DARE UK

From capability to research: Meet the DARE UK Real-world Research Exemplars

Najmeh Modarres, Programme Manager

14 May 2026

UK Research and Innovation

HDRUK Health Data Research UK

ADR UK Data-driven change

DARE UK

Sensitive data: affecting people, communities, and populations…

Data linkage: safely connecting sensitive data to benefit people, communities and populations…

Vision

For all research and innovation to benefit from seamless, secure use of diverse sensitive data, at a pace, efficiency and scale approaching that of the open data ecosystem, that revolutionises research productivity and accelerates research to deliver public good

Mission

To put the UK at the forefront of sensitive data research and innovation by assembling the tools, technologies and standards needed to streamline secure data linkage and use

DARE UK

FUNDED BY

UK Research and Innovation (UKRI) – the UK's largest public funder of data and research innovation – through the UKRI Digital Research Infrastructure programme.

UK Research and Innovation

DELIVERED BY

Health Data Research UK (HDR UK) and Administrative Data Research UK (ADR UK).

HDRUK Health Data Research UK

ADRUK Data-driven change

Vision

For all research and innovation to benefit from seamless, secure use of diverse sensitive data, at a pace, efficiency and scale approaching that of the open data ecosystem, that revolutionises research productivity and accelerates research to deliver public good

Mission

To put the UK at the forefront of sensitive data research and innovation by assembling the tools, technologies and standards needed to streamline secure data linkage and use

DARE UK

Phase 1:
Design & Dialogue

July ’21 – March ‘24

£7.5m

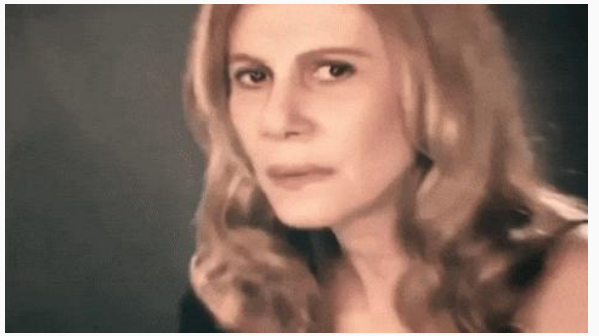
Phase 2:
Build, Test & Establish

August ’24 – March ‘27

£20.0m

Phase 3:
Deliver, Optimise & Federate

TBC



Phase 2

DARE UK

TREvolution
A DARE UK PROJECT

Partners
Build | Develop

DARE UK
EARLY ADOPTERS

TREs / SDEs
Test | Configure | Adopt

DARE UK
RESEARCH EXEMPLARS

Researchers
Do science | Deliver impact

DARE UK
COMMUNITY GROUPS

Community
Sharing | Best practice | Open science

DARE UK
INNOVATORS

Innovators
Test | Proof-of-concept | Pilot

Our Data
Our Say

Public
Involvement | Engagement

UK Research and Innovation

HDRUK
Health Data Research UK

ADRUK
Data-driven change

Phase 2

DARE UK

TREvolution
A DARE UK PROJECT

Partners
Build | Develop

DARE UK
EARLY ADOPTERS

TREs / SDEs
Test | Configure | Adopt

DARE UK
RESEARCH EXEMPLARS

Researchers
Do science | Deliver impact

DARE UK
COMMUNITY GROUPS

Community
Sharing | Best practice | Open science

DARE UK
INNOVATORS

Innovators
Test | Proof-of-concept | Pilot

Our Data
Our Say

Public
Involvement | Engagement

UK Research and Innovation

HDRUK
Health Data Research UK

ADRUK
Data-driven change

Phase 2

TREvolution
A DARE UK PROJECT

Partners
Build | Develop

DARE UK
EARLY ADOPTERS

TREs / SDEs
Test | Configure | Adopt

DARE UK
RESEARCH EXEMPLARS

Researchers
Do science | Deliver impact

DARE UK
COMMUNITY GROUPS

Community
Sharing | Best practice | Open science

DARE UK
INNOVATORS

Innovators
Test | Proof-of-concept | Pilot

Our Data
Our Say

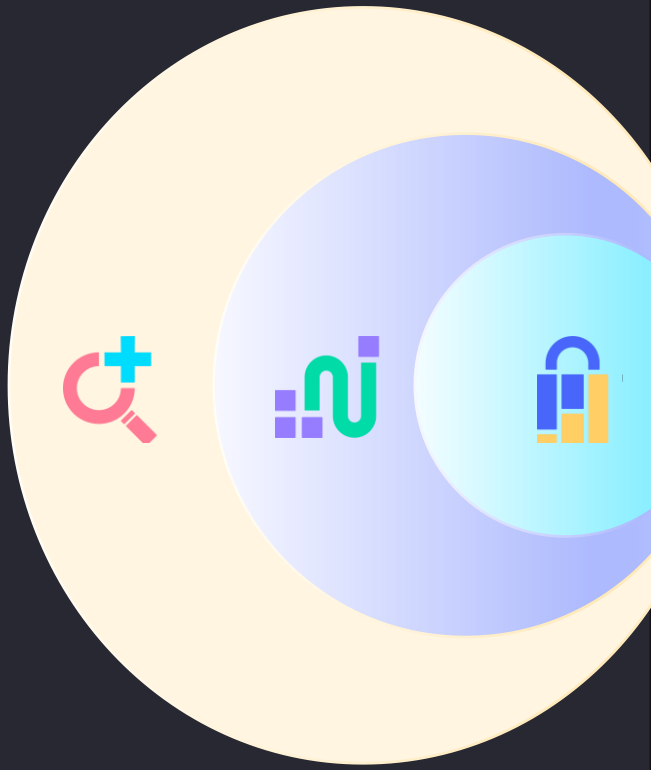
Public
Involvement | Engagement

UK Research and Innovation

HDRUK
Health Data Research UK

ADRUK
Data-driven change

DARE UK



Phase 2

TREvolution
A DARE UK PROJECT

Partners
Build | Develop

DARE UK
EARLY ADOPTERS

TREs / SDEs
Test | Configure | Adopt

DARE UK
RESEARCH EXEMPLARS

Researchers
Do science | Deliver impact

DARE UK
COMMUNITY GROUPS

Community
Sharing | Best practice | Open science

DARE UK
INNOVATORS

Innovators
Test | Proof-of-concept | Pilot

Our Data
Our Say

Public
Involvement | Engagement

UK Research and Innovation

HDRUK
Health Data Research UK

ADRUK
Data-driven change

DARE UK

Phase 2

TREvolution
A DARE UK PROJECT

Partners
Build | Develop

DARE UK
EARLY ADOPTERS

TREs / SDEs
Test | Configure | Adopt

DARE UK
RESEARCH EXEMPLARS

Researchers
Do science | Deliver impact

DARE UK
COMMUNITY GROUPS

Community
Sharing | Best practice | Open science

DARE UK
INNOVATORS

Innovators
Test | Proof-of-concept | Pilot

Our Data
Our Say

Public
Involvement | Engagement

UK Research and Innovation

HDRUK
Health Data Research UK

ADRUK
Data-driven change

DARE UK

Phase 2

TREvolution
A DARE UK PROJECT

Partners
Build | Develop

DARE UK
EARLY ADOPTERS

TREs / SDEs
Test | Configure | Adopt

DARE UK
RESEARCH EXEMPLARS

Researchers
Do science | Deliver impact

DARE UK
COMMUNITY GROUPS

Community
Sharing | Best practice | Open science

DARE UK
INNOVATORS

Innovators
Test | Proof-of-concept | Pilot

Our Data
Our Say

Public
Involvement | Engagement

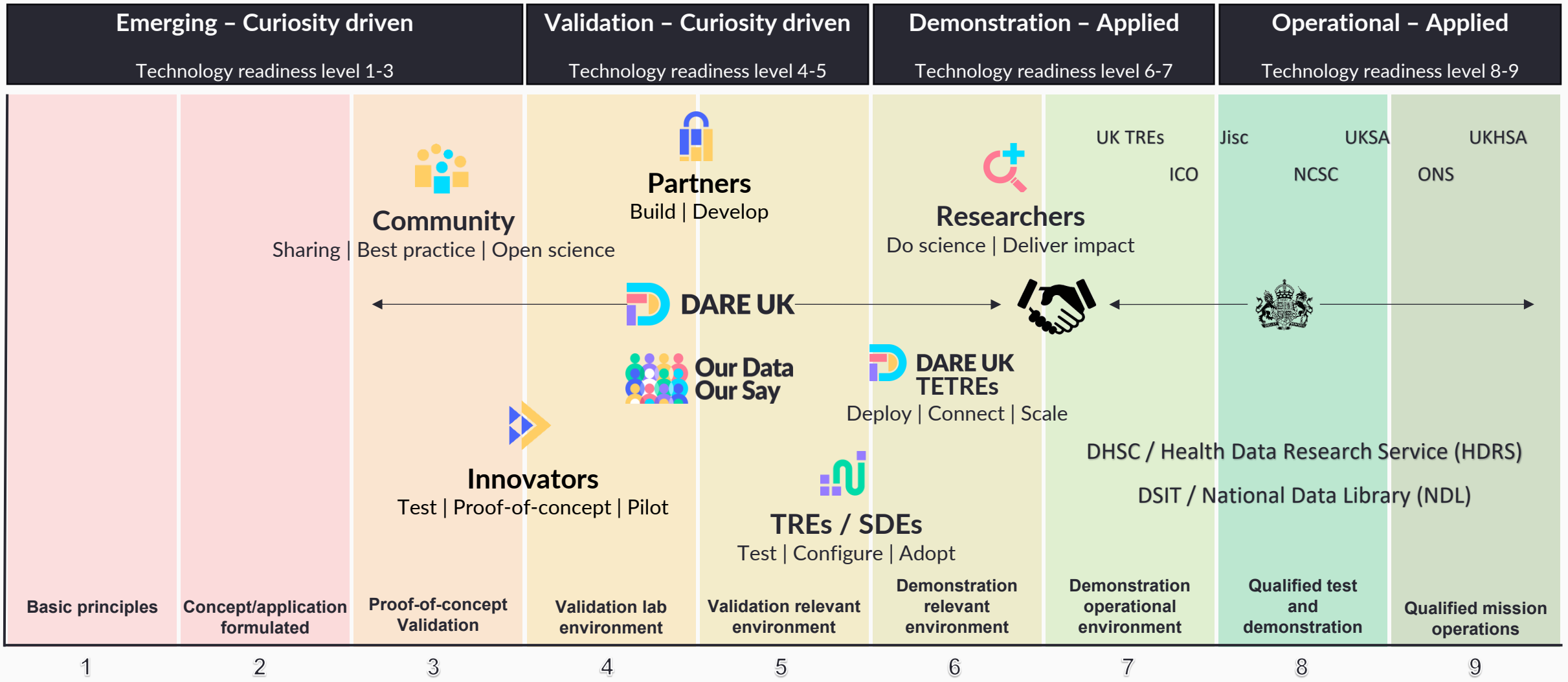
UK Research and Innovation

HDRUK
Health Data Research UK

ADRUK
Data-driven change

DARE UK

DARE UK


Emerging – Curiosity driven
Technology readiness level 1-3
Validation – Curiosity driven
Technology readiness level 4-5
Demonstration – Applied
Technology readiness level 6-7
Operational – Applied
Technology readiness level 8-9
Community
Sharing | Best practice | Open science
Partners
Build | Develop
Researchers
Do science | Deliver impact
UK TREs
Jisc
UKSA
UKHSA
ICO
NCSC
ONS
DARE UK
Our Data Our Say
DARE UK TETREs
Deploy | Connect | Scale
Innovators
Test | Proof-of-concept | Pilot
TREs / SDEs
Test | Configure | Adopt
DHSC / Health Data Research Service (HDRS)
DSIT / National Data Library (NDL)
Basic principles
Concept/application formulated
Proof-of-concept Validation
Validation lab environment
Validation relevant environment
Demonstration relevant environment
Demonstration operational environment
Qualified test and demonstration
Qualified mission operations
1
2
3
4
5
6
7
8
9

Real-World Exemplars (Mar 2026 – Mar 2027)

- AIRR-BRIDGE: Bridging Research Infrastructure for Data Governance Extension on AIRR
  - **The Alan Turing Institute**, King's College Hospital NHS FT, UCL, University of Bristol, University of Cambridge, UK Biobank
- BRAID: Brain Frailty Integrated through Data Federation
  - **University of Nottingham**, Nottingham University Hospitals NHS FT, Dementias Platform UK (DPUK)
- CONNECT-AF: Cross-TRE Network for Evaluating Clinical Outcomes and National Trends in Embolic Complications of Atrial Fibrillation
  - **Swansea University**, SAIL Databank, Eastern England SDE, DPUK
- FRAME: Federated Research on Anti-hypertensives Maternity Emulation Trial
  - **Swansea University**, SeRP, CPRD, King's College Hospital NHS FT, Guys and St Thomas NHS FT, University of Edinburgh, University of Birmingham, SAIL Databank
- HEAL-Scot: Housing, Environment and Location Data Linkage in Federated TREs to Map Geospatial Inequalities
  - **University of Edinburgh**, DataLoch, Health Informatics Centre
- MELODY: Federated Machine Learning for Dermatology
  - **University of Dundee**, Health Informatics Centre (HIC), Thames Valley and Surrey SDE, NHS Tayside, Oxford University Hospitals NHS FT
- SAFEVID: Spasms Analysis using Federated Learning from Videos Across Multiple TREs
  - **University of Glasgow**, Health Informatics Centre, West of Scotland Innovation Hub
- TransPECT: Securing AI NLP-Transformer Models for Safe Release in TREs
  - **University of Edinburgh**, DataLoch, Health Informatics Centre, King's College London, Public Health Scotland

DARE UK

Now to introduce the DARE UK Real-world Research Exemplars….

UK Research and Innovation

HDRUK Health Data Research UK

ADR UK Data-driven change

Stay in touch!

DARE UK

Visit our website

SCAN ME

Subscribe to our newsletter

SCAN ME

Follow us on LinkedIn

SCAN ME

Follow us on X (Formerly Twitter)

SCAN ME

UK Research and Innovation

HDRUK Health Data Research UK

ADRUK Data-driven change

TransPECT
A DARE UK PROJECT

Beyond the Airlock: TransPECT, Securing AI NLP-Transformer Models for Safe Release in TREs

Arlene Casey, University of Edinburgh, PI
Richard Walls, University of Dundee, Co-I
Pasquale Minervini, University of Edinburgh, Co-I
Stuart Dunbar, DataLoch (University of Edinburgh / NHS Lothian), PIE Lead

THE UNIVERSITY of EDINBURGH
DataLoch
UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change
Health Informatics Centre
Public Health Scotland
KING'S College LONDON

TransPECT
A DARE UK PROJECT

Project Team

Arlene Casey,
NLP Programme Lead,
DataLoch

Pasquale Minervini,
NLP Lecturer,
School of Informatics

Richard Walls,
Operational Director,
Health Informatics Centre

Alba Crespi Boixader,
Health Data Scientist,
Health Informatics Centre

Judit Kuti,
Data Analyst,
DataLoch

Franz Gruber,
Data Analyst,
DataLoch

John McCullough,
Public Contributor

C,
Public Contributor

Stuart Dunbar,
Engagement Manager,
DataLoch

Fahrurrozi Rahman,
NLP Research Fellow,
DataLoch

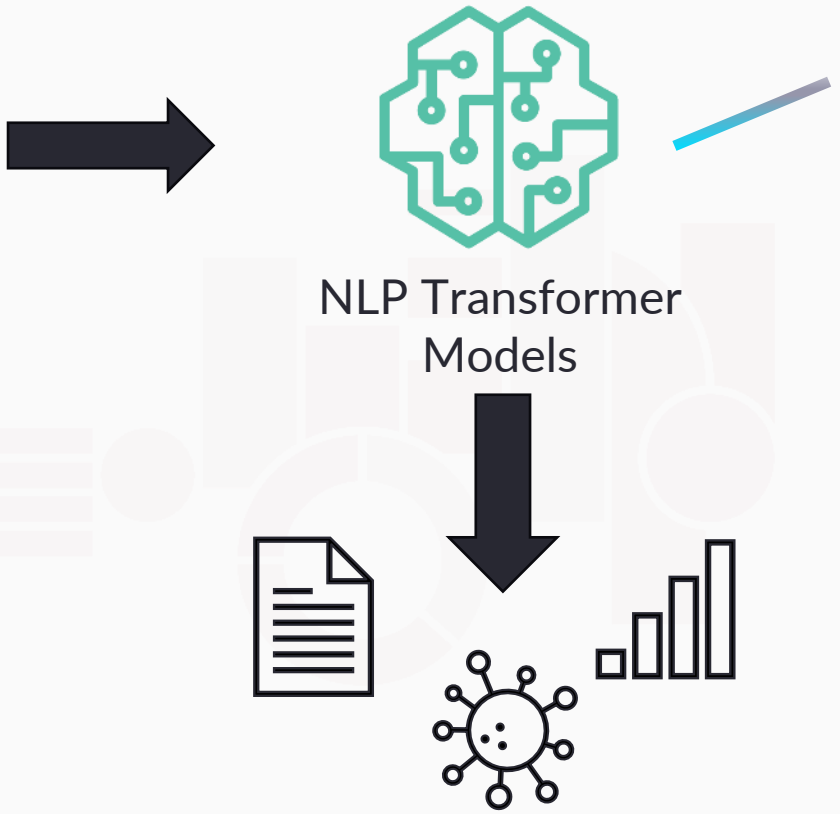
Simba Doka,
Administrator,
University of Edinburgh

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change
Health Informatics Centre
THE UNIVERSITY of EDINBURGH
DataLoch

Natural Language Processing (NLP) Transformer Models – Opportunities

Sally lives alone in a 2-floor detached – skipping diuretic to avoid climbing stairs to bathroom at night. She has forgotten to take BP readings due to tiredness in evenings. Changed medications timing and referred for home health support.

