# Health Data Research and the HDR Facility

Anthony Brookes

# HDR Facility Website - https://brookeslab.le



**LEICESTER HDR FACILITY**

Home    About    Help Desk    Get Started

## Welcome to Leicester HDR Facility

Health data research is becoming a major topic of interest that bridges academia and healthcare, with funders very keen to support projects, and AI adding further exciting possibilities. To significantly boost health data research in the Leicester region, the College of Life Sciences recently provided a dedicated set of office spaces for an "HDR facility" (Room G21 in the Maurice Shock Building), within which practitioners and trainees from across the University and UHL will be able to claim a space, desk-share, or simply hot-desk as needed.
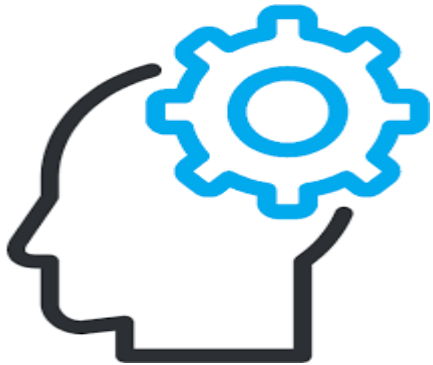
Get Started

# Acknowledgements

# (Health) Data Science
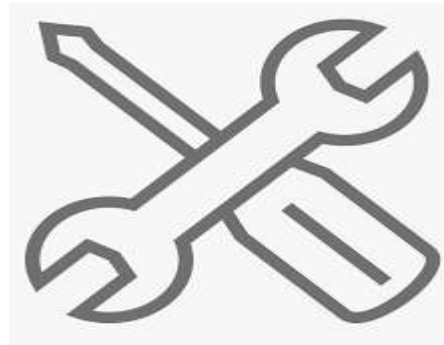
**Methods**      **Engineering**      **Application**

# F1 Racing Team

Methods → Engineering → Application

Lewis Hamilton + Max Verstappen

# Who wants/needs the HDRF ?
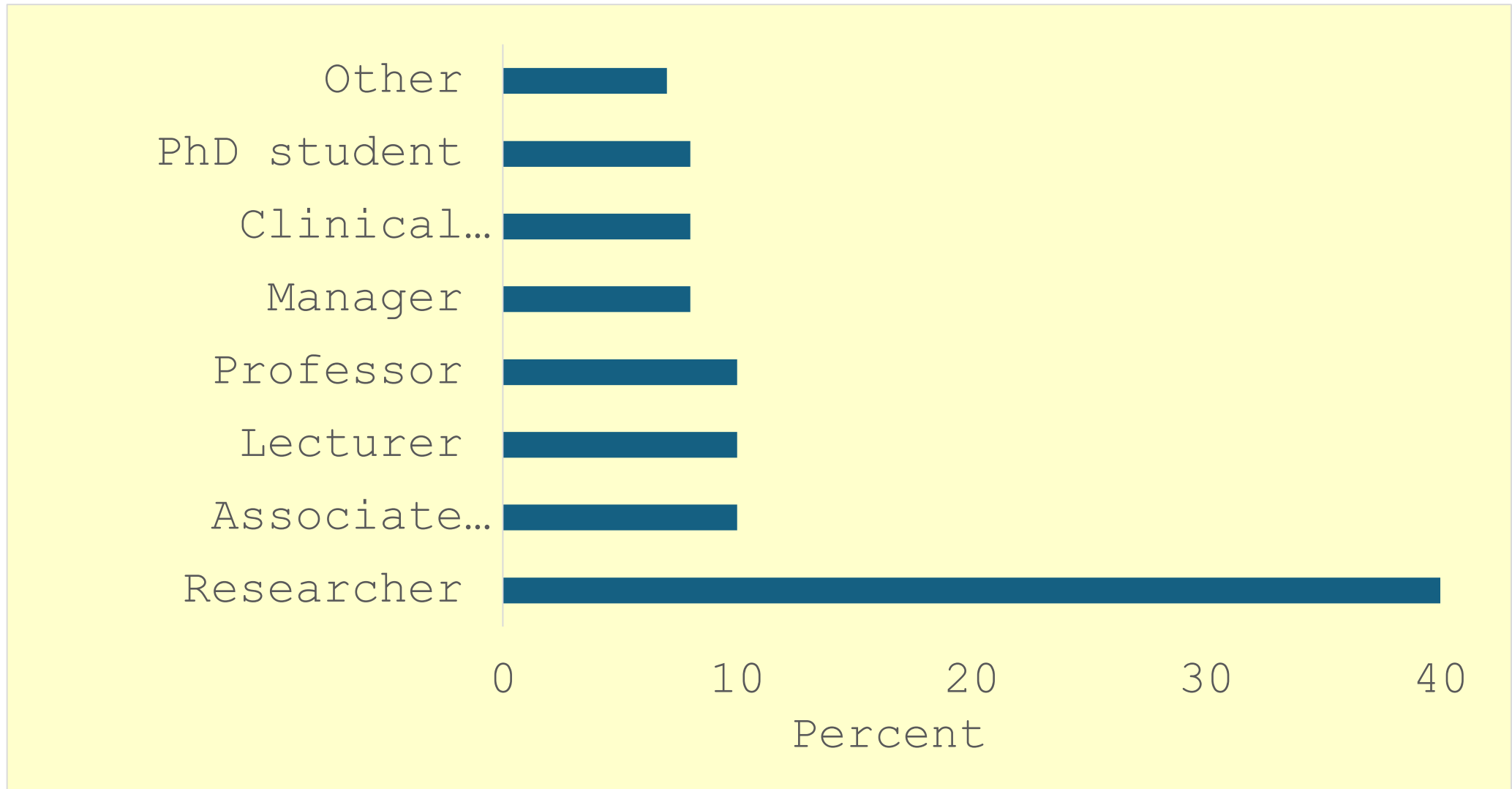
Not prominent:
statistics, data management, databasing standards,
data sharing, HPC, coding, curation/harmonisation,
data quality, PPIE, training…

