

digitalhealth

REWired

LONDON 14-15 MARCH 2023

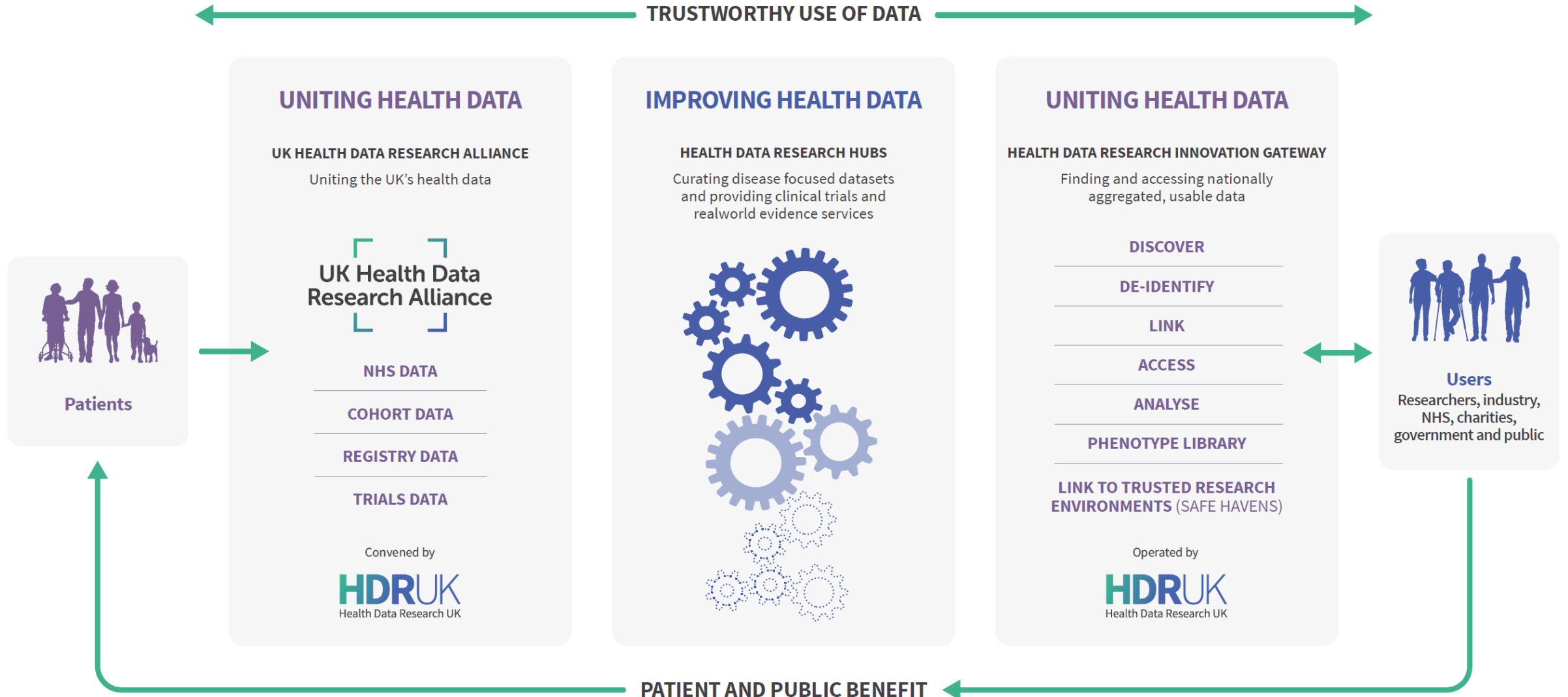
Headline Sponsors:



Monica Jones

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Associate Director - HDRUK

UNITING THE UK'S HEALTH DATA TO MAKE DISCOVERIES THAT IMPROVE PEOPLE'S LIVES

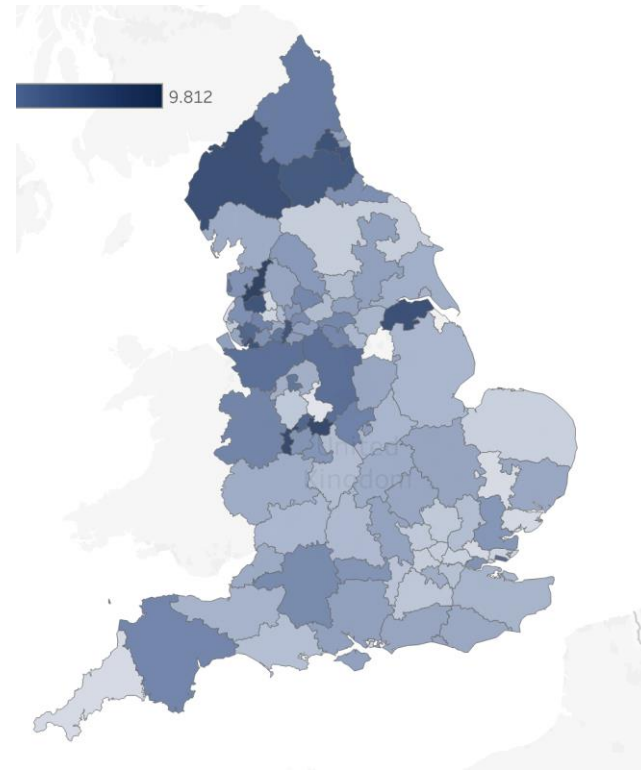


Analysis of the impact of COVID-19 on Cancer, using open standards, in both local and national cancer data

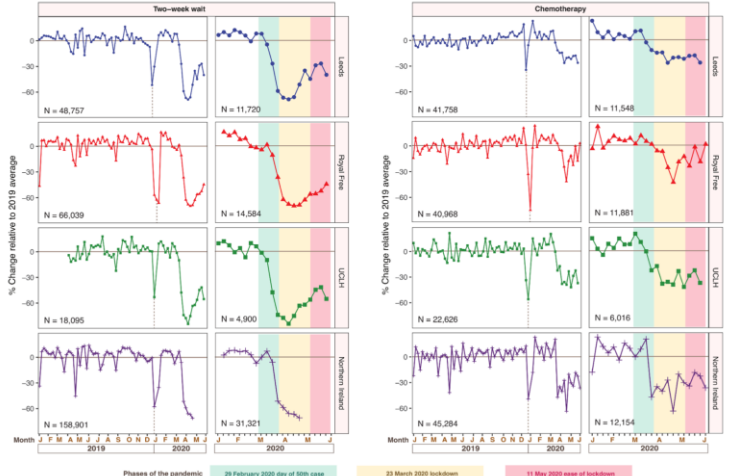
Covid-19 has been shown to impact cancer referrals and have a significant impact on projected excess deaths.¹

Google Cloud Platform

Access to a TRE holding over **12 billion rows** of data and more than **50 million patients** in England



Leeds
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N.I.



databricks **DELTA LAKE**

1. Lai AG, Pasea L, Banerjee A, Jones M, et al. Estimated impact of the COVID-19 pandemic on cancer services and excess 1-year mortality in people with cancer and multimorbidity: near real-time data on cancer care, cancer deaths and a population-based cohort study. *BMJ Open* 2020;10:e043828

Data Quality, Standards and Governance

The HDRUK Data Improvement work in first five years supported researchers and custodians across multiple areas of the “FAIR” approach (Findable, Accessible, Interoperable, Reusable).

Across the institute, HDR UK has made great progress in ensuring data is Findable and Accessible in QQ1, and for the next five years the focus in Data Improvement will be on make data Interoperable and Reusable.

Standards and data quality improvements will support research taking place in a federated manner across data custodians, as there must be consistency in data standards and use of data elements for analysis across multiple datasets.