Sensitive free-text data holds rich narratives about people



e.g. ChatGPT

Uses such as Clinical Summaries, Disease Detection, extracting key information

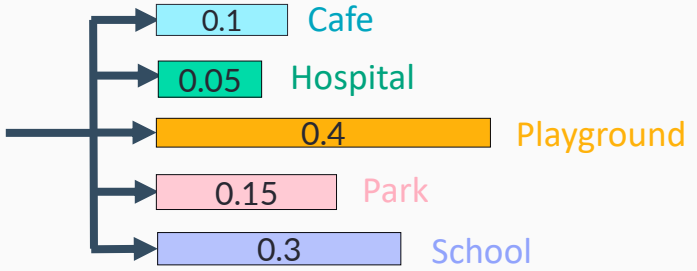
Natural Language Processing (NLP) Transformer Models

NLP Transformer Models for text

The girl went to the

Previous words (tokens) provide context

Learns patterns of how words appear together

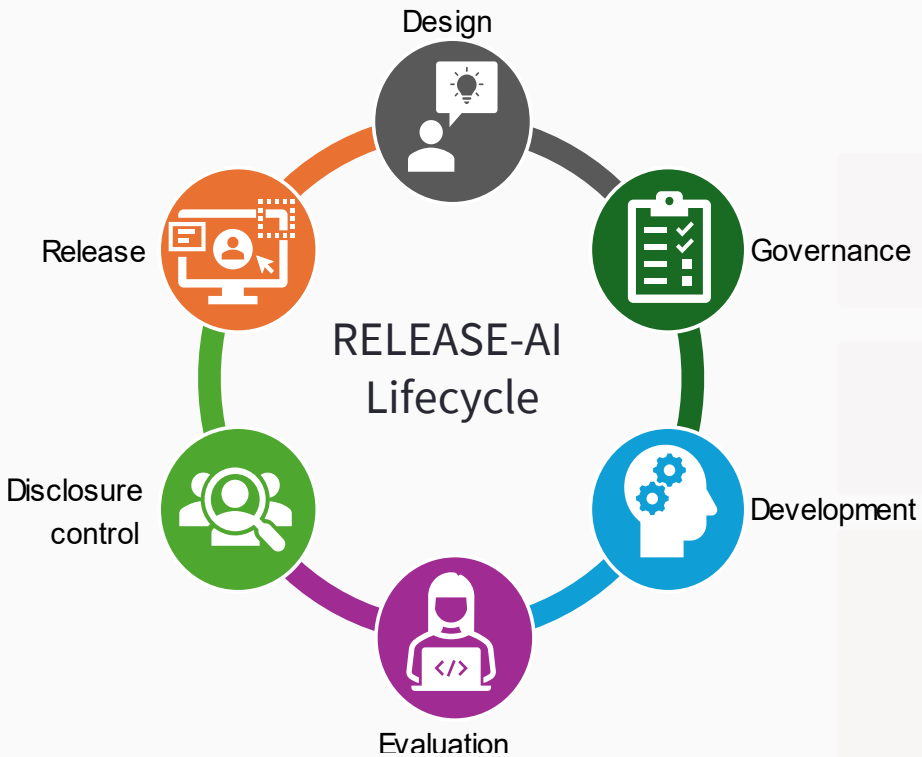


Words being predicted

Challenge: What makes models powerful also means they can memorise tokens and reproduce small fragments of text which can lead to privacy leakage

Sensitive data is de-identified and we have the 5 Safe Frameworks but disclosure control at the safe outputs is not designed for assessing NLP Transformer models

Integration with TREvolution



Our Goals:

Measuring and understanding risks and mitigations for NLP Transformer Models:

- Support TRE governance teams to make proportionate disclosure decisions
- Provide tools to support disclosure risks
- Help researchers design models in safer ways

Working with SACRO element: Building on gaps identified and aligning to existing tools and frameworks

TransPECT : Work Packages & Deliverables

TransPECT
A DARE UK PROJECT

WP1

- Embed public and stakeholder involvement and governance throughout the project, (4 public members)
- Public tested communications and policy-ready guidance mapped directly to existing frameworks in use within the TRE community

Understanding & Measuring Risks

Mitigations & Tools

WP2: Systematically measure data leakage giving evidence on privacy risks using UK-based sensitive free text

WP3: Test mitigation strategies in exemplar cases, and develop tools for SACRO-ML and approaches for disclosure checking

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change
Health Informatics Centre
THE UNIVERSITY of EDINBURGH
DataLoch

TransPECT
A DARE UK PROJECT

Thank You

Visit the project webpage

SCAN ME

UK Research and Innovation

HDRUK
Health Data Research UK

ADR UK
Data-driven change

Health Informatics Centre

THE UNIVERSITY of EDINBURGH

DataLoch

BRAID

A DARE UK PROJECT

Brain Frailty Integrated through Data Federation

UK Research and Innovation

HDRUK Health Data Research UK

ADR UK Data-driven change

Characterising Brain Health is Challenging

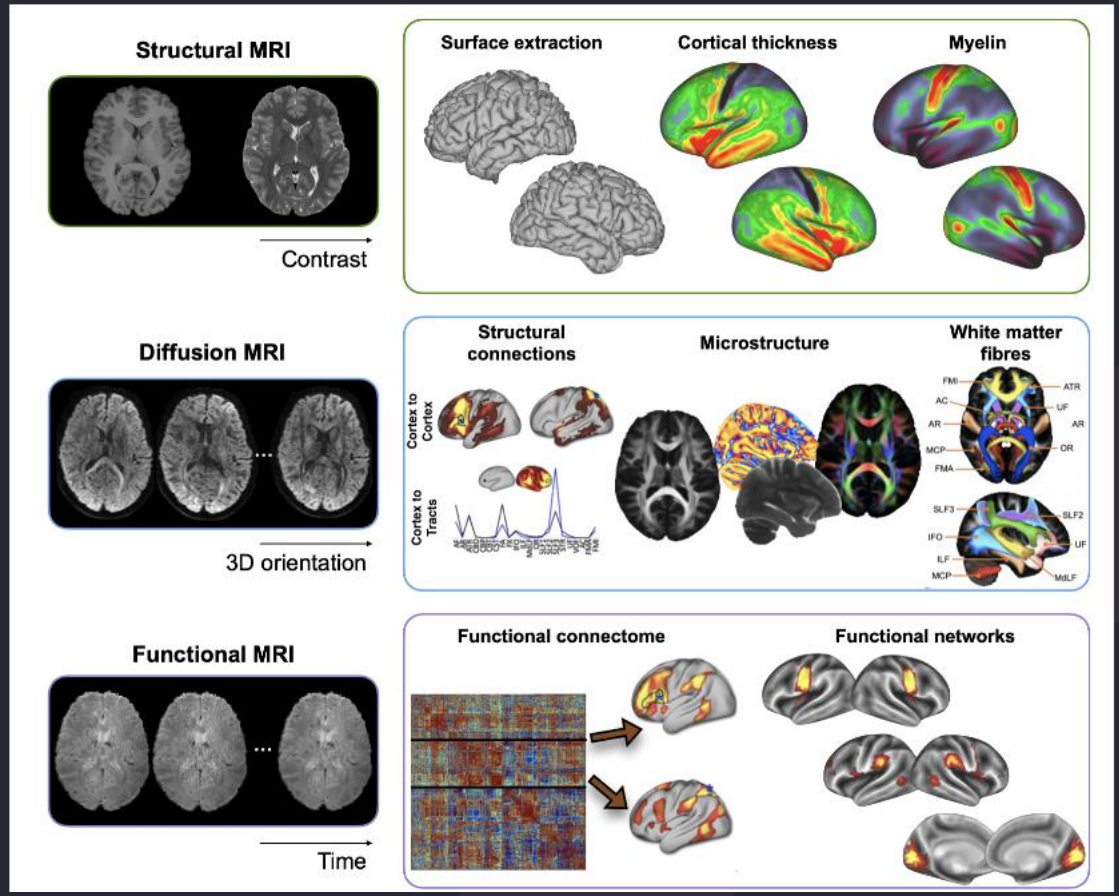
Large scale image analytics provide unique ways to do identify markers and individual phenotypes

Severely limited by:

- Inconsistent data recording
- Accessing data
- Poor data sharing
- Disconnected analytics

<u>Consequence:</u>

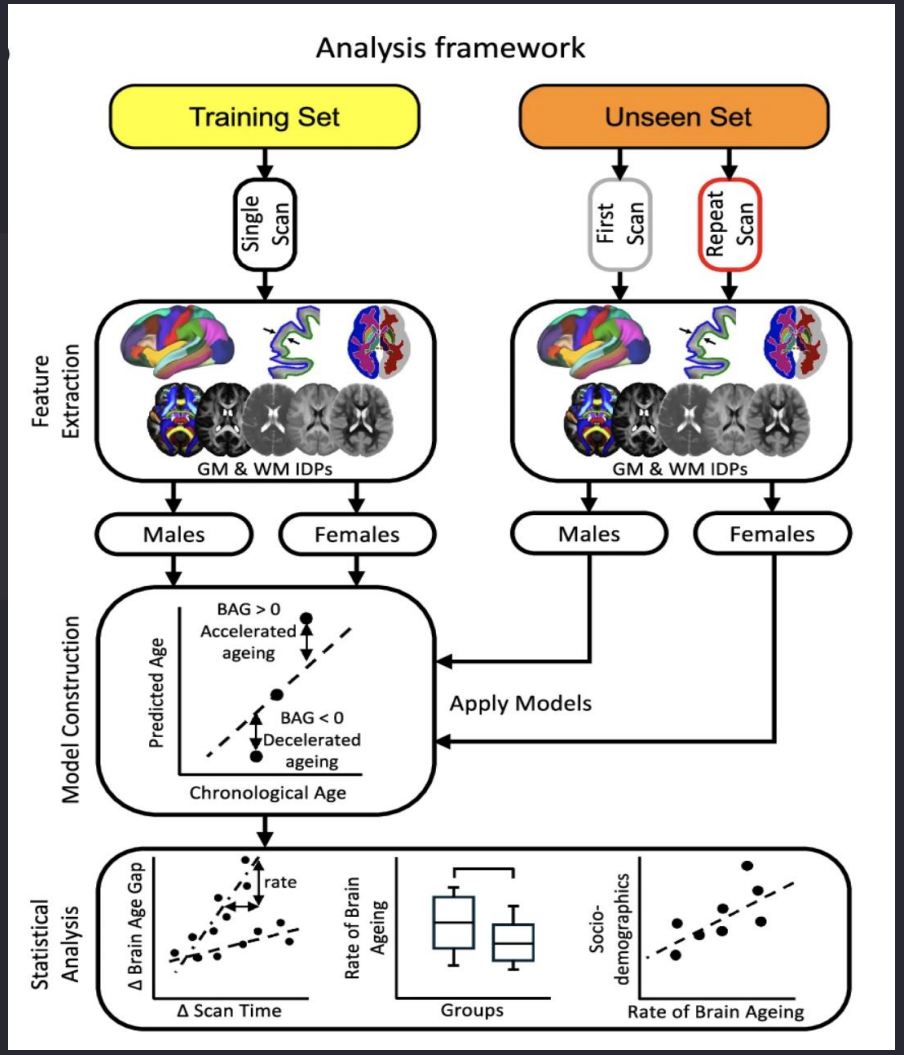
Not easy to translate research & scientific advances into clinic for **patient benefit**



Miller et al, Nature Neuroscience 2016
Alfaro-Almagro et al, Neuroimage 2018

Case Study: Brain Frailty

- Wear and tear of the brain, making it less able to cope with stress
- Imaging characterisation show early signs of brain frailty
- Combining brain scan with routine health data help predict outcomes and define treatment
- Our team has developed relevant analytics
- Data access and scalability for clinical translation remains a challenge
- DARE-TREvolution can help address that



Mohammadi-Nejad et al, Nature Comms 2025

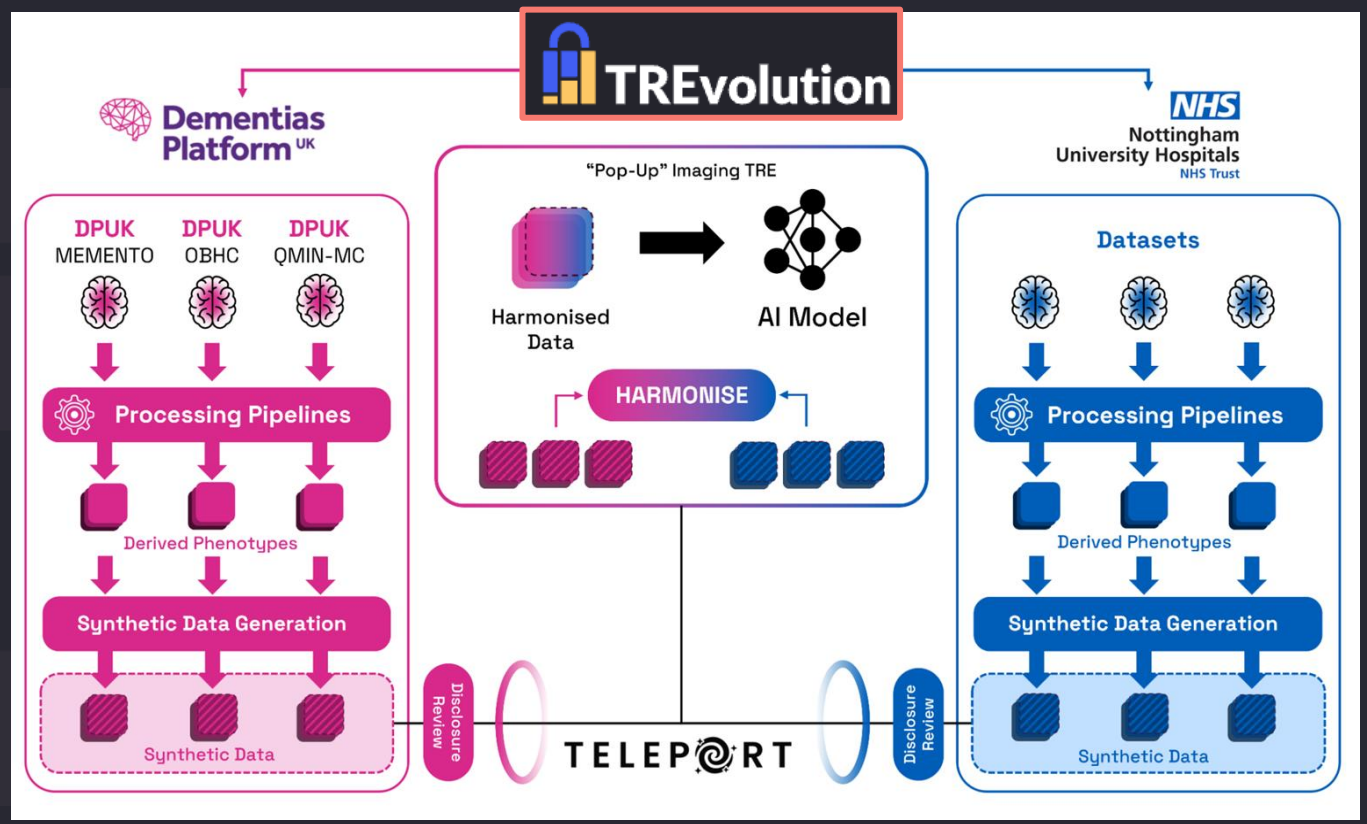
Project Goals

Support federated neuroimaging and multimodal analytics in TREVolution

Advance large scale, privacy-preserving research on brain health

Evaluate and contribute to **TREvolution**:

- **Infrastructure readiness**
- **Disclosure control**
- **Public and patient perspectives on** technology stack, reliability, security and patient data



