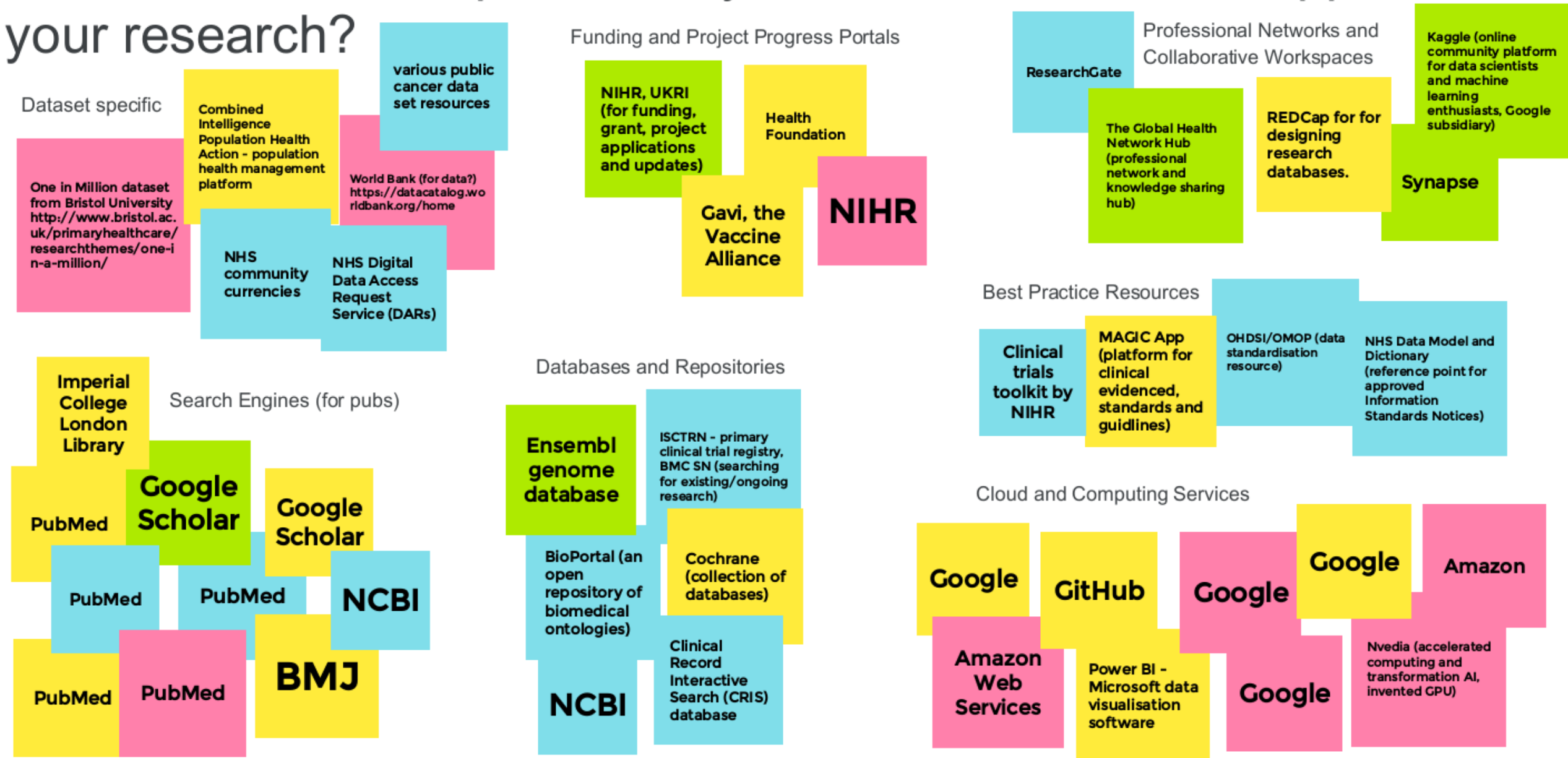
- Search engines (for publications mostly)
- Professional networks and collaborative workspaces
- Best practice resources
- Databases and repositories
- Dataset specific (like the Gateway)
- Cloud and computing services

6. What is the biggest challenge you face when searching for and accessing the right data for your research?

The most common challenges related to:

- Data information
- Data access (approval process)
- Data availability
- Latest research
- Data discovery platforms
- User experience

# 5. What web-based portals do you use most often to support your research?





# 6. What is the biggest challenge you face when searching for and accessing the right data for your research?

## Data Discovery Platforms

data available here and there but no comprehensive database

Too few sites for discovery, each with small/local coverage (hence use PubMed and Google)

The need for a single search engine for all health data

Always a snapshot, not end-to-end data.