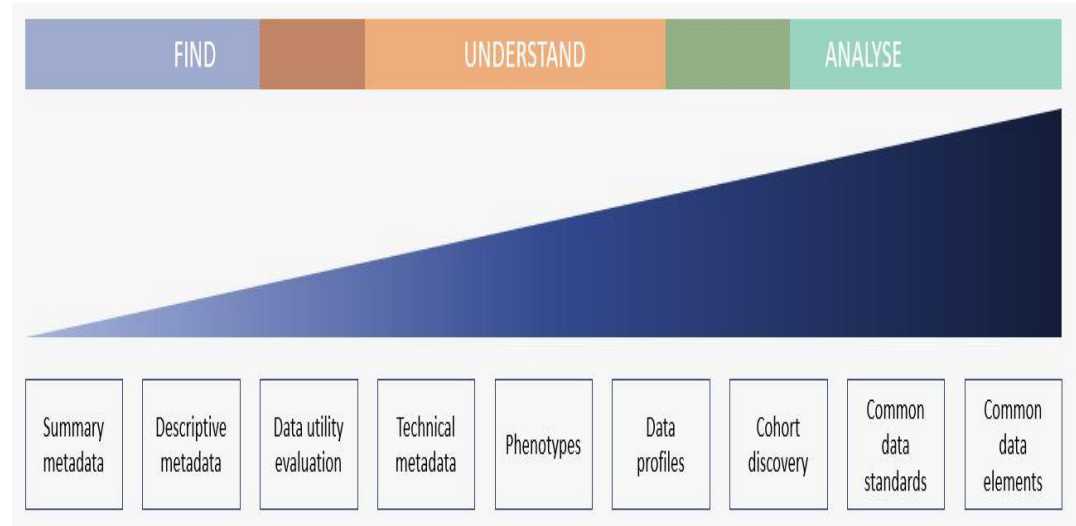


Fig 1. Metadata maturity gradient - information availability for a dataset.

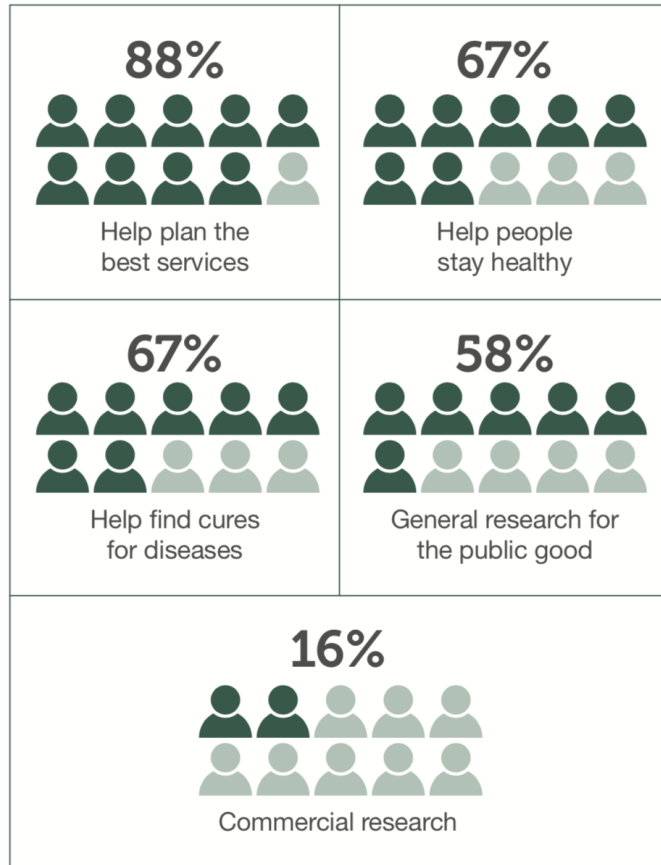
Listening to patients and carers on data sharing and privacy



- We're proud of what we've achieved so far, but there is so much more to do
- Yorkshire & Humber Care Record programme has delivered innovative solutions and tools to support organisations and improve care of people across our region
- NHS owns this innovative solutions set and we'll continue to develop them to meet the needs of our patients, carers, citizens and staff
- The trust of the public in how we use data is hugely important so we asked them what they thought with the "Joined Up Yorkshire & Humber" engagement

For more detail visit <https://yhcr.org/resources/citizen-engagement/>

What did people think about the secondary use of data?