Team


Grazziela Figueredo


Stam Sotiropoulos


Xin Chen


Dorothee Auer


Rob Dineen


Andy Rae


Emma Squires


Lewis Hotchkiss


Richard Preen


Claire Newman

Machine learning

Image analysis

Brain imaging

Synthetic data generation

Disclosure control

Clinician & product owner

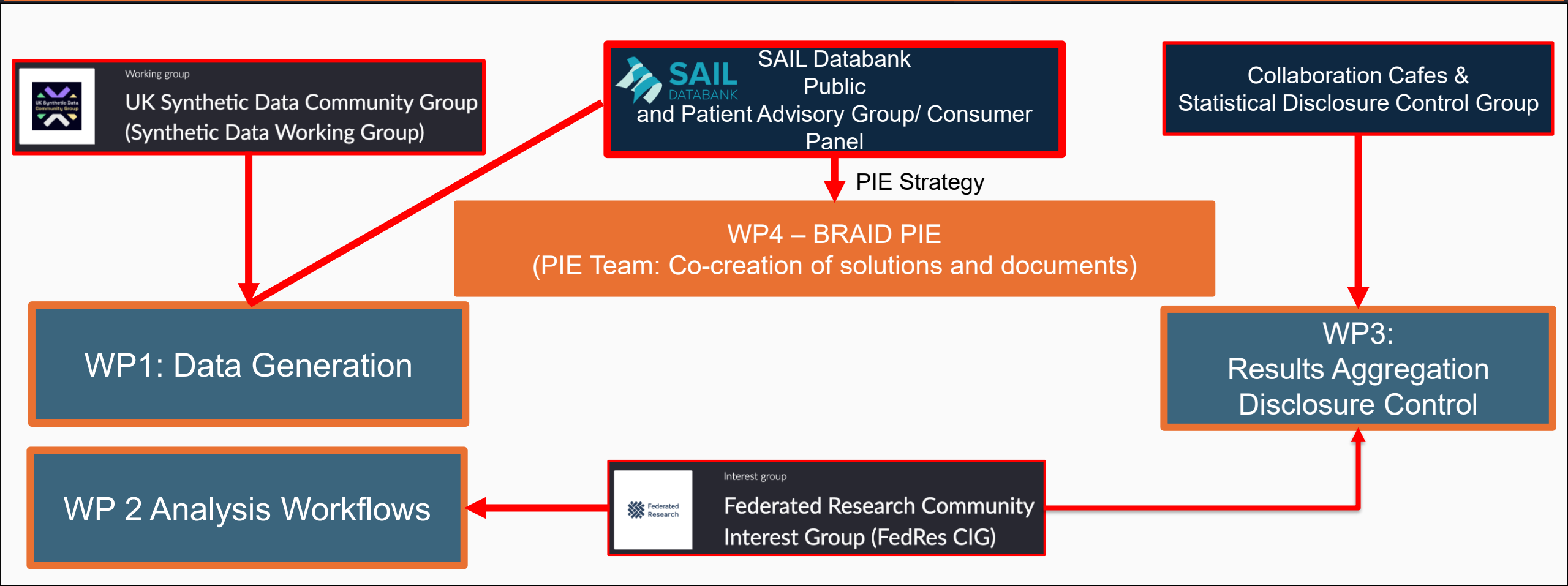
PIE specialist

TRE provider

TREvolution

PIE Activities

Aim: Co-design technical methodologies with members of the public.
Diverse PIE groups participating in each stage of the project



BRAID
A DARE UK PROJECT

Project Contributions and Patient Benefit

- Enabling federated analysis of large-scale multimodal neuro-imaging data
- Improvement & feedback to TREvolution
- TRE-compatible FAIR analytics for brain data for a range of neurological and psychiatric disorders
- Foundations for phenotyping and precision imaging
- **Application to real-world data from NUH TRE node**

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

Stay in Touch

Visit our website

SCAN ME

Thank you and stay in touch

BRAID
A DARE UK PROJECT

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

CONNECT-AF

A DARE UK PROJECT

Cross-TRE Network for Evaluating Clinical Outcomes and National Trends in Embolic Complications of Atrial Fibrillation

14/05/26

UK Research and Innovation

HDRUK Health Data Research UK

ADR UK Data-driven change

CONNECT-AF
A DARE UK PROJECT

Our Team

Dr. Fatemeh Torabi

Project Lead

Assistant Professor of Healthcare Data Science
& Senior Researcher

Prof. Ashley Akbari

SAIL co-lead

Professor of population data science and Head of SAIL User and Data Support Services

Laura Clarks

Eastern SDE co-lead

Senior Product Manager for Eastern England Secure Data Environment

Mark Avery

Eastern SDE co-lead

Director of Health Informatics for Cambridge University Health Partners

Prof. Michael Gravenor

Analytics co-lead

Professor of Biostatistics and Epidemiology and head of institute

Emma Squires

DPUK co-lead

COO of DPUK Data portal and Head of Programmes and Innovation for SeRP

Chris Orton

UK SeRP co-lead

Head of Business Development for SeRP and SAIL, Technical Lead for Population Research UK, and Technical Lead for HDR UK Inflammation and Immunity

Jillian Beggs

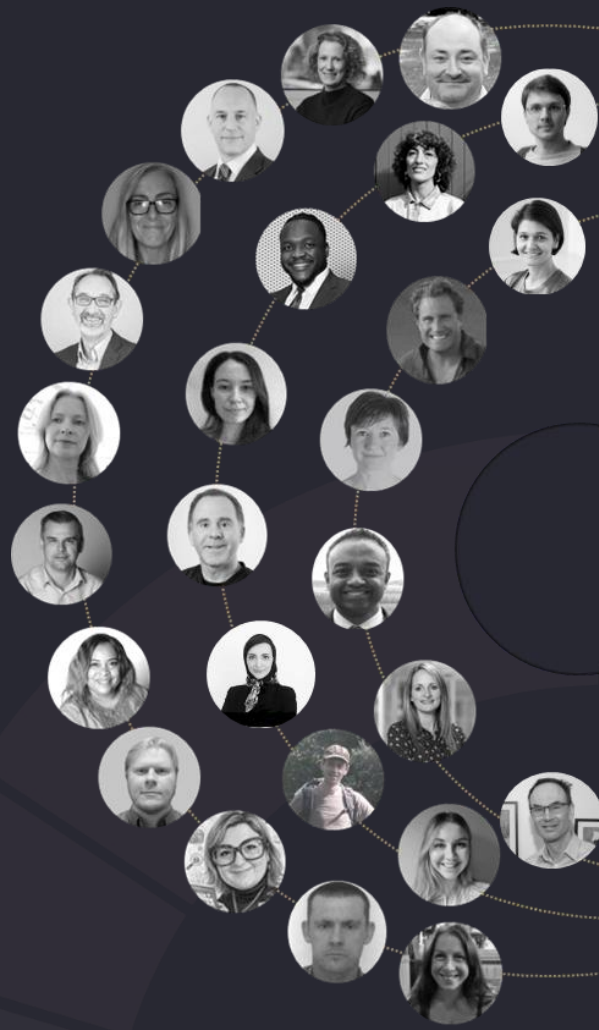
PPIE Co-lead

Expert PPIE research advisor

Antony Chuter

PPIE Co-lead

Expert PPIE research advisor



UK Research and Innovation

HDRUK Health Data Research UK

ADR UK Data-driven change

Background and importance of this research topic

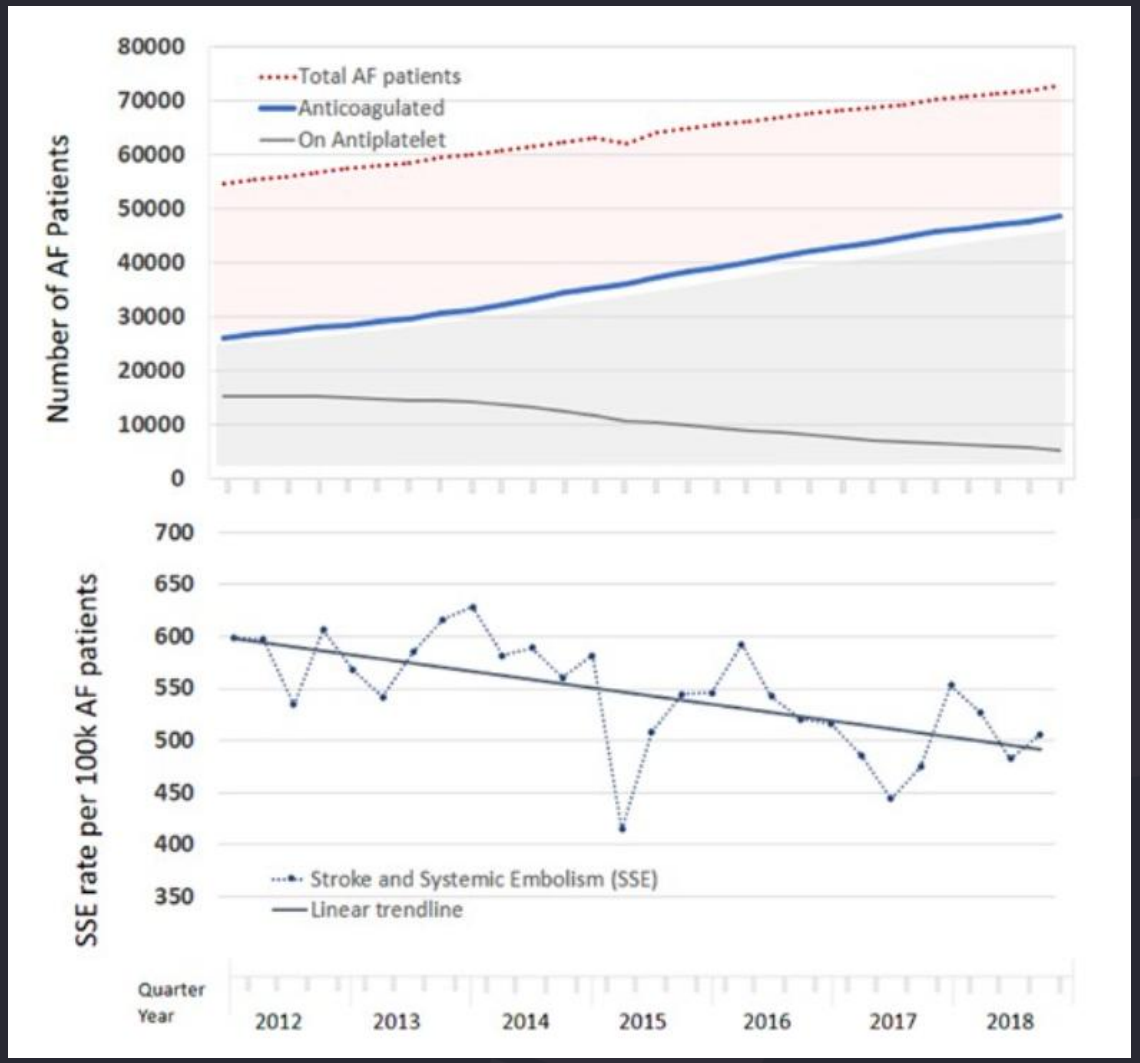
Atrial Fibrillation (AF) is the most common heart rhythm disorder.

1.5 million people in the UK

it increases the risk of stroke by 5 to 7 folds and the risk of dementia by 2 folds.

We can manage these known risks

Anticoagulant medication significantly reduces the risk of stroke in AF patients by two-third (~66%).



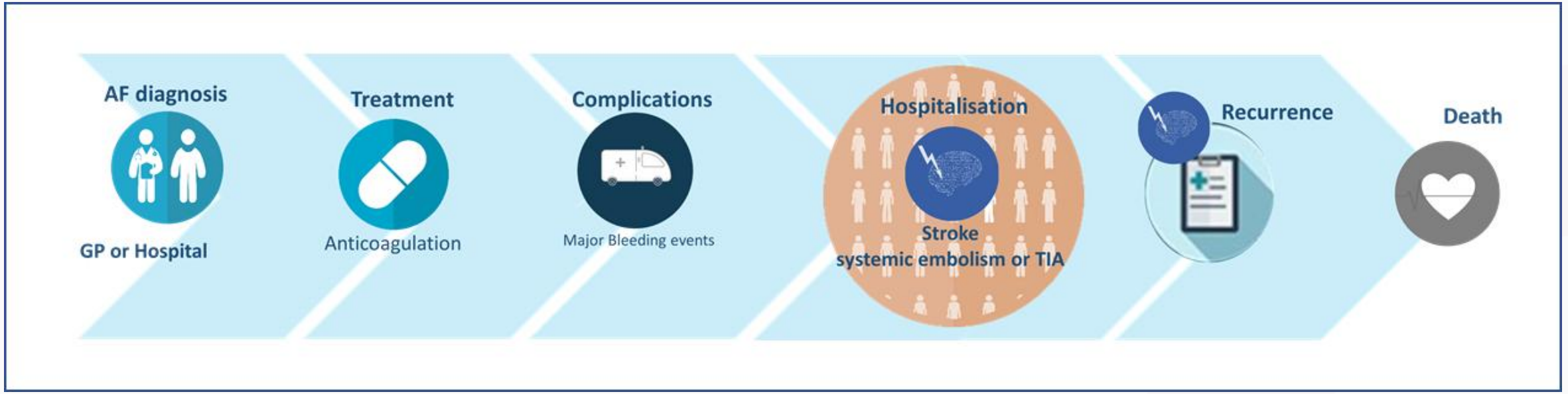
Torabi & Harris et al. 2022

AF patient pathways

Entire pathway

Secondary care

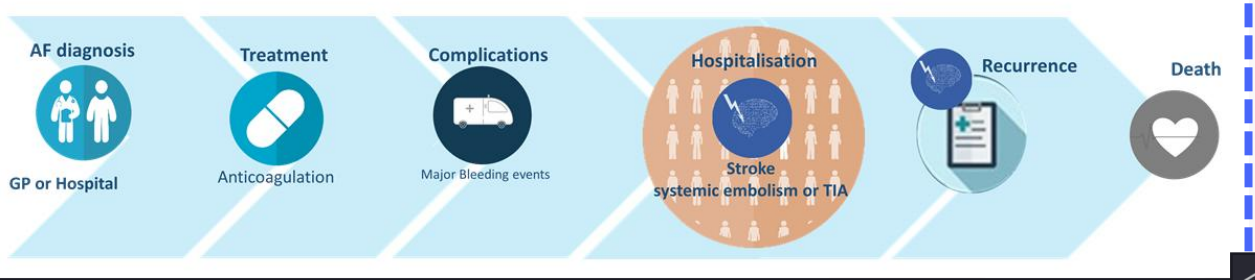
Self-reported outcomes



WP1 – Scientific: quantify and compare hospitalisation rates for stroke, systemic embolism and Transient Ischaemic Attach among AF patients across Wales and the Eastern SDE

CONNECT-AF
A DARE UK PROJECT

AF pathway in base layer



AF-Wales

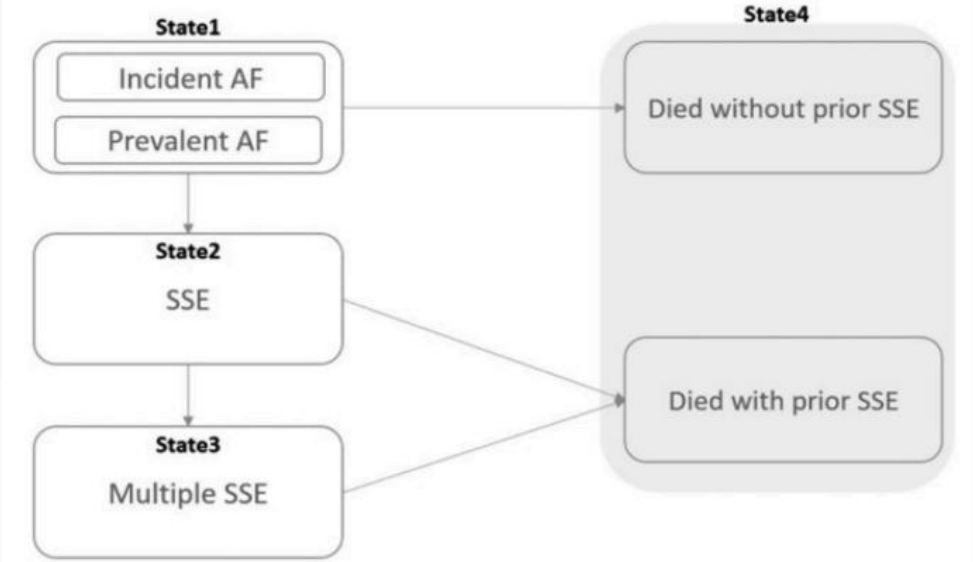
AF-ESDE

Self-reported outcomes

UKSeRP
(TRE-FX)

