



FED- NET

CREATING A CROSS-COUNCIL NETWORK

DARE: Creating the blueprint for a federated network of next generation, cross-council Trusted Research Environments



Big societal issues require data & partnerships which span sectors and disciplines.

3 main challenges :

- Public trust and support
 - Data interoperability
 - Balance between data security & data access
-

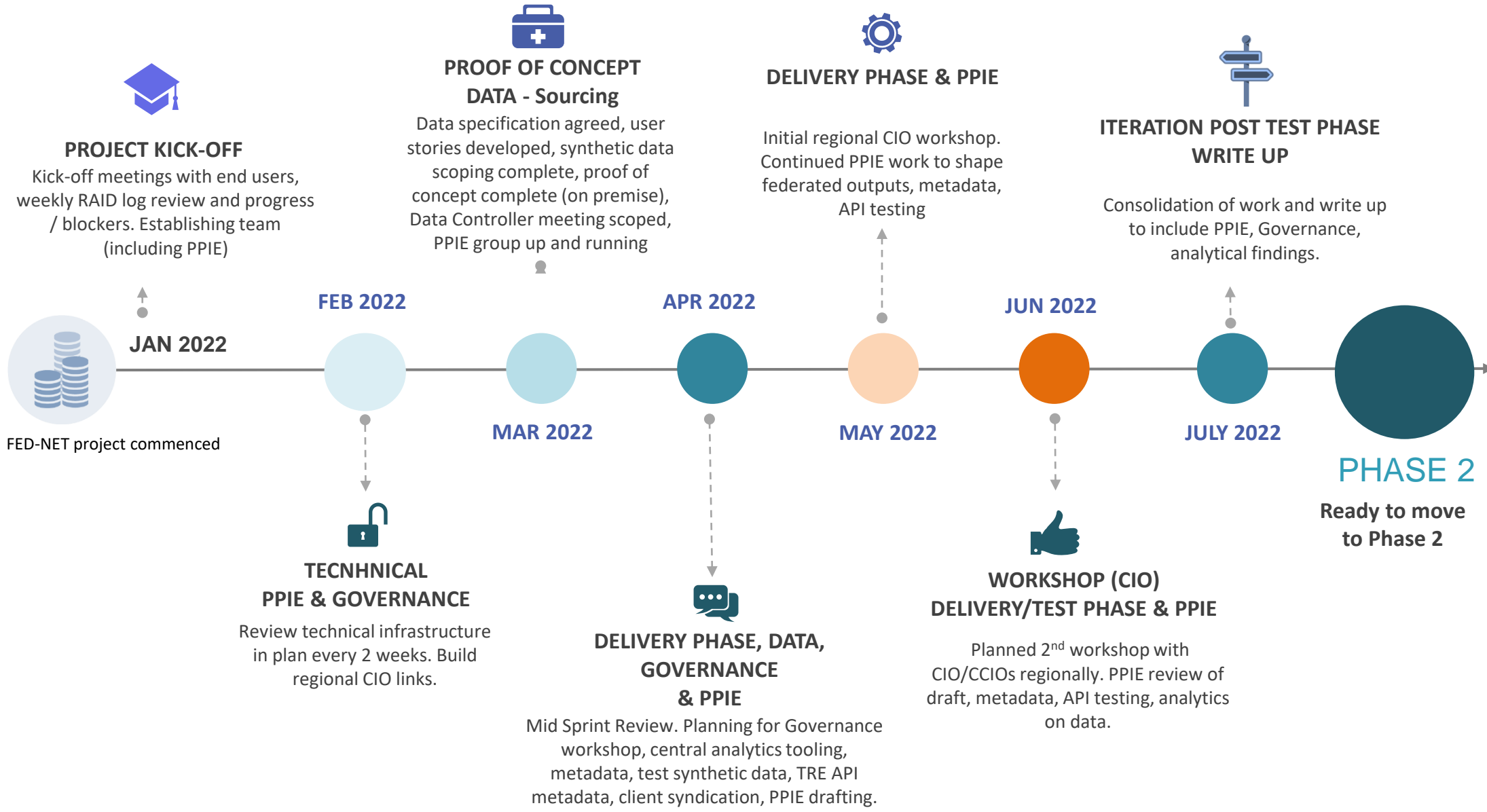
Data Controllers need to understand and trust federated systems