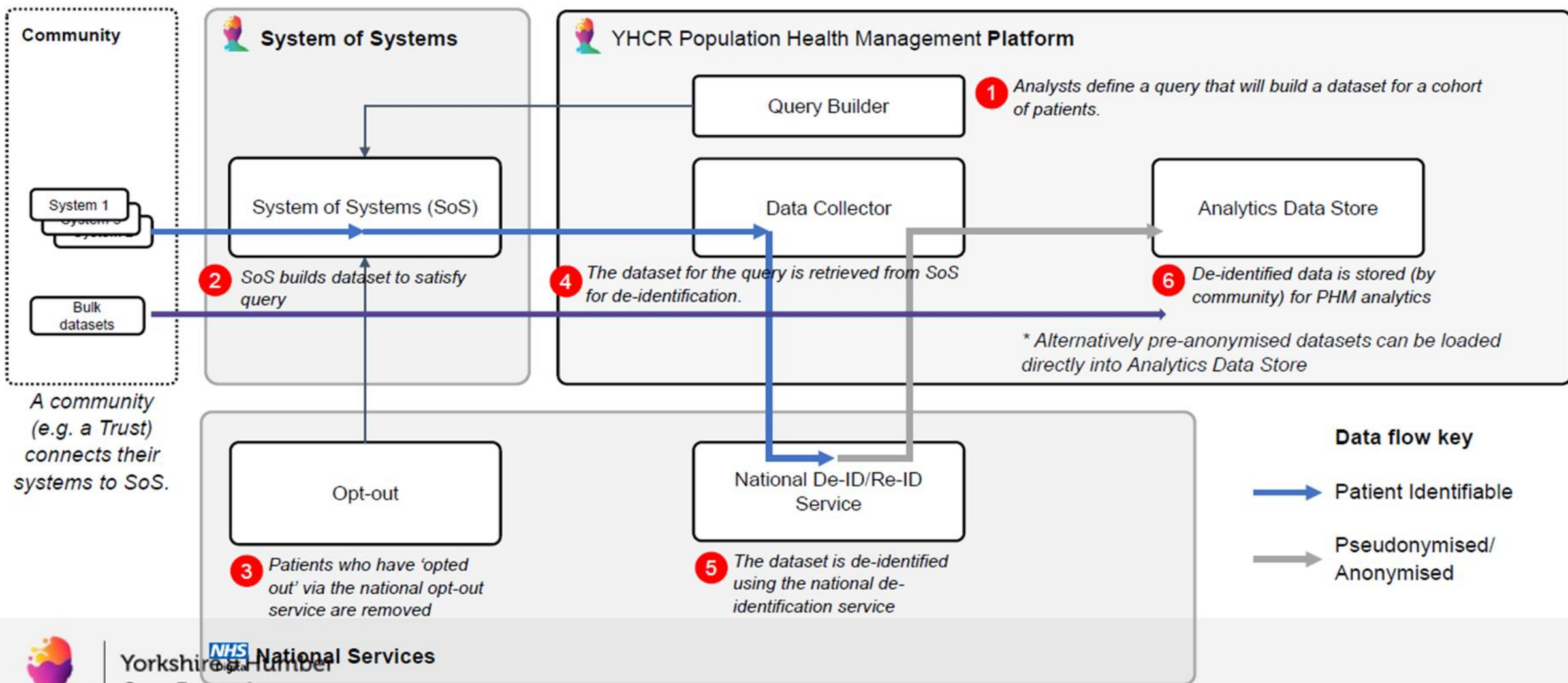


- 95% supported one or more use
- Strong support for public health uses: screening invitations (73%); health advice (60%)
- Concerns about data sold to private companies, not stored securely and used to cut services
- People prefer short, clear and simple explanations
- People trust NHS more than other public sector services
- Younger people have more trust than older people
- It's useful to use an example when explaining population health management
- Most common concern is about data security – data breaching and hacking
- Also feel that the data used should be accurate and up-to-date

Note: engagement was before the COVID-19 pandemic, involving over 2,000 people across Yorkshire & Humber

Population Health Management – Data Flow

This shows the flow of data for the single processing activity to get approved data into the Analytics Data Store. The initial dataset scoping (Step 1) initiates a process to build a dataset (Step 2-4) for the purpose of de-identification (Steps 5), before the storage of the de-identified data (Step 6) for future visualisation.





Questions ?