SeRP

Federated analytics: Multi-state modelling of AF care

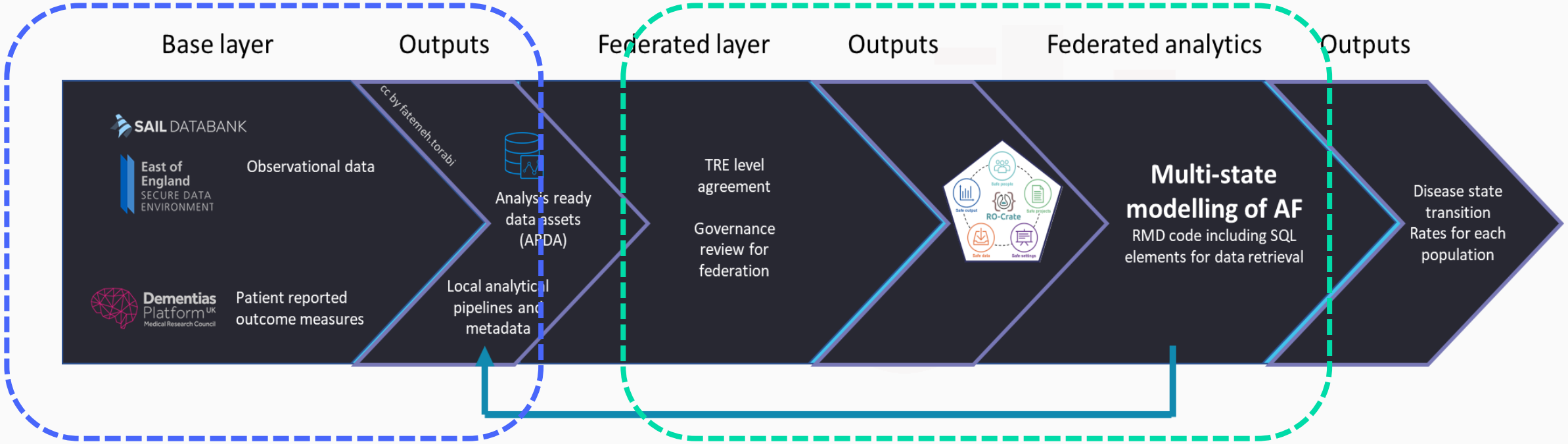


UK Research and Innovation

HDRUK Health Data Research UK

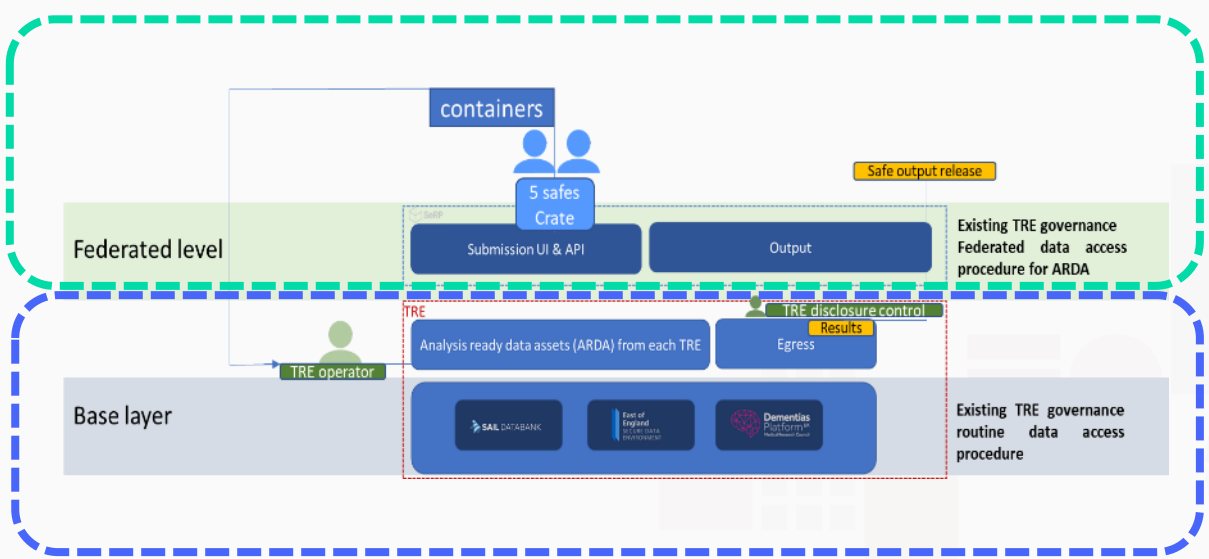
ADR UK Data-driven change

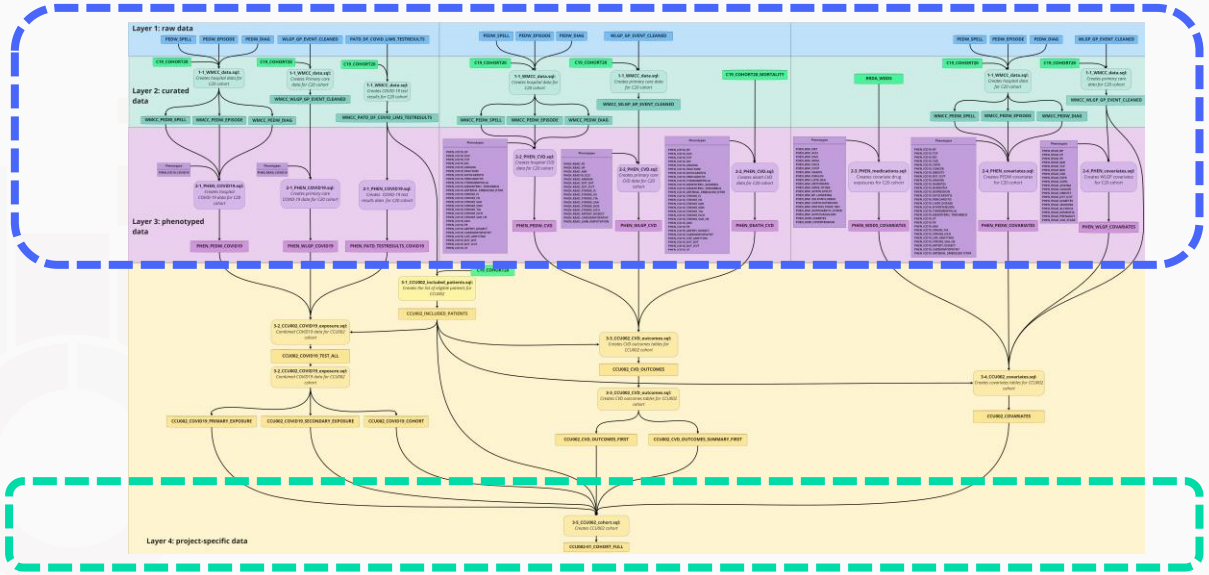
WP2 - Technical: Assess and analyse the systems effectiveness on each TRE node for adoption of DARE UK's federated analysis capabilities.



WP3 - Data Integration: Harmonise core AF cohort structures across both TRE nodes and develop containerised analytical pipelines that enable consistent, portable, and secure federated analyses across environments.

CONNECT-AF
A DARE UK PROJECT





Abbasizanjani & Torabi et al. 2023

SAIL DATABANK — AF-Wales

Eastern England SECURE DATA ENVIRONMENT — AF-ESDE

Dementias Platform UK Medical Research Council — Self-reported outcomes

UK Research and Innovation

HDRUK Health Data Research UK

ADR UK Data-driven change

CONNECT-AF
A DARE UK PROJECT

WP4 - Engagement: Embed meaningful public and patient involvement and engagement (PIE) throughout the project to ensure transparency, accountability, and public trust.

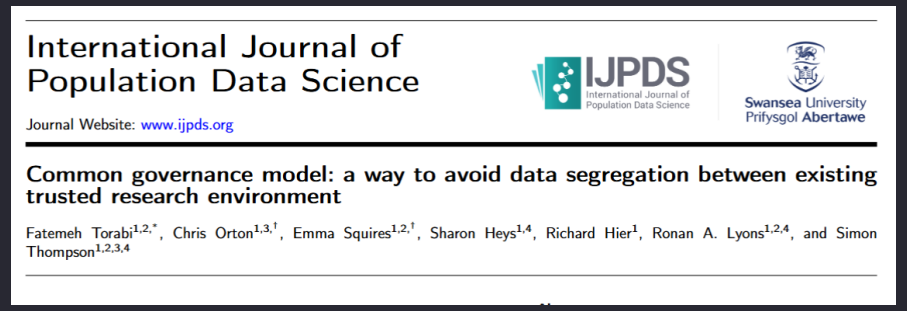
Co-design from the start
Our PPIE representatives are those who experienced AF themselves and found value in federated way of accessing data for AF-research

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

Enablers

- SAFER: SAIL Advancing Federated Exploration and Readiness
- VISTA: Viable Implementation of SATRE, SACRO and Tools for AI
- 5S-TES: Delivering a federated network of trusted research environments to enable safe data analytics
- TELEPORT: Connecting researchers to big data at speed

Torabi & Orton et al. , 2023



International Journal of Population Data Science

IJPDS International Journal of Population Data Science

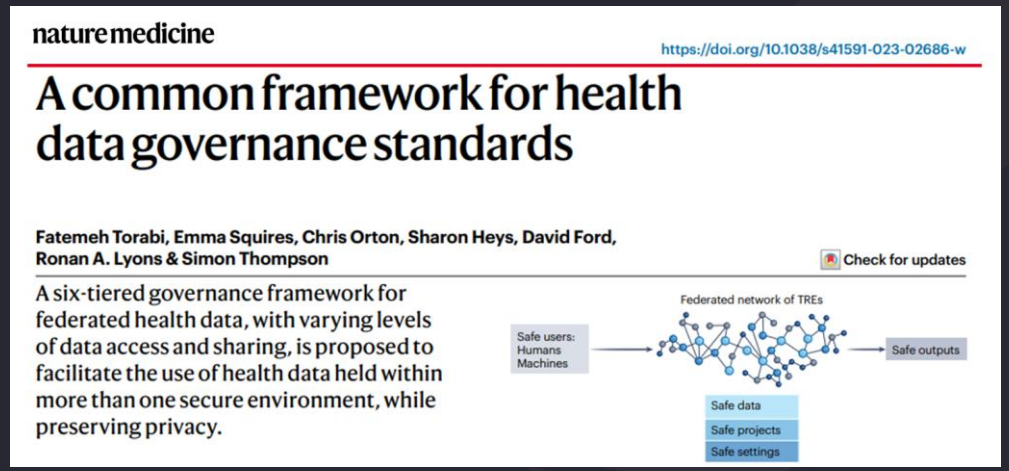
Swansea University Prifysgol Abertawe

Journal Website: www.ijpds.org

Common governance model: a way to avoid data segregation between existing trusted research environment

Fatemeh Torabi[1,2,*], Chris Orton[1,3,†], Emma Squires[1,2,†], Sharon Heys[1,4], Richard Hier[1], Ronan A. Lyons[1,2,4], and Simon Thompson[1,2,3,4]

Torabi & Squires et al., 2024



nature medicine

https://doi.org/10.1038/s41591-023-02686-w

A common framework for health data governance standards

Fatemeh Torabi, Emma Squires, Chris Orton, Sharon Heys, David Ford, Ronan A. Lyons & Simon Thompson

Check for updates

A six-tiered governance framework for federated health data, with varying levels of data access and sharing, is proposed to facilitate the use of health data held within more than one secure environment, while preserving privacy.

CONNECT-AF
A DARE UK PROJECT

Thank you!

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

AIRR-BRIDGE

A **DARE UK** PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

Martin O'Reilly, The Alan Turing Institute

UK Research and Innovation

HDRUK Health Data Research UK

ADRUK *Data-driven change*

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

3 TRE builders

The Alan Turing Institute

UCL

King's College London

2 supercomputers

University of Cambridge

University of Bristol

DAWN

BriCS

AIRR: AI Research Resource

3 health datasets

UK Biobank

PharosAI

AI Centre for Value Based Healthcare

UK Research and Innovation

HDRUK Health Data Research UK

ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

The key idea

- To enable the safe use of large-scale sensitive datasets on the UK's national AI supercomputers
- Demonstrate this can be done for three real-world health datasets using real-world research projects
- While validating solutions developed in DARE UK programme against real-world governance requirements

UK Research and Innovation
HDRUK Health Data Research UK
ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

The datasets

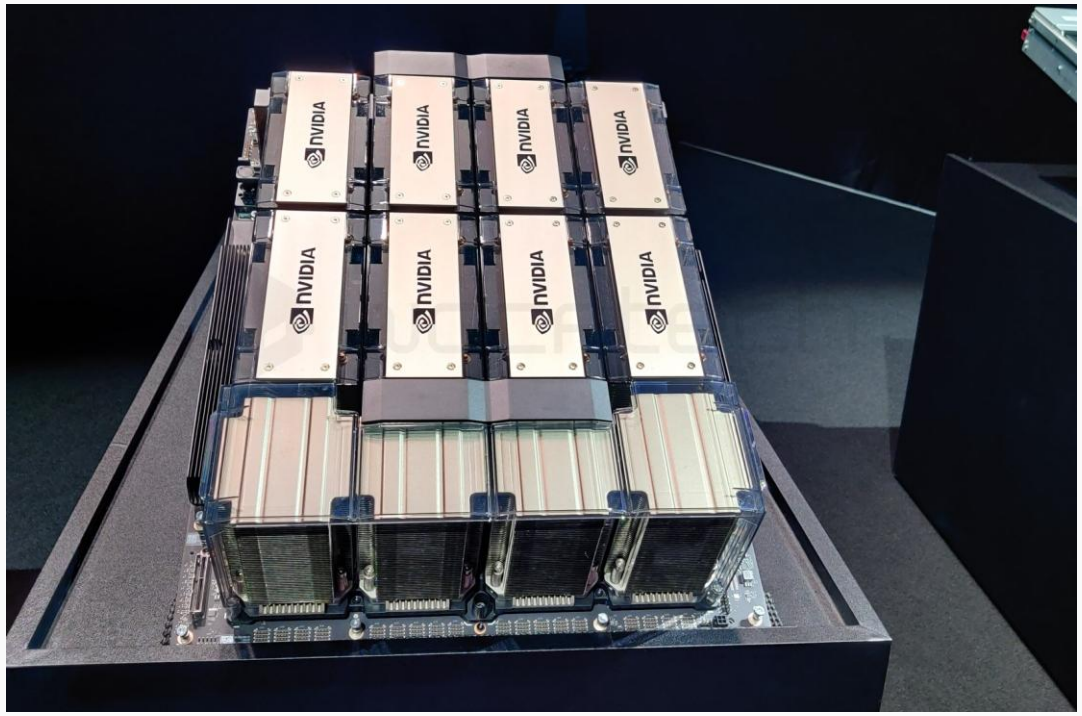
- UK Biobank: Large 500,000 subject longitudinal research cohort. Long follow-up includes many different health outcomes.
- PharosAI: Large-scale multimodal data. 12,000 patients per year. Digital pathology, imaging, DNA/RNA, longitudinal clinical data.
- AI Centre for Value Based Healthcare: 170,000 brain MRI images from 40,000 patients with metadata and clinical radiology reports.

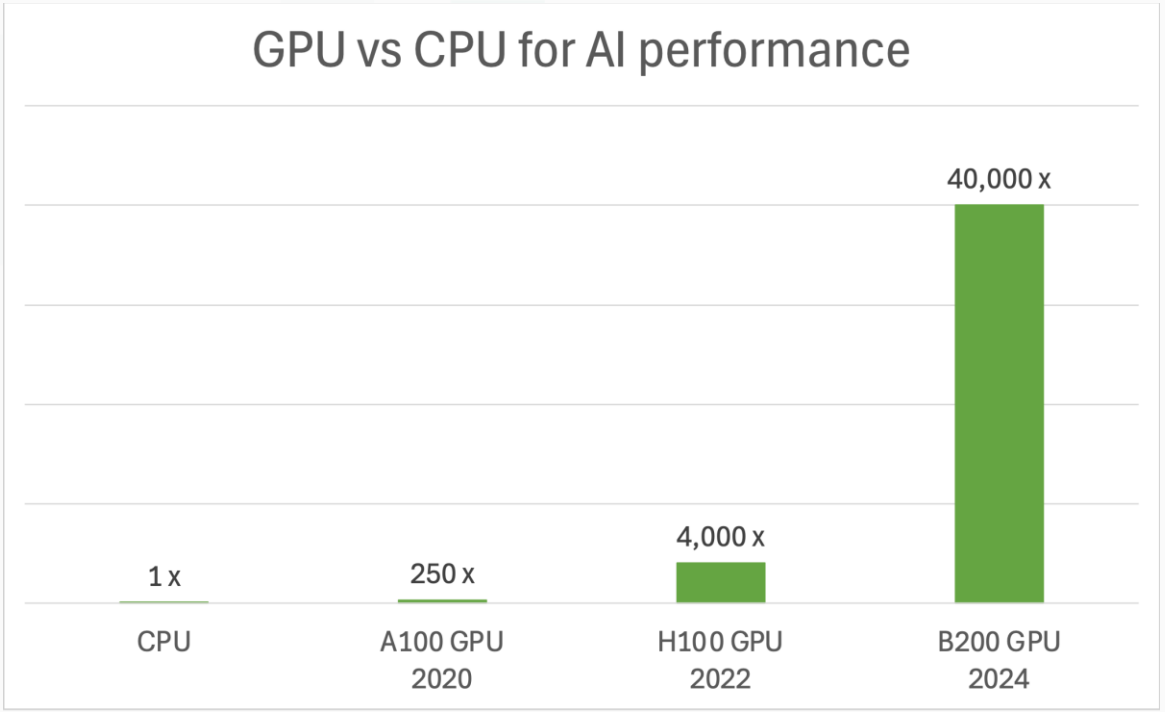
UK Research and Innovation
HDRUK Health Data Research UK
ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

AI research needs specialised “GPU” computer processors …



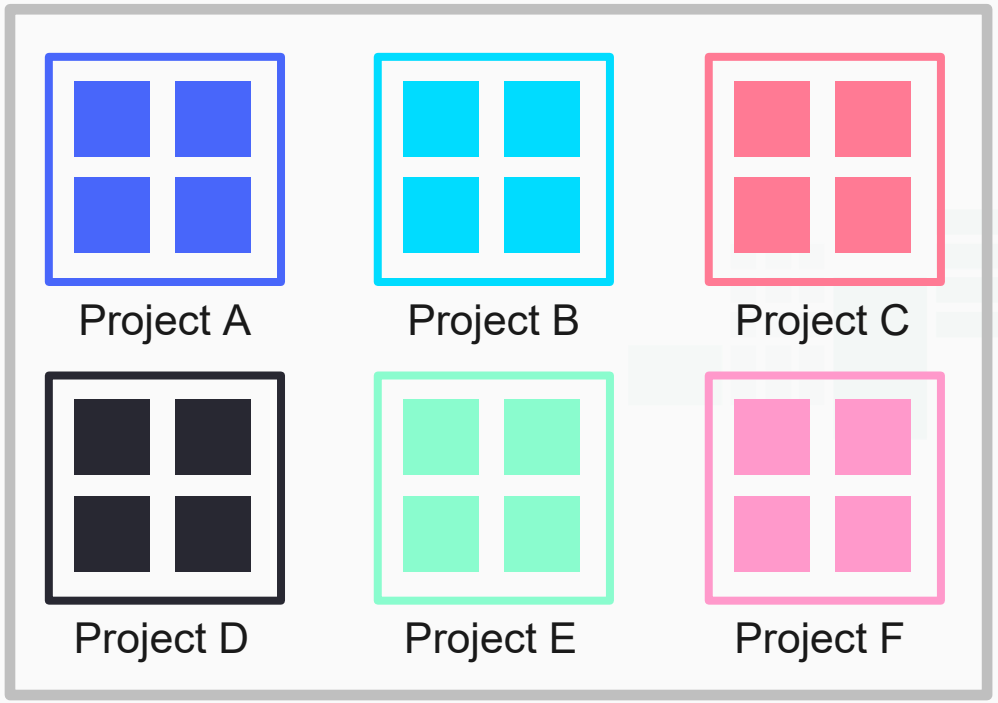


UK Research and Innovation
HDRUK Health Data Research UK
ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

Sensitive research needs Trusted Research Environments (TREs) …



TREs combine strong technical controls and strong information governance controls to support safe research using sensitive data.