**Methods**     **Engineering**     **Application**

Analysis Technologies
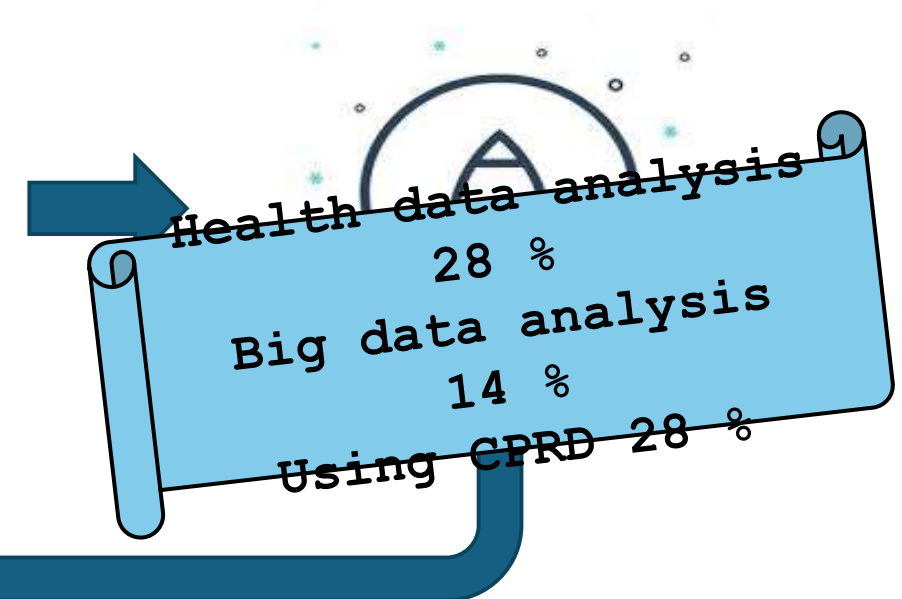21 %

Health data analysis
28 %
Big data analysis
14 %
Using CPRD 28 %
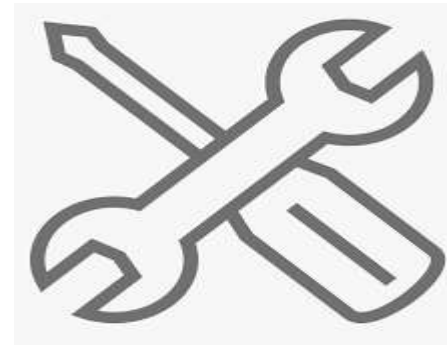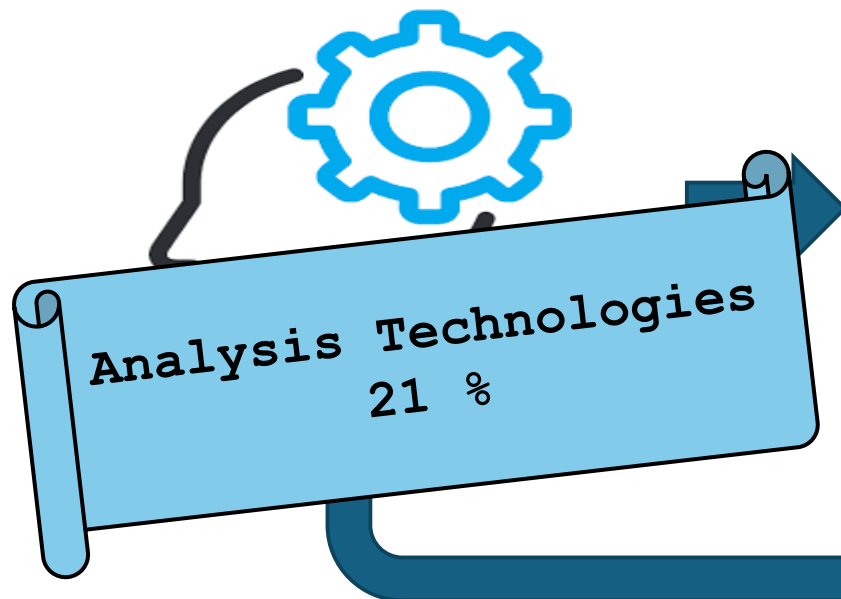
# UoL Collaboration with the Apollo Group
Tim Coats