Case Study: Midlands-wide effort to improve asthma outcomes

- 1 > Deliver cross-council use-case on regional clinical need (asthma)
- 2 > Develop & test federated analytical environment
- 3 > Working towards open & trusted data alliances without moving data
- 4 > Use common data models & enhanced metadata catalogues
- 5 > Expand our tested governance structures
- 6 > Build public trust by transparency & involvement

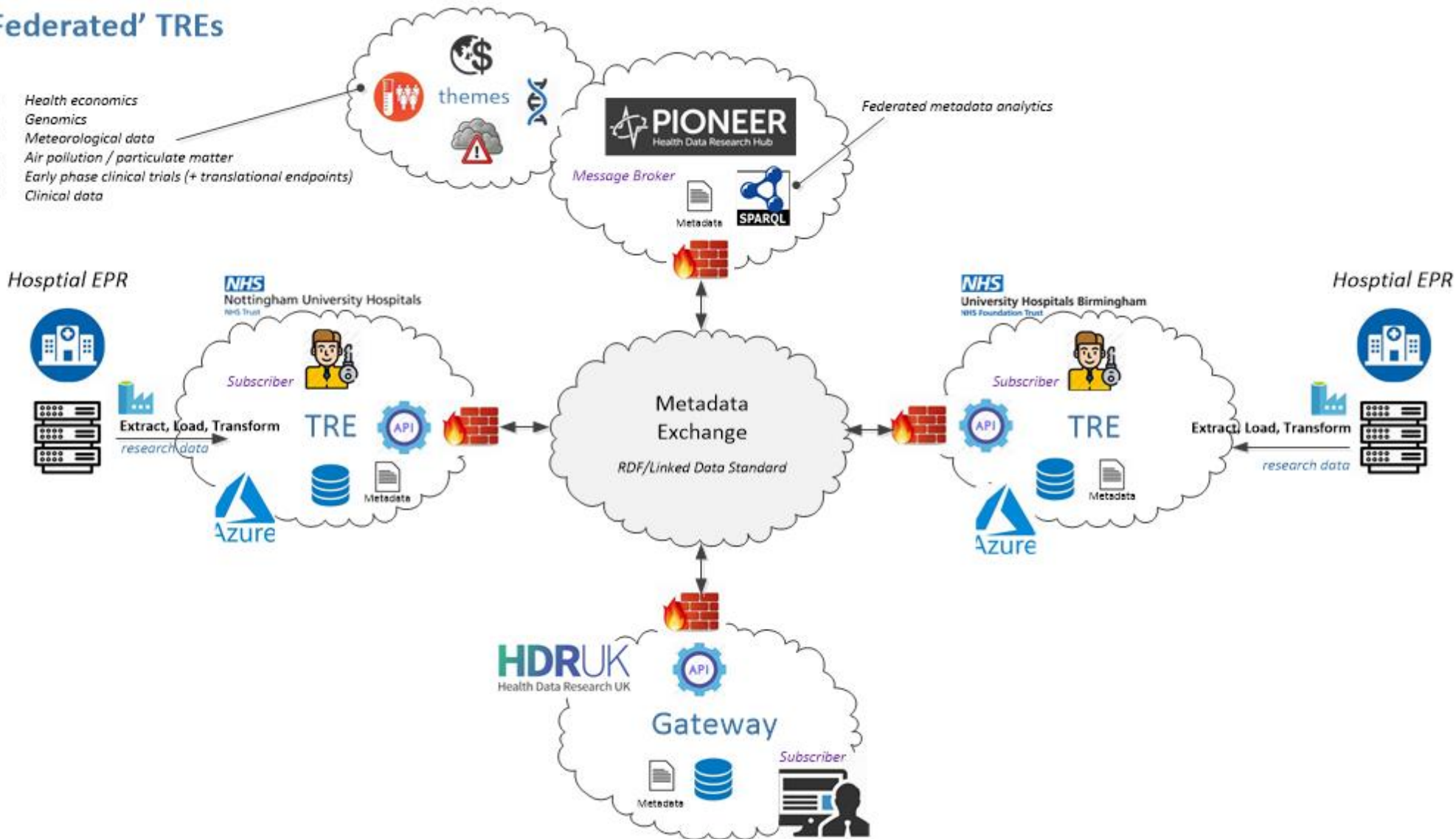
A system which is **resilient, fit for purpose** and **affordable**

PROJECT TIMELINES



'Federated' TREs

- Health economics
- Genomics
- Meteorological data
- Air pollution / particulate matter
- Early phase clinical trials (+ translational endpoints)
- Clinical data





PIONEER UHB Technical team have produced synthetic data for FED-NET, which will be staged in TRES.