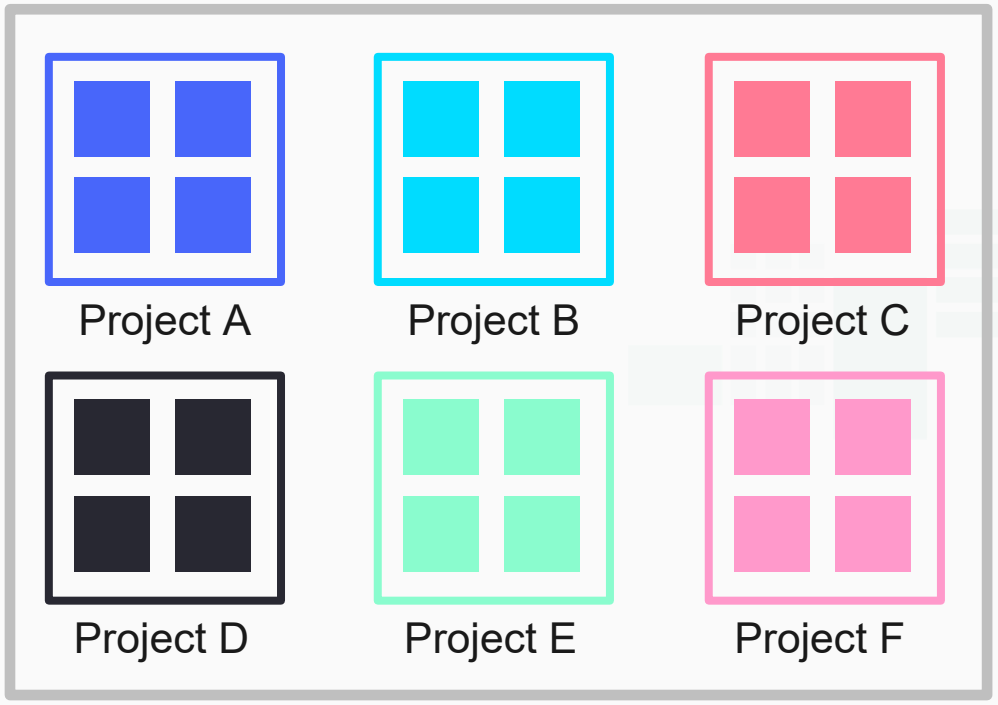
- Isolated projects
- De-identified data
- No internet or copy + paste
- Secure connections
- Approved projects
- Approved researchers
- Review of outputs

UK Research and Innovation
HDRUK Health Data Research UK
ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

… but TREs don't have many GPUs



TREs provide a small number of strongly isolated computers per project

UK Research and Innovation
HDRUK Health Data Research UK
ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

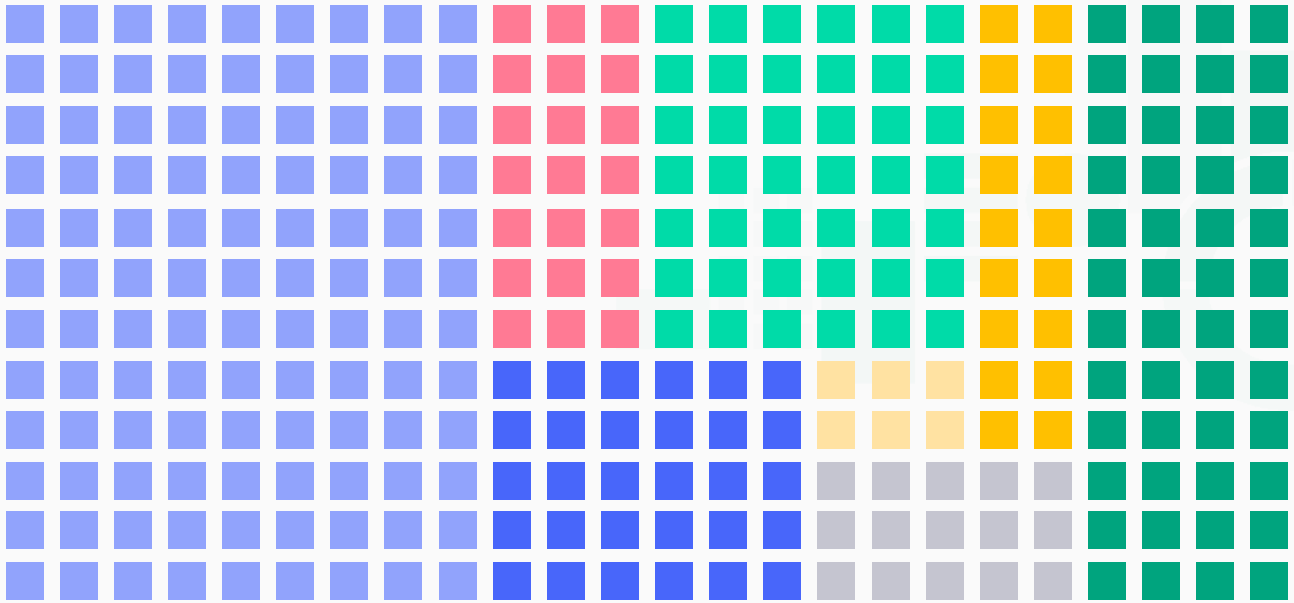
The AIRR supercomputers have lots of GPUs …

UK Research and Innovation
HDRUK Health Data Research UK
ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

… but these supercomputers aren't TREs



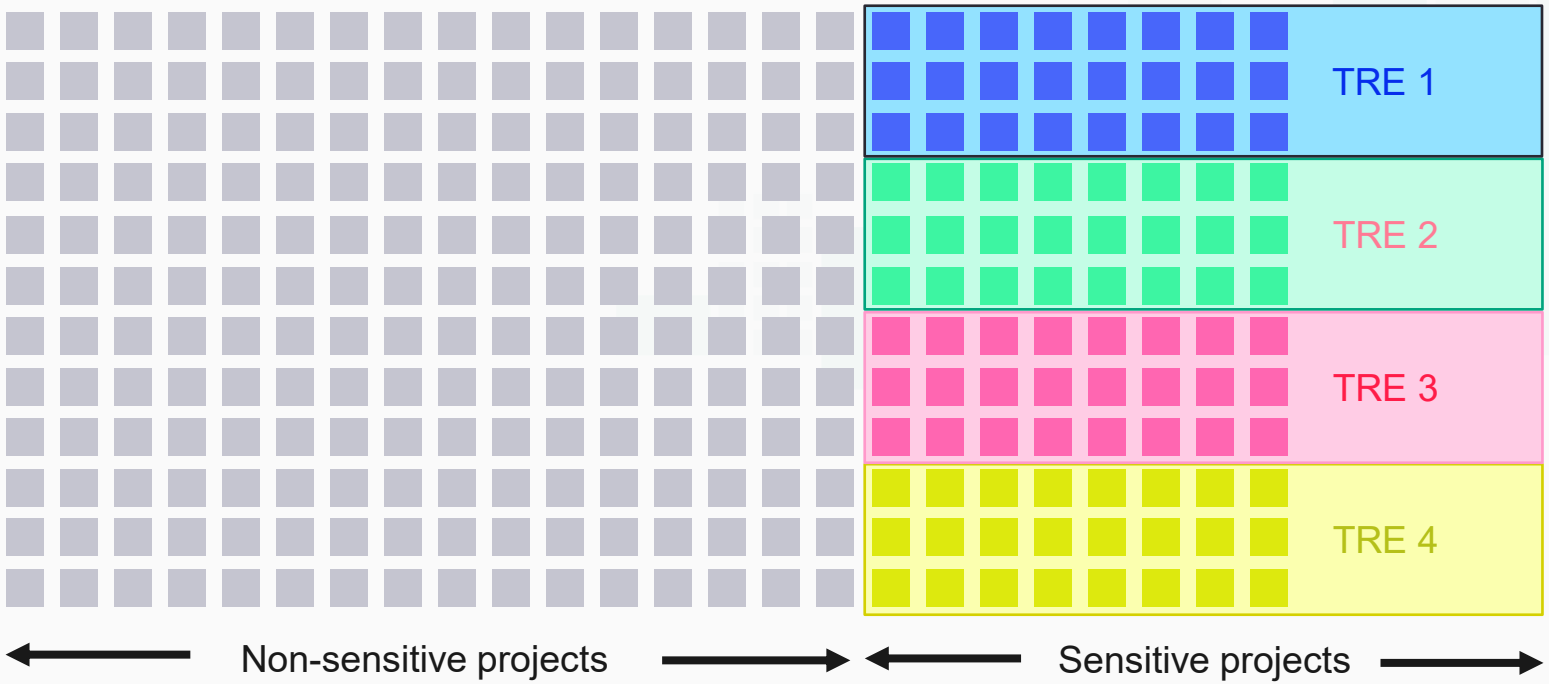
Different projects and users are not strongly isolated from each other in the same way as they are in a TRE

UK Research and Innovation
HDRUK Health Data Research UK
ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

… but these supercomputers aren't TREs … yet



FRIDGE is a satellite TRE model that isolates different parts of a supercomputer for different TREs

AIRR-BRIDGE will validate this approach in a production environment

UK Research and Innovation
HDRUK Health Data Research UK
ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

Demonstrate this with real projects using real health data …

Federate the Turing and KCL TREs…

UCL

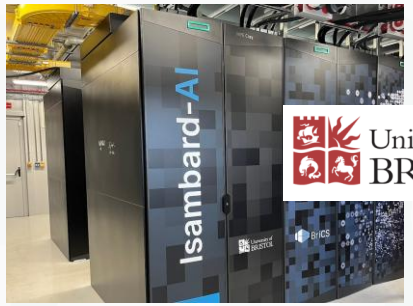
uk biobank

The Alan Turing Institute

PharosAI

KING'S College LONDON

AI CENTRE for Value Based Healthcare



University of BRISTOL

UNIVERSITY OF CAMBRIDGE

…with the Isambard-AI and Dawn supercomputers

UK Research and Innovation

HDRUK Health Data Research UK

ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

… while leveraging and validating other TREvolution components

Build a SATRE compliant TRE-on-supercomputer solution

UCL

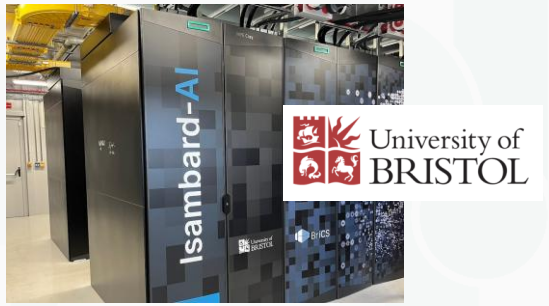
uk biobank

The Alan Turing Institute

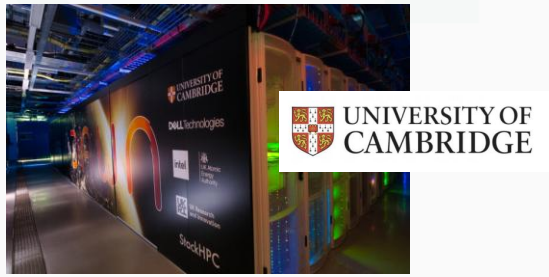
PharosAI

King's College London

AI CENTRE for Value Based Healthcare



Test the K8TRE "full stack" TRE on the AIRR supercomputers



Test the SACRO-ML disclosure control tools for AI models

UK Research and Innovation

HDRUK Health Data Research UK

ADRUK Data-driven change

AIRR-BRIDGE
A DARE UK PROJECT

Enabling large-scale health datasets on UK national AI supercomputers

PIE and community engagement

- Dedicated public member co-lead for PIE
- Turing TRE PIE group embedded in project
- Engagement with data provider and DARE UK PIE groups
- Wider public engagement via collaboration cafes
- Engaging with TRE and supercomputer communities

UK Research and Innovation
HDRUK Health Data Research UK
ADRUK Data-driven change

FRAME
A DARE UK PROJECT

Federated Research on Antihypertensives Maternity Emulation Trial

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

What is the problem ?

10%-15% of women have high blood pressure in pregnancy and this is harmful for the mother and baby

Trials are rarely big enough to be able to examine if recommendations for medications should differ by ethnicity and they rarely look at long term outcomes for mother and baby.

Medical records of women who have had high blood pressure could help answer these question.

We want to bring together the medical records from women across the UK so we can compare people with the same ethnicity who took different drugs in pregnancy.

We also want to see the long term health of the baby (in the first 2 years of life)

However, data can not just be shared across countries

We are using the technology developed by DARE to create a Pop-up Trusted Research Environment where data can be held and shared but still meet all the governance requirements of the data holders.
A space where all the data providers can come together.

This platform is called TELEPORT

Overview of the project

- **Four birth studies in UK have come together to makes sure their data the same.**
- There are 19 million pregnancies in these birth studies.
- This means we will have the power to compare women of the same ethnicity taking different drugs to see what works for African woman, or Asian women or White women and we believe it will be different.
- We have the power to follow infants up for 24 months after their birth to examine:

If health visitors had any concern with growth and development

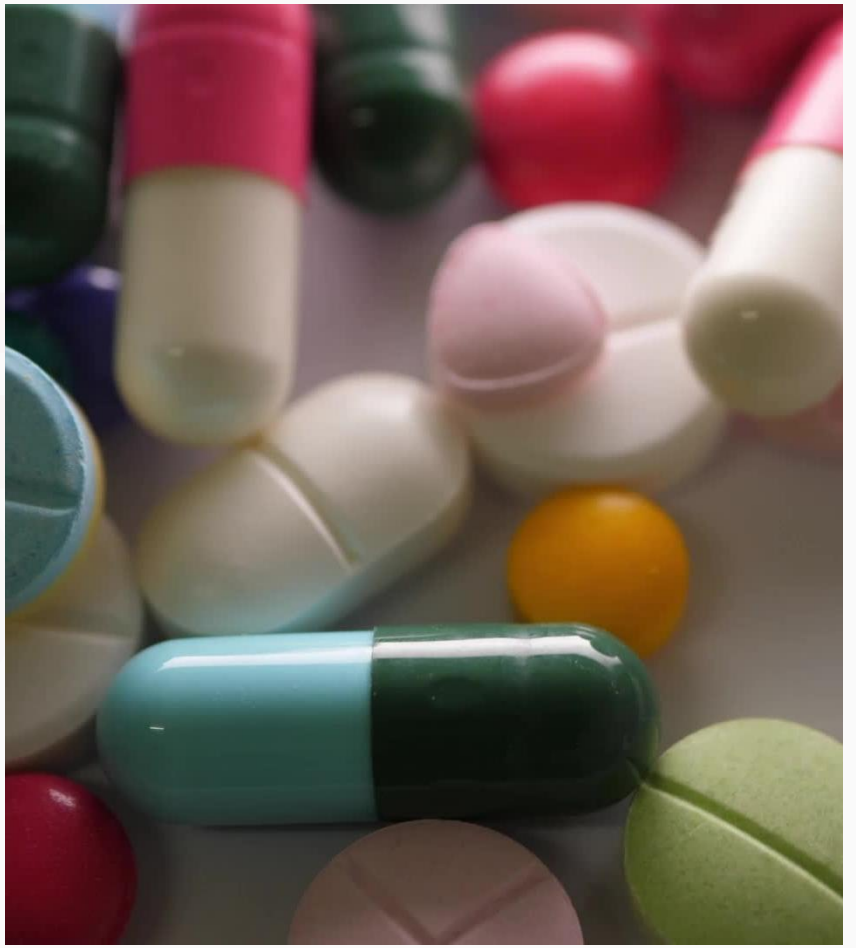
If infants were diagnosed with low heart rate, failure to grow or any heart or breathing disorders

Public involvement

- This work was developed because our Born In Wales Public Involvement group said research should improve safety of medicines in pregnancy.
- Women have taken drugs not knowing the long-term effects, we should learn from their experiences.
- The work is developed with the SAIL Consumer Panel
- The findings will be taken to a workshop to work with the public to interpret findings on medications, develop recommendations, develop community facing summaries. Working with existing PIE members in Born in Wales, Scotland and South London.
- It is vital that the findings are interpreted with the public to ensure messages are clear and can help women and their families.

What difference could it make ?

- This would make a major difference in medicines in **pregnancy, infancy** and long term follow up.
- Trials face ethical barriers and are difficult in to do in pregnancy or infancy, but people still need to take medication. We need to learn from their experiences
- Bring different data sets together is especially important when comparing smaller groups (e.g. different ethnic groups or people taking multiple medicines). In a single data source, the numbers in each group are often too small to spot real differences.
- It would also be used for rare conditions where you need to bring all data together to match individuals



The team includes:

- Obstetric physician
- Pediatric pharmacist
- Fetal and maternal medicine clinicians
- Data Scientists
- Epidemiologists
- Co-production Public Involvement lead

.