Google and Amazon are paid ones

## Data Information

Having the right information on how to access- REC, CAG, DARs and what order to approach each organisation

Data quality - what data can be used as reliable source data, mandatory completion, quality checks etc

understanding Dataflows!- is the data anonymised, de-identified? harmony on terminology and contractual terms

Project design and proposal

complex (meta) data models

data sensitivity, patient data

## Latest Research

Getting current literature

Literature not open access

Understanding what research is underway

Keeping up ! Rate and pace of publication is very high

## User Experience

Ease of use interface

Use of language - data dictionaries etc not in plain english

Poor narrative on datasets

Unintuitive interfaces

## Data Access

Application process - delays in receiving data, often data received beyond grant timelines

Understanding the scope of [approval] committees

using AI for anonymisation and de-identification - adoption process is slow and very much regulated

Accessing dataset is complex and time consuming

turn around time for data access approvals

## Data Availability

Local vs. national data

Access to primary care data

Related datasets [not] listed

UK wide data - trials recruiting across nations, which data matches

data not available for commercial research

## Group Findings: Page 7 and 8

7. What interests you the most about the Gateway as a platform to discover and request access to health datasets?

This is what appeals to you most:

- Data discovery
- Trust and transparency
- The datasets!
- Service and support
- Open source and open access

8. What would encourage you to use the Gateway more? And why?

These are your suggested areas of improvement:

- Federation
- Search
- PPIE
- Development (focus)
- Visibility

# 7. What interests you the most about the Gateway as a platform to discover and request access to health datasets?

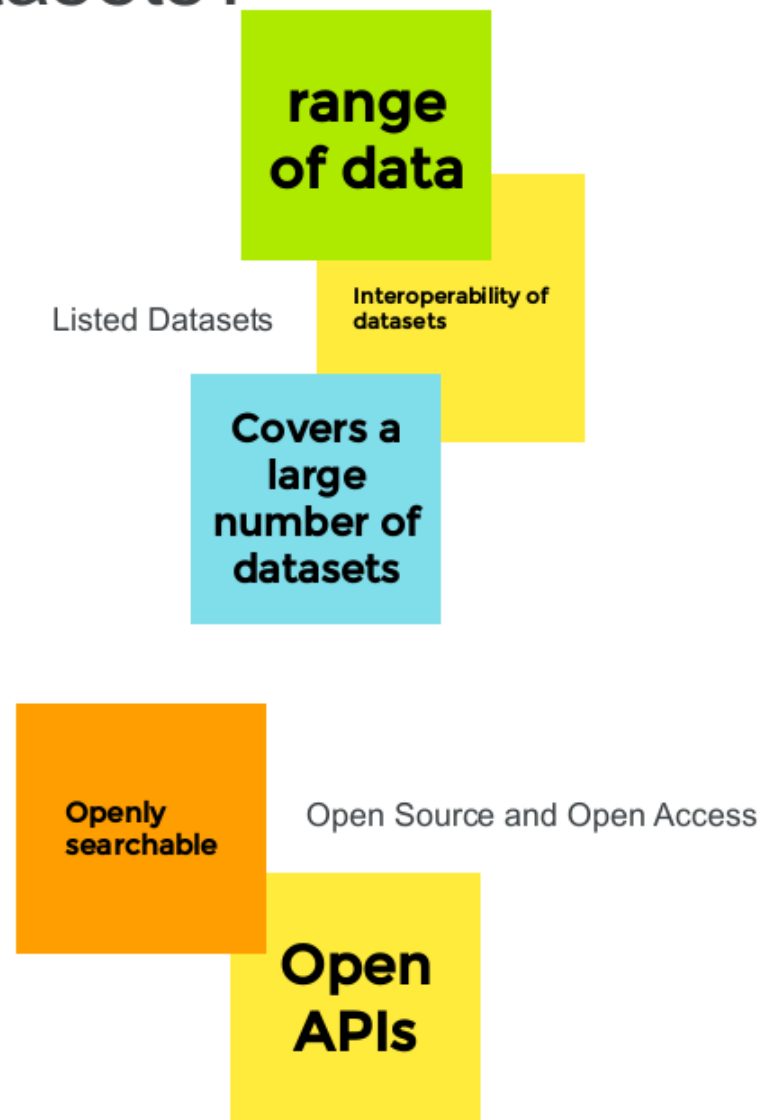
## Data Discovery



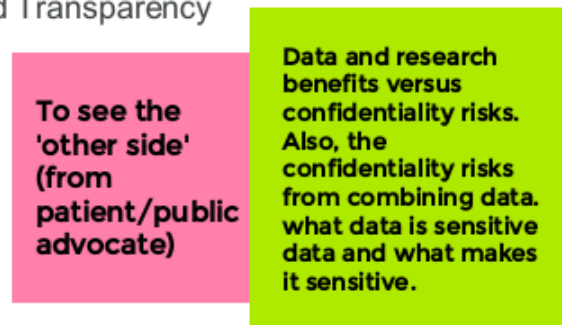
## Service and Support



## Listed Datasets

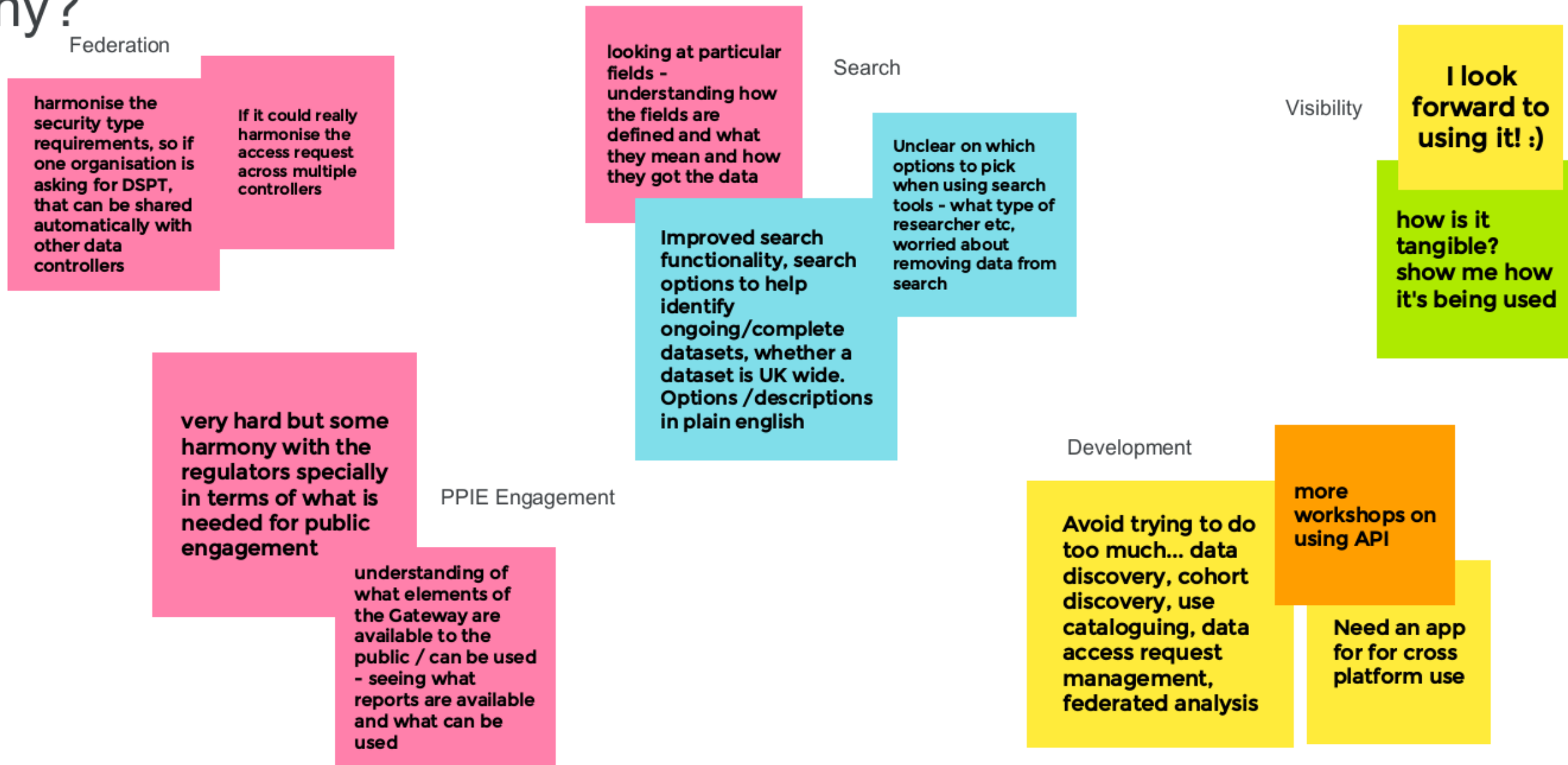


## Trust and Transparency





# 8. What would encourage you to use the Gateway more? And why?



**Thank you for taking part in our  
Breakout Room sessions!**