20,000

Synthetic acute care episodes for Asthma

ICD-10 codes and SNOWMED codes for Asthma.

Synthesised on 4 hospital Emergency Department data from 2018 onwards.

Created using approx. 11K real presentations.

Representative



42.1%

Simulated non-white population



37.7%

Simulated <15 years in age

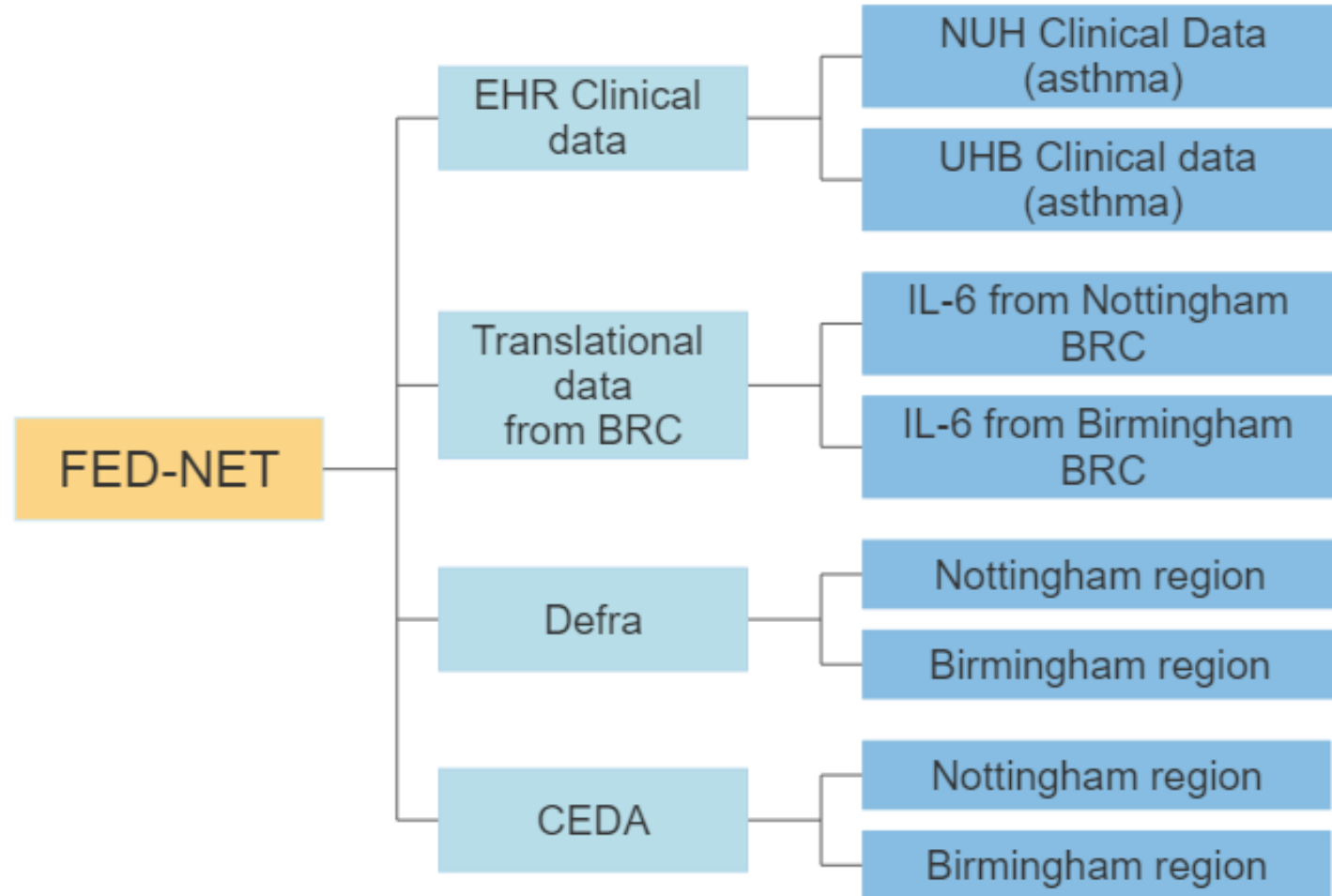


66.8%

Simulated obese patients

Data fields available

- Demographic data
- Medications
- Observations
- Lung function



By end of phase 1, will have loaded real data and performed initial analysis using a federated system tested on synthetic data.