FRAME
A DARE UK PROJECT

mireda
mother & infant research electronic data analysis

UK Research and Innovation

HDRUK
Health Data Research UK

ADR UK
Data-driven change

DataLoch Health Informatics Centre

HEAL-Scot
A DARE UK PROJECT

Housing, Environment and Location data linkage in federated TREs mapping geospatial inequalities

Dr Laura Ward
lward001@dundee.ac.uk
Public webinar 14/05/26

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

Our Team Linking Safe Havens

HEAL-Scot
A DARE UK PROJECT

DataLoch

Health Informatics Centre

SOUTH-EAST

Kathy Harrison
Project Lead

Amy Chong
Data Analyst

Richard Walls,
Project Co-lead

Chris Hall
TRE

Magalie Guignard-Duff, Data

Derek O'Sullivan
Developer

Stuart Dunbar
PIE/ Comms

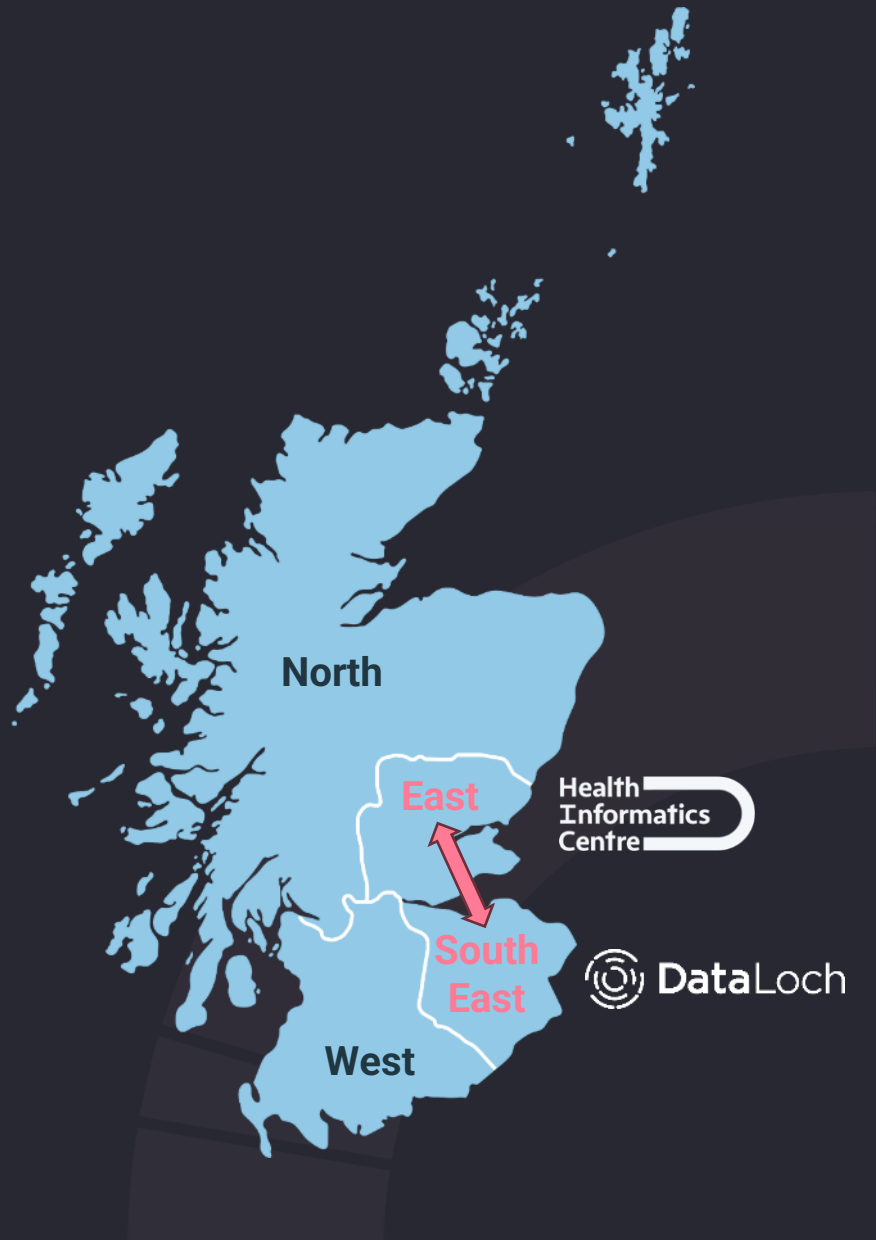
Jenny Johnston
Governance

Aaron Jackson
Infrastructure

Laura Ward,
RWE Research

EAST

Kathy Kennedy & John McCullough are our 2 Public contributors

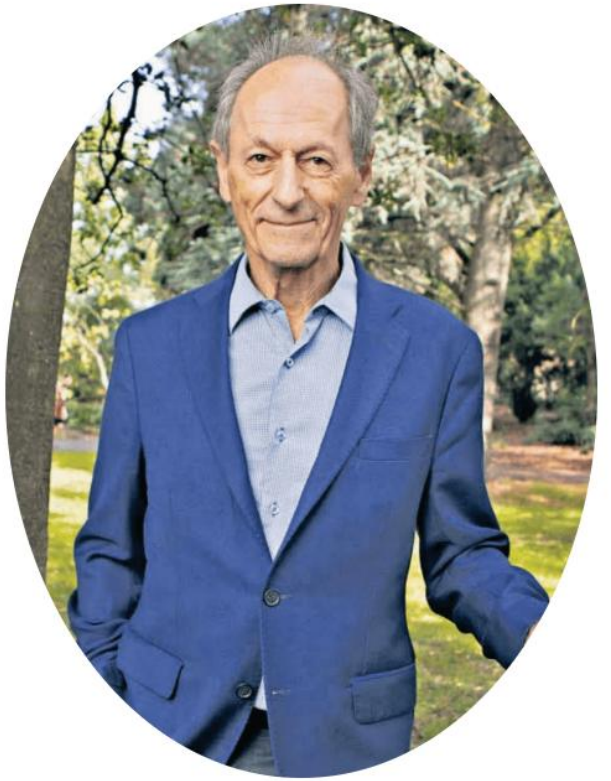


Social determinants of health

- **Prof Michael Marmot** founded the Institute of Health Equity
- His book, the "Health Gap" opens with this story of him training as a medic in the 1960's

  "'Oh doctor' said the patient, 'my husband is drinking again and beating me, my son is back in prison, my teenage daughter is pregnant, and I cry most days, have no energy, difficulty sleeping. I feel life is not worth living.' It was hardly surprising that she was depressed. …The psychiatrist told the woman to stop taking the blue pills and try these red pills. He wrote out an appointment for a month's time and, still a picture of misery, she was gone. That's it? No more? To incredulous medical students he explained that there was very little else he could do. "

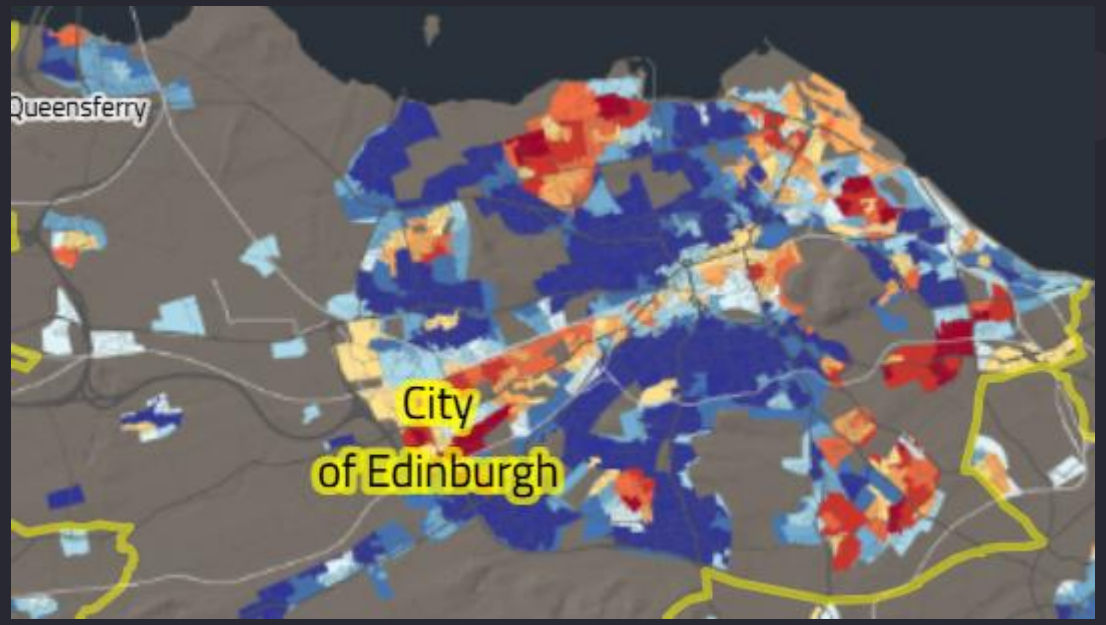
- **Social determinants of health are the 'causes of the causes'**

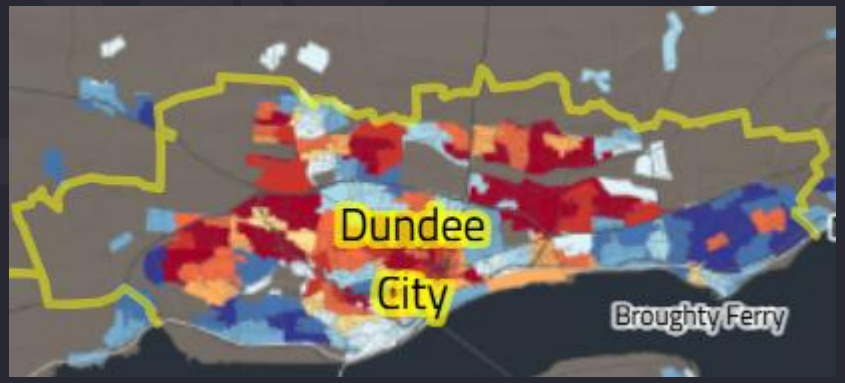


Professor Michael Marmot

HEAL-Scot
A DARE UK PROJECT

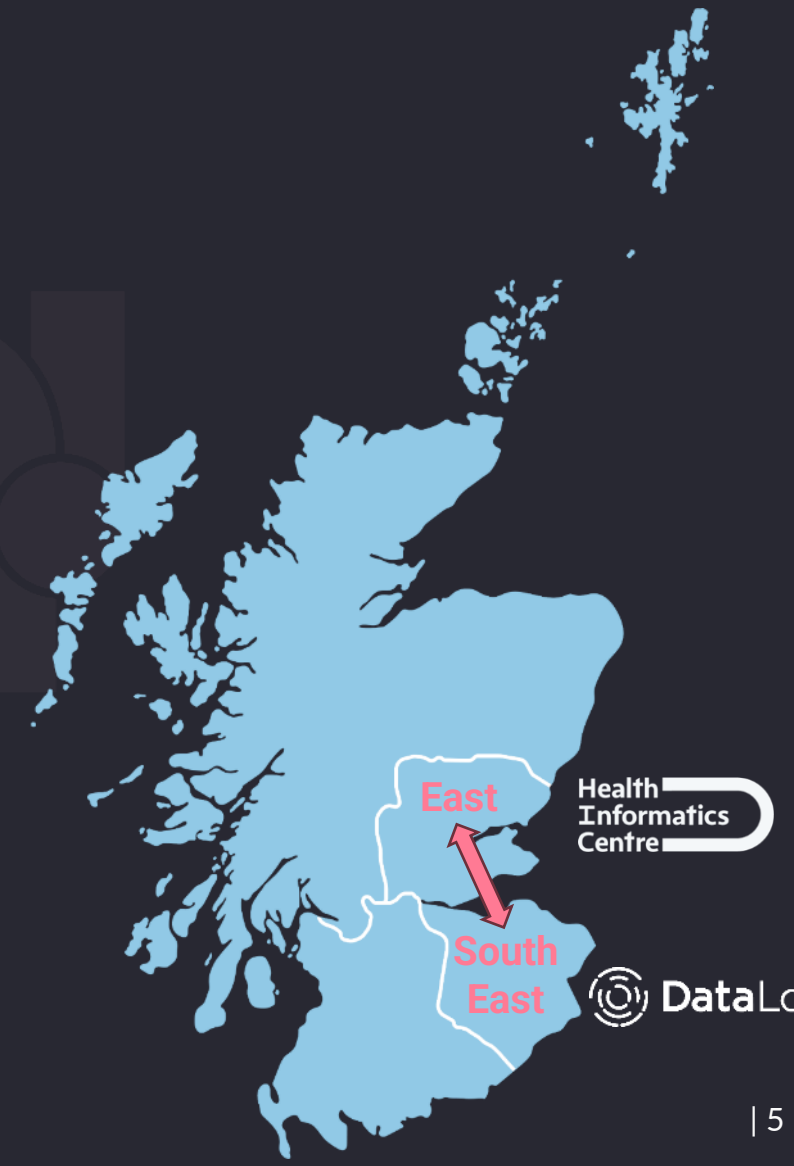
If I am born, live, work, and age in a relatively deprived area, how much does this influence my health?





Geospatial and health inequalities

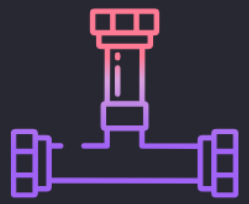
- Our social, economic, and environmental conditions are the main drivers of our health and health inequalities
  - For early deaths, they are responsible for **54%** variation
- **HEAL-Scot** links different sources of information across the **health and non-health**
  - Housing, neighbourhood access to health care, proximity to green spaces, air quality
- We will compare regional differences to begin to **try understand where differences are in terms of geospatial inequalities**
- This will be done in each safe haven (federated approach), hosting data for NHS Lothian, NHS Tayside, and NHS Fife,
- Research conducted inside a TRE



Technical pipelines for cross-sector data

PPIE governance safeguards

TRE federation and scalability



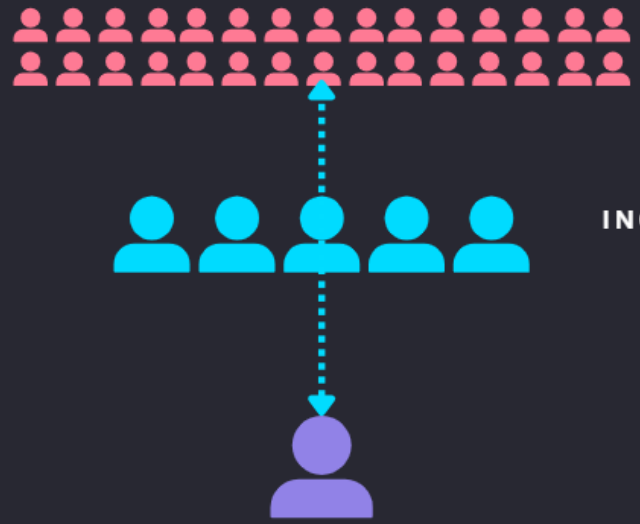
Social determinants of avoidable hospitalisations and early death

HEAL-Scot
A DARE UK PROJECT

LOCATION
- Economic wellbeing
- Air pollution
- Access to services
- Proximity to green/ blue space

HOUSEHOLD
- UPRN coordinates
- Type
- Housing instability

INDIVIDUAL
- Hospital
- Death
- Demography



INCREASING SIZE OF AREA

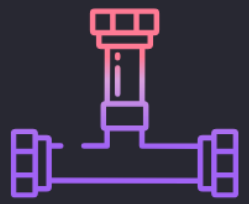
Technical pipelines for cross-sector data

PPIE governance safeguards

RO-Crate

SATRE K8TRE

TRE federation and scalability



Social determinants of avoidable hospitalisations and early death

SACRO

HEAL-Scot
A DARE UK PROJECT

So what? How is public involvement shaping HEAL-Scot?

- **Team members**: 2 contributors will join the monthly team meetings and help shape decisions
- **Shaping safeguards**: public workshops will help define what is acceptable and what is not, when linking health and non-health geospatial data
- **Feedback loops**: governance designs, communications and results will be tested with public groups and feedback listened to
- How are we doing this? Working with **existing groups** -
  - **DataLoch** public panel
  - **RDS** public panel – Scotland Talks Data
  - **TREvolution** Collaboration Cafes

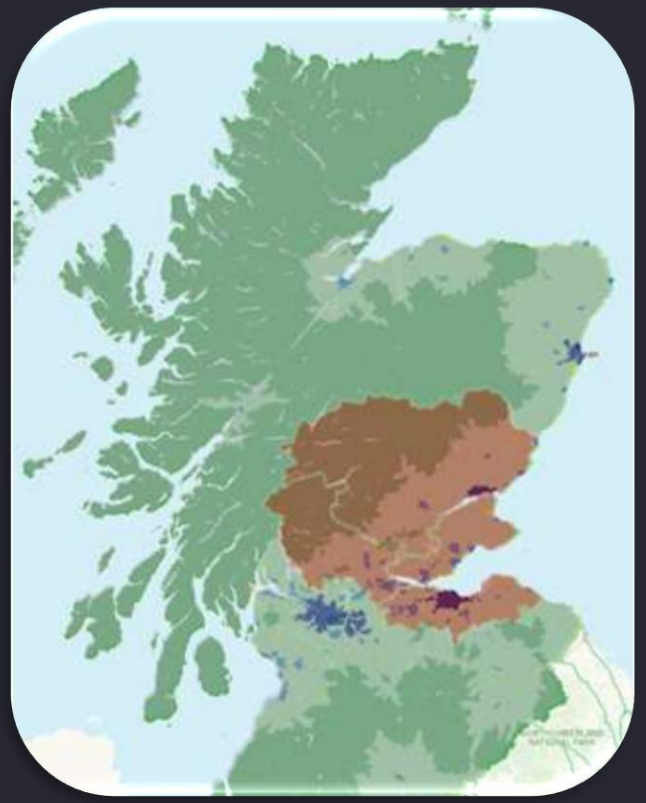
DataLoch

Research Data Scotland

TREvolution
A DARE UK PROJECT

HEAL-Scot
A DARE UK PROJECT

Stay in touch with our team



Visit our website

SCAN ME

Thank You & Get in Touch

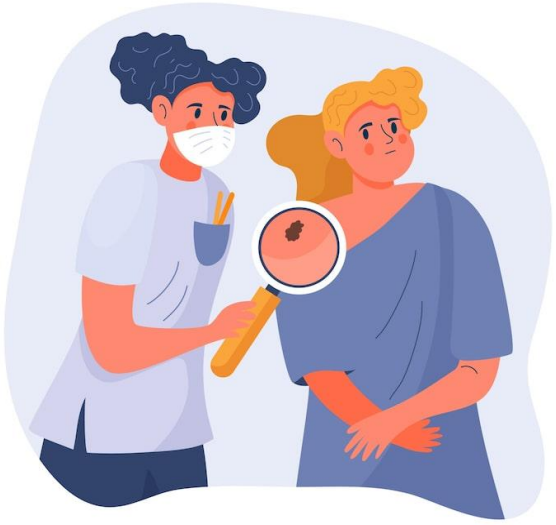
HEAL-Scot
A DARE UK PROJECT

Kathy.Harrison@ed.ac.uk

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

MELODY :

federated MachinE Learning fOr DermatologY (RWE - Real World Evidence Project)



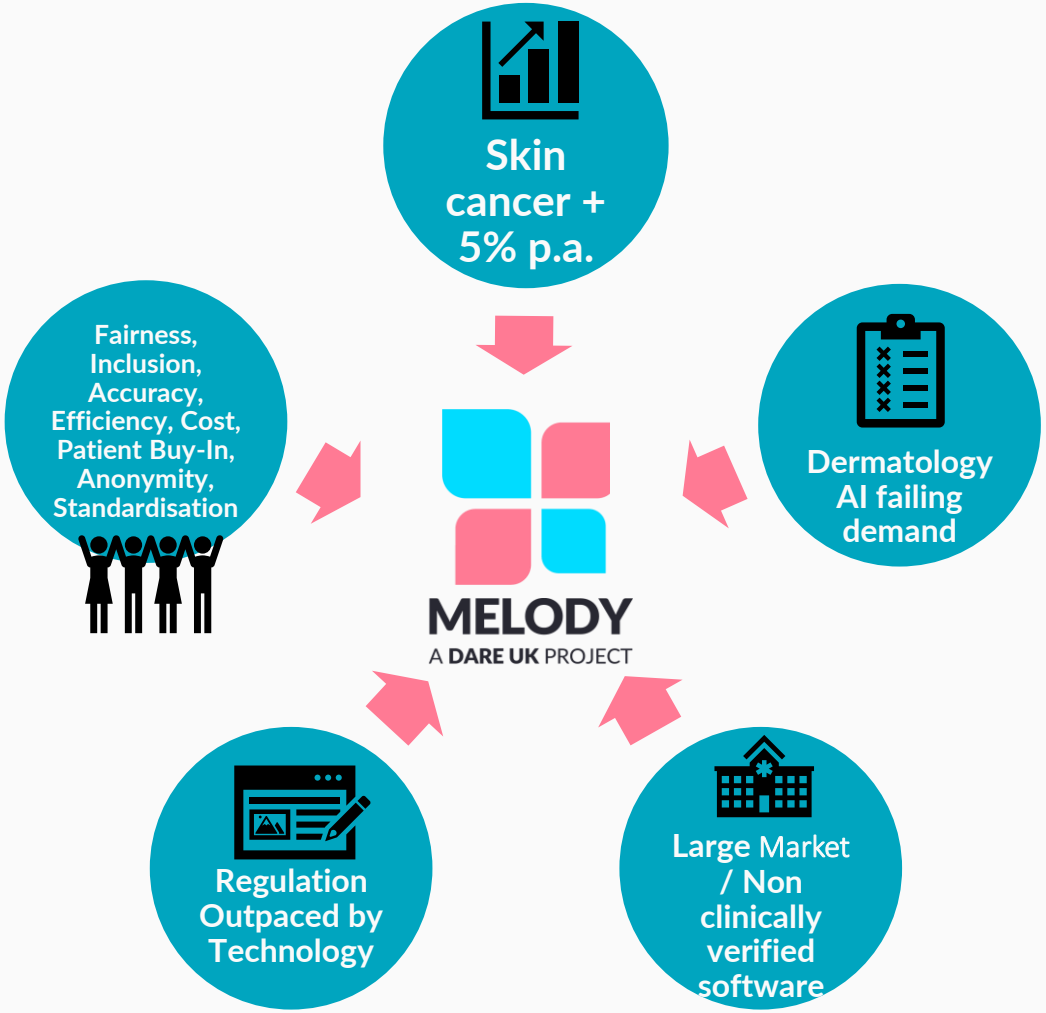
'From capability to Research' Webinar

Richard Walls
Operations Director, Health Informatics Centre (HIC), University of Dundee

14.05.2026

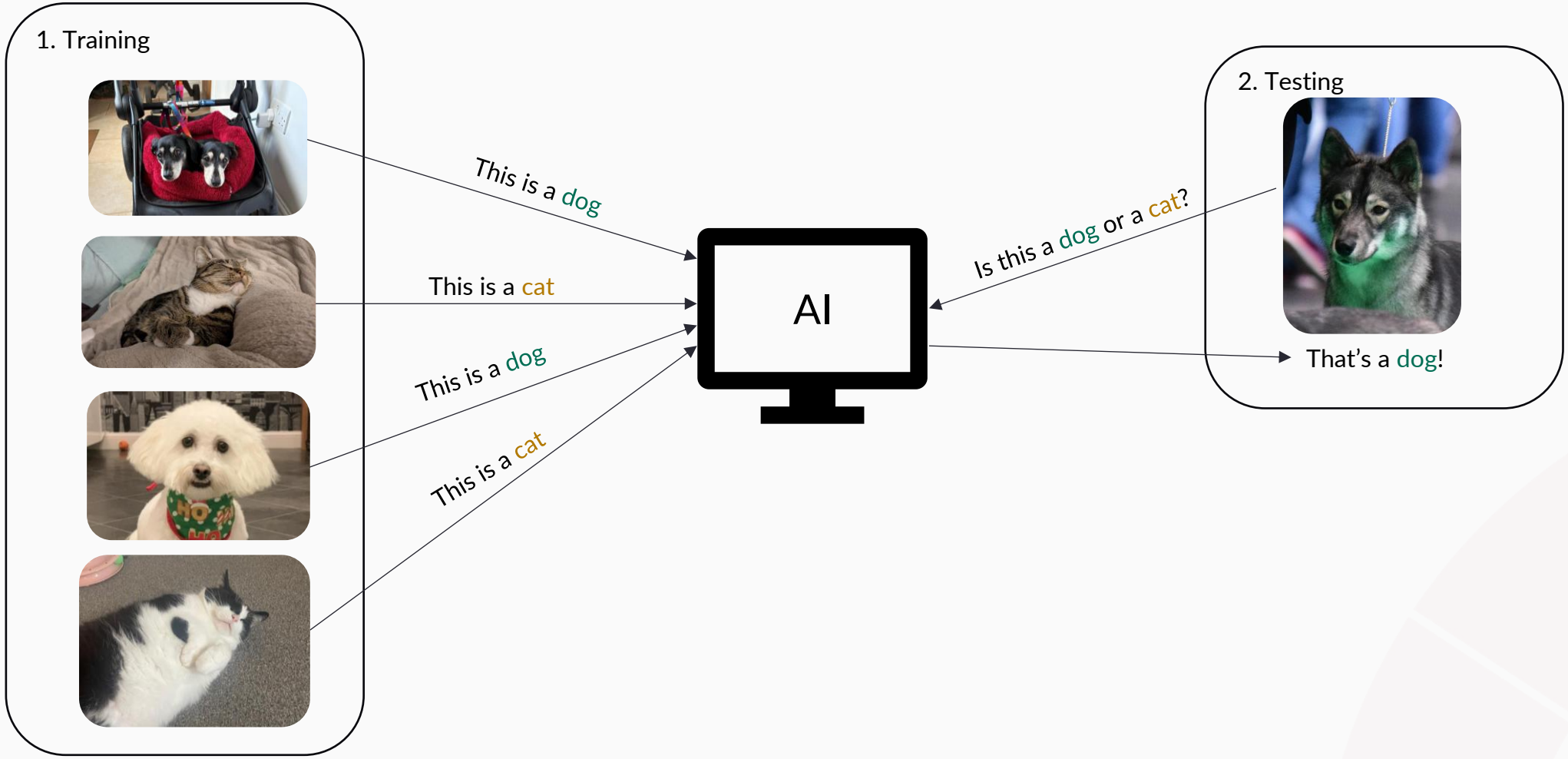
MELODY - federated MachinE Learning fOr DermatologY

MELODY
A DARE UK PROJECT

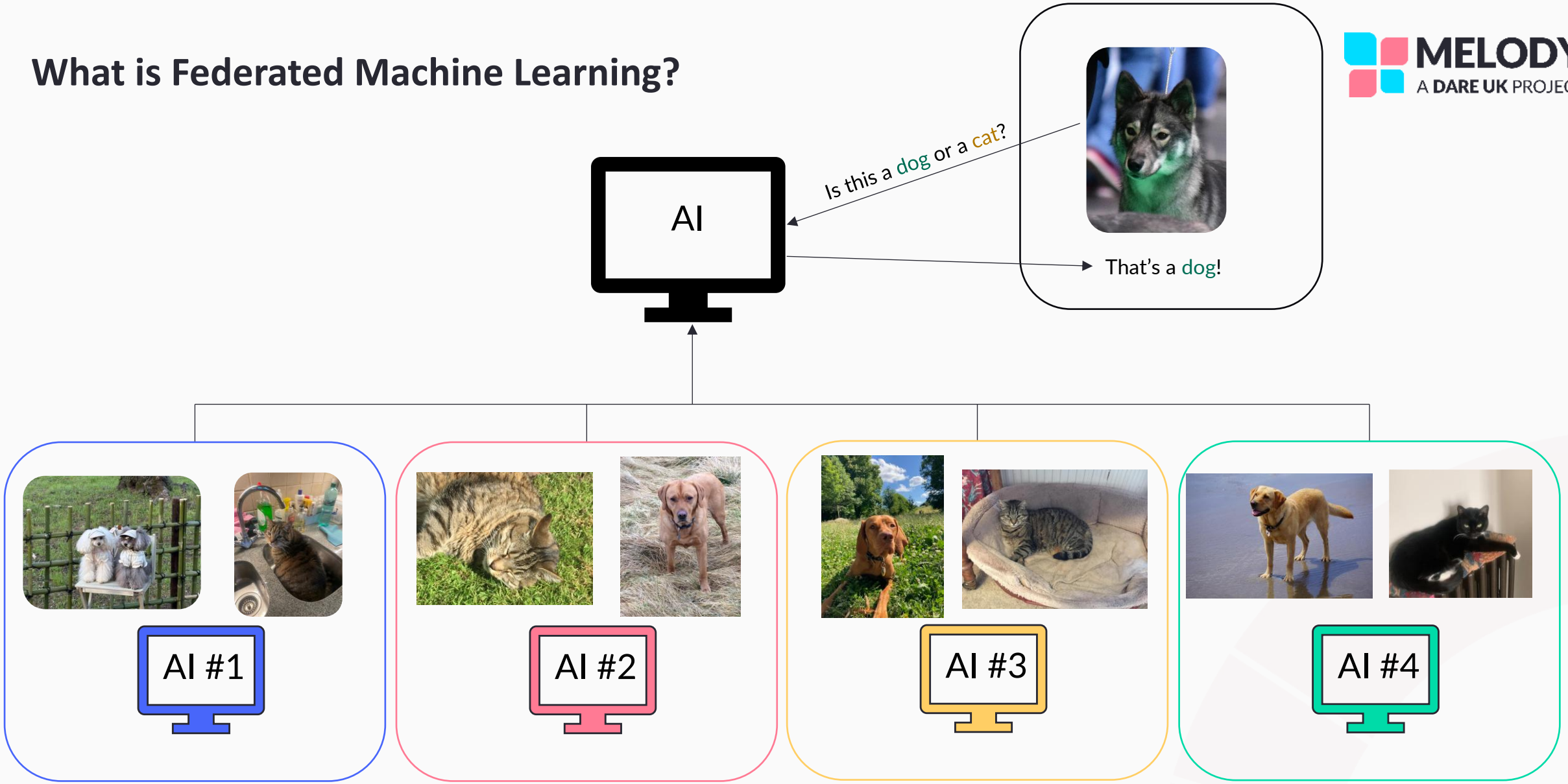


UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

What is Machine Learning?



What is Federated Machine Learning?



Project Aims & Objectives

MELODY
A DARE UK PROJECT

Aim: Develop a platform for federated machine learning (ML) across multiple TREs.

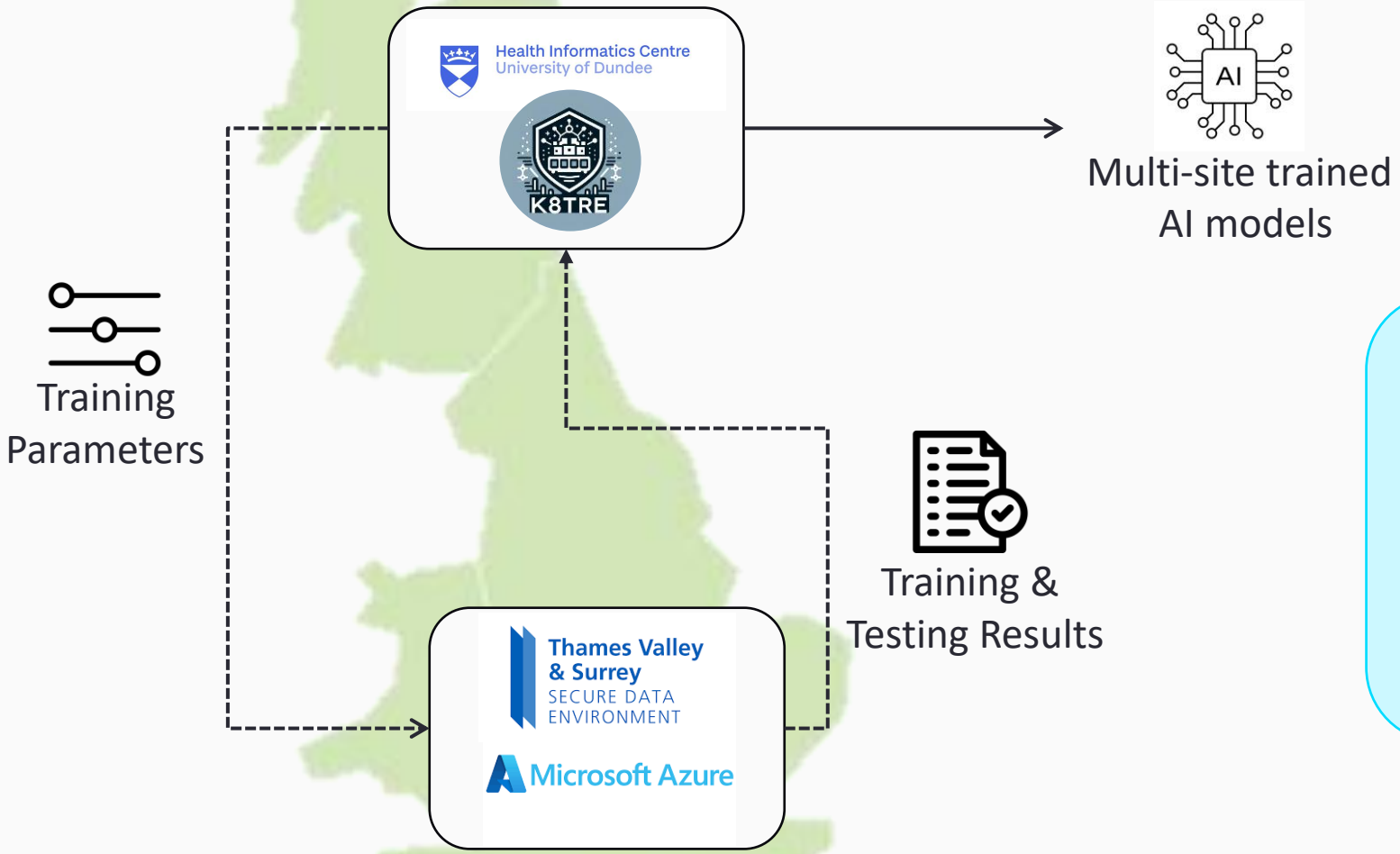
'Big Picture' Aim: To develop a national skin AI assurance platform (with real world, inclusive and carefully curated skin disease data) to use in testing and developing skin AI.

Project Objectives:

- Develop **a solution to allow federated ML** across TREs.
- Create **real-world dermatology datasets** across two locations (NHS Tayside and Oxford University Hospitals NHSFT).
- Train and assess **a ML model on skin-lesions across the two sites**, using federated ML techniques as a proof of concept.