WP2 DATA MODEL (*REAL-WORLD*)

 INTRODUCTION

 WP1 & WP3
TECHNICAL

 WP2
DATA MODEL

 WP4
FEDERATION

 WP5
GOVERNANCE

 WP6
PPIE

 SUMMARY



SAFE DATA

Process is being tested with synthetic data before any real world health data is used.

PRO



AZURE TREs

System is being tested on 2 different Azure TRE blueprints, using system agnostic process. Need to test on Google/AWS.

CON



OMOP vs NATIVE

Explore the limitations for initial datasets of using common data models vs native language

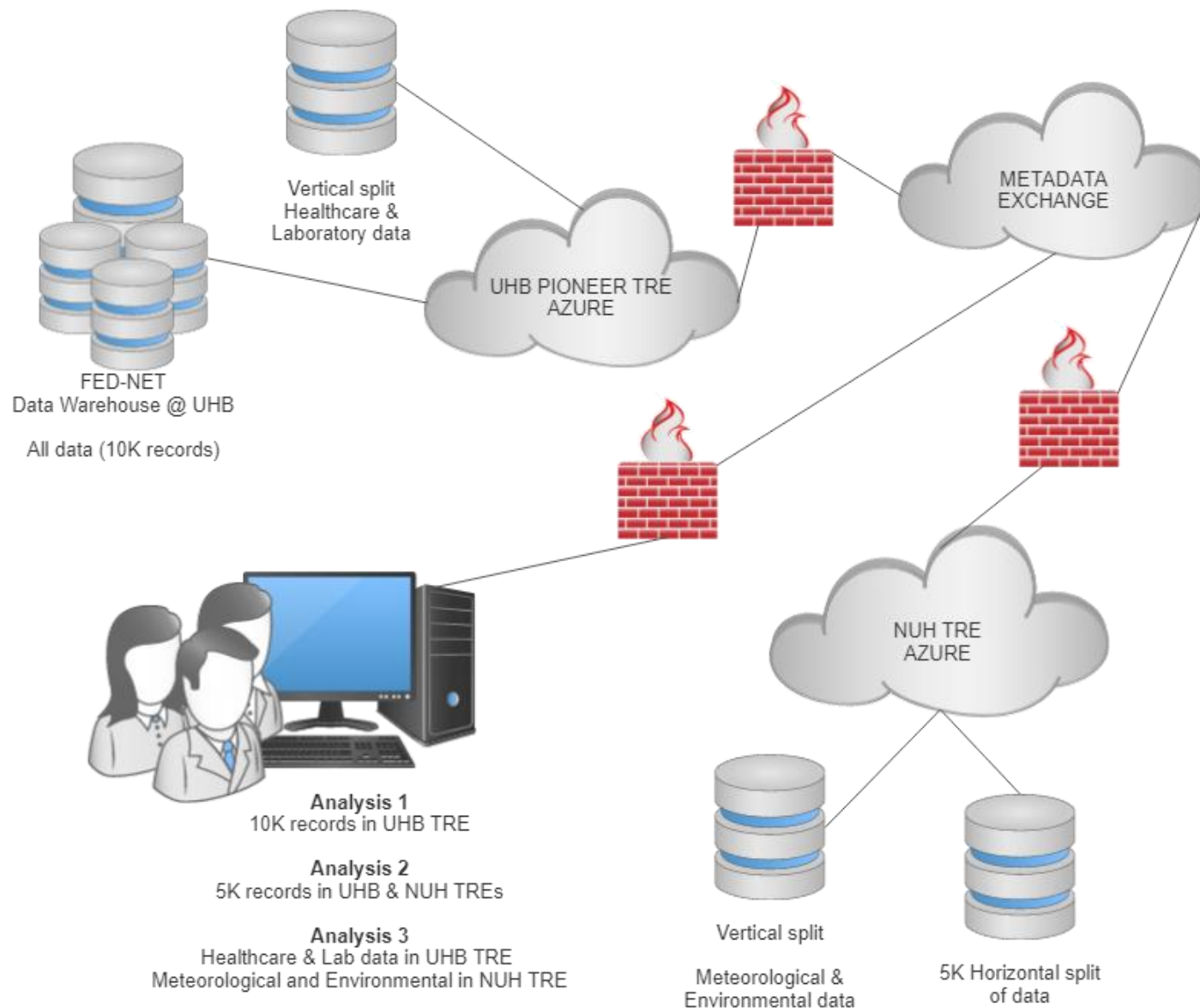
PRO



BLUEPRINTS

Creates blueprints and code for federated TREs as well as regional asthma initiative for expansion across region.

PRO



Data Controllers share data assets (acute asthma presentations) in this use case.

MetaData services perform the following functions:

- Encrypted metadata created
- Validates new data packages
- Registers new members
- Collates and federates metadata
- Persists new analytics
- Collate and federate analytics

Visualisation and analytics using SPARQL.

WP5 GOVERNANCE & ETHICS

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 SUMMARY

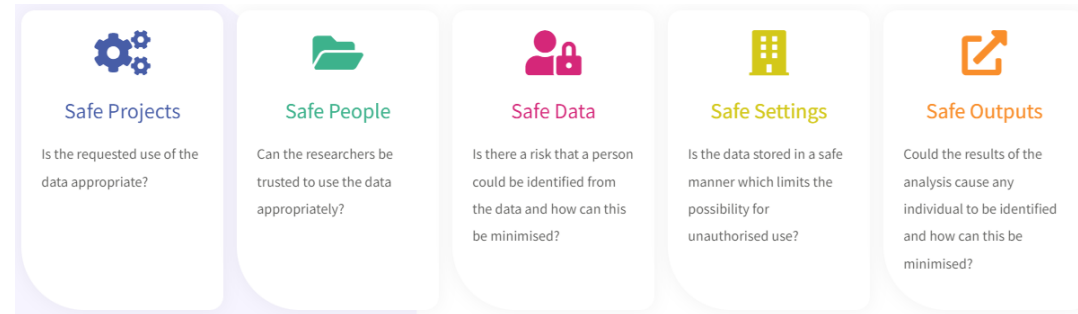
PROCESS

Building on **existing** and **proven governance process**.

PIONEER has HRA and Section 251 for data access.



Aligns with the Five Safes Framework



- 1 > Same structure but a joint data controller model between UHB and NUH
- 2 > Federated analytics should make governance easier once established