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

MELODY Approach: Federation



TREvolution tools being tested

TRE Disclosure Control (SACRO-ML)

TRE Standards (SATRE)

TRE Architecture (K8TRE)

TRE RO-CRATE

Public Involvement in MELODY

NHS SKIN

SHARE

UNIVERSITY of STIRLING

independent cancer patients' voice

NIHR | Oxford Biomedical Research Centre

Health Informatics Centre
University of Dundee

CO-CONNECT

Scotland Talks Data

Alleviate
The Advanced Pain Discovery Platform (APDP) Data Hub

Apr/May 26

Engage with PIE group to identify 3 project champions

June 26

Host Collaboration Cafés/workshops to build technical understanding and identify any initial project concerns

June/July 26

Develop ML platform with PIE input and validation

Integrate project champions into technical and governance discussions

Sep 26

Solution evaluation from PIE perspective

Develop output communication strategy jointly with our project champions

UK Research and Innovation

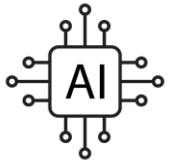
HDRUK Health Data Research UK

ADR UK Data-driven change

How we would like the public to get involved in MELODY

MELODY
A DARE UK PROJECT

Technology



- How should we approach federated ML in practice?
- What technical checks and balances should be put in place?
- How can we ensure data privacy for individuals?
- How should we monitor what researchers are doing with this new technology?

Data & Governance

- What dermatology images can be used?
- How can dermatology images be used?
- How can we make them non-identifiable?

Evaluation & Communica

- Is this federated ML approach safe?
- Is this ML approach trusted by the public?
- Explore developing federated machine learning policies
- Co-lead engagement and disseminations events

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

If you are interested in getting involved in MELODY, please get in touch!

MELODY
A DARE UK PROJECT

Sign up to our focus group

UK Research and Innovation

HDRUK Health Data Research UK

ADR UK Data-driven change

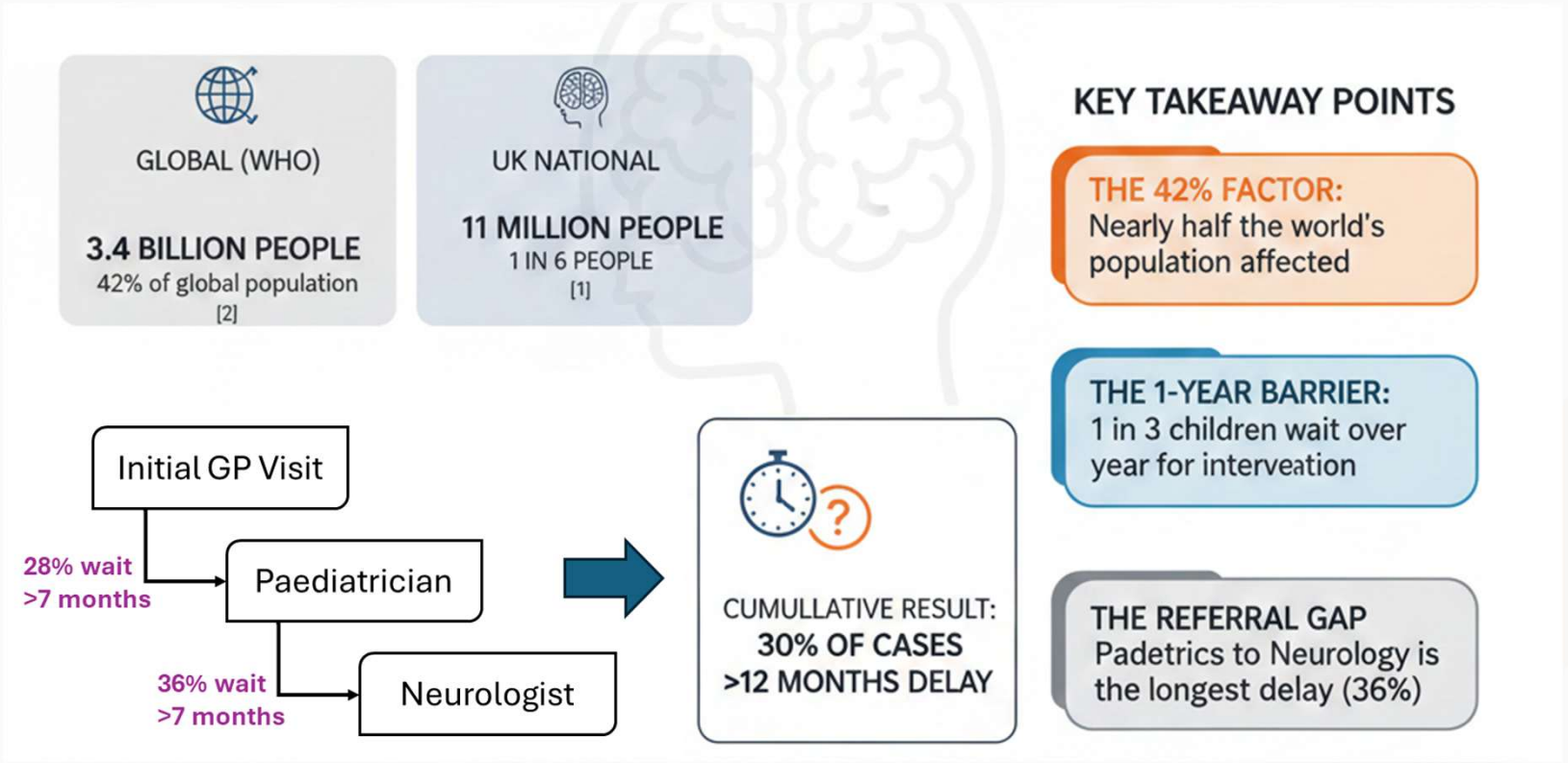
SAFEVID
A DARE UK PROJECT

SAFEVID: Spasms Analysis using Federated Learning from Videos Across Multiple TREs

Edmond S. L. Ho, University of Glasgow

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

Neurological conditions - a major public health crisis



Infantile Epileptic Spasms (IES)

- IES is the most common epilepsy syndrome in early childhood
- **Lead time** - time from epileptic spasms beginning to treatment beginning
- Can smartphone videos be used to reduce Lead Time?

THE JOURNAL OF PEDIATRICS • www.jpeds.com ORIGINAL ARTICLES

The Effect of Smartphone Video on Lead Time to Diagnosis of Infantile Spasms

Chethan K. Rao, DO, MS[1,2,3], Douglas R. Nordli, III, MD[1,2], Joshua J. Cousin, MD[4,5], Danielle S. Takacs, MD[4,5], and Raj D. Sheth, MD[1,2]

Table II. Lead times and treatment outcomes of video and nonvideo groups

Characteristics	Nonvideo group, n = 37	Video group, n = 43	*P* value
Lead time, d			
Infantile spasms start to first encounter	15 [2.5, 67.5]	6 [2, 10]	.02
Infantile spasms start to first EEG	23 [4.5, 67.5]	7 [3, 14]	.007
Infantile spasms start to diagnosis	25 [9, 84.5]	8 [4, 30]	.006
Infantile spasms start to treatment initiation	26 [9, 87.5]	9 [5, 30]	.008
Treatment outcomes			
Treatment responder	18 (49%)	32 (74%)	.02
Ongoing infantile spasms at last follow-up	13 (35%)	6 (14%)	.03
Developmental delay at last follow-up	34 (92%)	36 (84%)	.27
LGS at last follow-up	6 (16%)	1 (2%)	.03

Data are presented as n (%) or median [25%-ile, 75%-ile].

Shorter Lead Time

Improved Treatment Response Rate

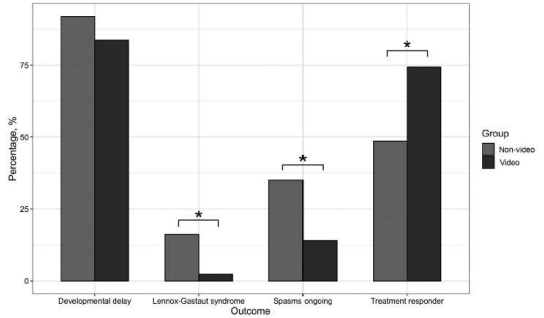


Figure 3. Comparison of treatment outcomes including developmental delay, LGS, ongoing infantile spasms, and successful response to treatment between video and nonvideo groups.

The Effect of Smartphone Video on Lead Time to Diagnosis of Infantile Spasms 5

Rao et al.,"The Effect of Smartphone Video on Lead Time to Diagnosis of Infantile Spasms", *J Pediatr*, Jul 2023.

Infantile Epileptic Spasms (IES) – Lead Time

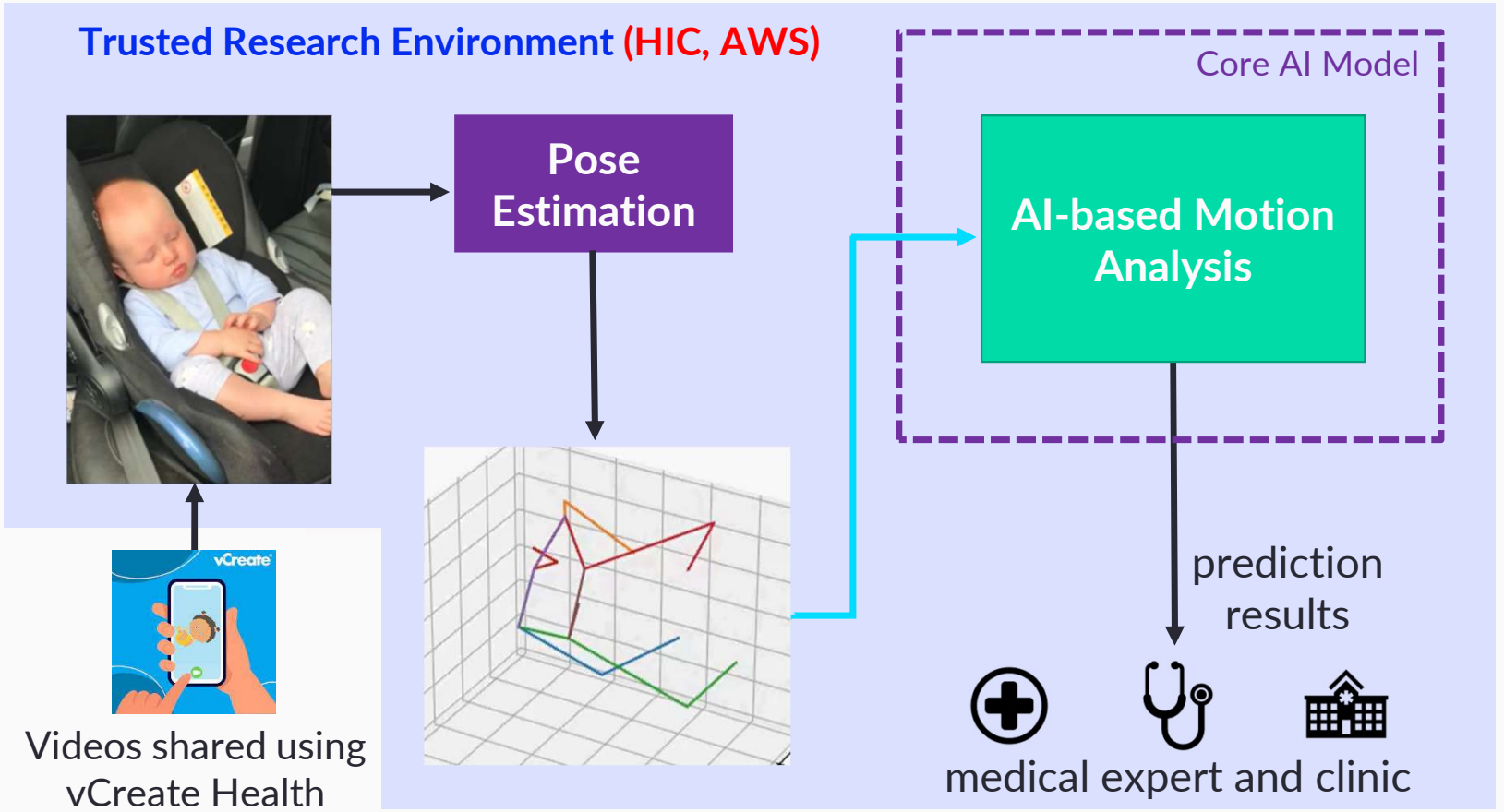
- Median lead time to treatment was 60 days (in high resource countries it is typically days)
- 80% of people with epilepsy live in low-resource settings. 70% do not receive an appropriate diagnosis and treatment
- AI analysis of smartphone video could be integrated into a clinical decision support tool and support timely diagnosis around the world

Table 3
Lead time to treatment and treatment response.

Lead time	N (%) responding to first line therapy	Cumulative N (%) responding to second line therapy	N (%) with resistant spasms at 3 months	χ^2 test for trend (resistant spasms at 3 months)	N with missing information of treatment response
≤7 days	10/11 (91%)	11/11 (100%)	0/11 (0%)	(χ^2 = 10.0 (1 d.f.),	1
8-14 days	9/16 (56%)	15/16 (94%)	1/16 (6%)	p = 0.0015)	0
15 days to 2 months	23/44 (52%)	30/44 (68%)	14/44 (32%)		2
> 2 months	19/38 (50%)	23/38 (61%)	15/38 (39%)		0

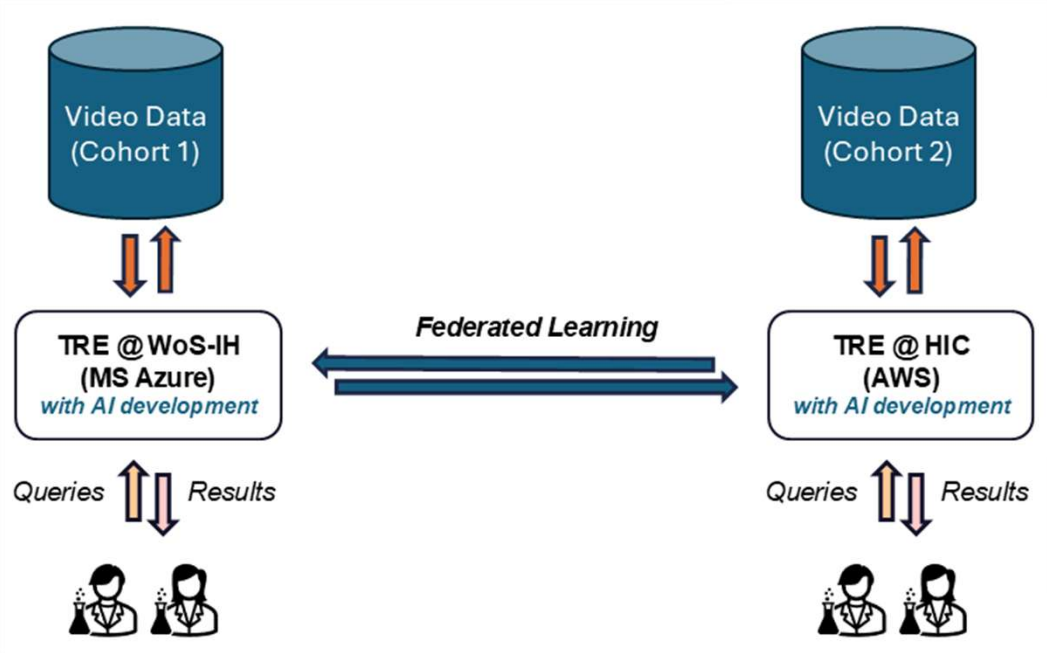
Surana et al., "Infantile spasms: Etiology, lead time and treatment response in a resource limited setting", *Epilepsy Behav Rep*, Oct 2020.

Our Work - Detecting Infantile epileptic spasms (IES) from smartphone videos using AI



Project Overview and Objectives – *upscaling our IES detection through Federated Learning across multiple TREs*

SAFEVID
A DARE UK PROJECT



To evaluate the feasibility of **federated learning** between TREs on **different cloud vendor** platforms.

To evaluate the feasibility of **federated learning** between TREs containing **patient data from distinct cohorts**.

To evaluate the most feasible and secure **federated learning options within the DARE ecosystem**.

To **quantify the benefits of federated learning** on our IES detection machine learning model **through uncertainty estimation** in the prediction results.

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

SAFEVID
A DARE UK PROJECT

Enablers and Our Progress

K8TRE – *SATRE compliant TRE*
Interoperability of TREs (eg with providers such as MS Azure, AWS, etc)

SACRO ML
Providing risk assessment on trained models

Neurology Video Dataset
35,000+ consented videos & Ethical approval

PPIE Partners
Epilepsy Research Institute UK, Epilepsy Scotland, and more

TRE for AI Development
supported by HIC and AWS

Mutual National Collaboration
including neonatal, paediatric teams

UK Research and Innovation
HDRUK Health Data Research UK
ADR UK Data-driven change

Patient, Public and Professional Involvement and Engagement (PPPIE) activities

- Established partners and ongoing PPPIE activities (since 2022) to inform our video-based AI research projects

- Proposed project activities
  - **Inaugural Workshop** – introduce our project and take early feedback
  - **Educational Workshop** - demystify TRE and AI, understand their views
  - **Research Showcase** – disseminate outcomes, encourage future engagement

SAFEVID
A DARE UK PROJECT

Our Interdisciplinary Team

Edmond Ho[1]

Senior Lecturer in Machine Learning

Sameer Zuberi[1,4]

Consultant Paediatric Neurologist

Neil Patel[1,2,4]

Consultant Neonatologist

Richard Walls[3]

HIC Operational Director

Isla Birnie[1]

PIE Lead Grant Manager

1 University of Glasgow

2 NHS SCOTLAND West of Scotland Innovation Hub

3 University of Dundee Health Informatics Centre

4 NHS Greater Glasgow and Clyde

UK Research and Innovation

HDRUK Health Data Research UK

ADR UK Data-driven change

Stay in touch! – QR codes

Visit our website

SCAN ME

Contact us

SAFEVID
A DARE UK PROJECT

Shu-Lim.Ho@glasgow.ac.uk