- 3 > Increases agility to service requests

BUILDING FROM OUR SUCCESSFUL DATA TRUST COMMITTEE

All data sharing decisions are overseen by our patient and public oversight group.



17 to >75
years in age

40% BAME
representation

2x

Workshops with patients and public and series of working groups

1x

Planned webinar with patients and public

Discussions included:

- Benefits and challenges for federated analytics
- What this might mean for less digitally mature health systems

Inclusive outputs:

- Recorded content
- Transcriptions
- Large print
- Commonly written languages



WORLD-CLASS ALLIANCE PARTNERS

GLOBAL LEADERS IN DIGITAL HEALTH

Integrated expertise of industry, NHS, academics, charities and patient partners for **transformative real-world outcomes**.

Strong Patient and Public involvement and engagement to **shape direction** and ensure **transparency** throughout the programme



Blueprint

Producing blueprints and code for sharing

Phenotyped

The cross-council, deeply-phenotyped data asset will expand

Interoperability

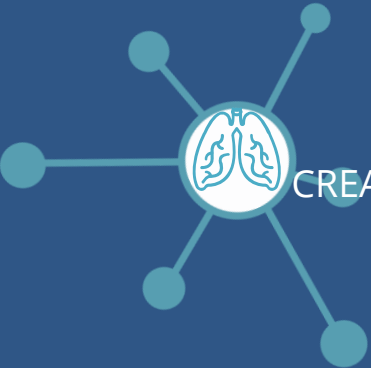
Comparing OMOP vs native language

Framework

Output will produce framework for regional/national initiatives

Governance

Publicly co-produced governance framework and templates for sharing



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Thank You

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