# Leicester starts initiative with Apollo to transform global healthcare

3 min read

## The University of Leicester has signed a Memorandum of Understanding with one the world's largest integrated healthcare service providers, The Apollo Hospitals Group. 🔗

The Memorandum will strengthen existing links with India and sets out a mutual desire to promote international cooperation and explore collaborative education and research programmes, particularly in the fields of healthcare management, healthcare and data science.

President and Vice-Chancellor of the University of Leicester, Professor Nishan Canagarajah, said: "The purpose of this Memorandum of Understanding is to set

# Apollo Healthcare



## Unified Single Electronic Health Record

45+ Million Patients

15+ Years of Longitudinal Records

# A Tripartite Partnership Between

# Leadership

Apollo HOSPITALS    UNIVERSITY OF LEICESTER    AHERF

## Co-Directors



Nilesh Samani and Sujoy Kar

## Executive Group



**Professor Huiyu Zhou**
Professor at University of Leicester

**Professor Kamlesh Khunti CBE**
Professor of Vascular Medicine at University of Leicester

**Ms. Ishita Shively**
Senior Vice-President at Apollo Research and Innovations

**Dr. Alfred J Augustine**
Dean at Apollo Institute of Medical Sciences and Research

## Oversight Group



**Professor Henrietta O'Connor**
Provost & DVC at University of Leicester

**Professor Thompson Robinson**
Pro Vice Chancellor & Dean of Medicine at University of Leicester

**Professor Ravi Mahajan CBE**
Director, Research & Innovation at Apollo Hospitals

**Professor H Vinod Bhat**
Vice Chancellor at The Apollo University

# The Chittoor and Leicester Hubs

## CHITOOR

## LEICESTER



**FEDERATED STRUCTURE**

# CDHPM: Vision and Mission

**VISION**

To become an internationally recognized research center that advances healthcare and its delivery through the development and deployment of novel digital health and precision medicine solutions.

**MISSION**

To harness the extensive patient database of the Apollo Hospitals Group, and datasets available at the University of Leicester and through other Partners

**+**

The research and clinical expertise of investigators at UoL, Apollo Healthcare and our partners

**→**

To deliver better care for patients

# Funding the Center



## AHEL / TAU    Up to £500,000

These funds will be used over the initial three-years to (i) appoint key staff for the Centre (ii) develop the cloud infrastructure and (iii) pump-prime innovative projects in the Centre with the potential to progress towards clinical utility and/or secure external funding

## University of Leicester    Up to £575,000

Funding for (i) one **four year PhD studentship** for each of the first five years of the Centre (~ £90K per student; Total £450K based on 2024/25 fees and stipend rates) (ii)  a discretionary award of **£25,000** per annum for the first five years (subject to annual review)

## Long Term Sustainability

a)  securing external national and international **competitive grant funding**;
b)  funding obtained through **collaborations**, including with industry;
c)  Funding obtained through philanthropic support
d)  funding through **research studentships** based in the Centre; and
e)  ongoing intramural support from TAU and UOL, including **API commercialisations**

# Potential Apollo data assets for CDHPM

- 45 million patient EPR based dataset.
- Data within a research TRE.
- Data governance system for research in place.
- Analyst funded and in place.
- Integrated with data science at Apollo University (AI academic unit).
- Current Questions:
  - Degree of curation
  - Population generalisability
  - Data quality
  - Alignment of academic cultures

# People

The Centre will have three types of staff:

- Core staff – including the Co-directors, Deputy Manager, Data Scientists and Engineers employed by the Centre, and Students. The Core staff will be responsible for the day to day scientific running of the Centre

- Faculty Members - researchers, scientists or clinicians employed by, or associated with, Apollo University, the Apollo Healthcare System, or the University of Leicester who will lead or contribute to the development and execution of projects within the CDHPM.

- Affiliated members and partners – These will include external individuals, consortia or organisations who establish collaborations with the CDHPM through its core or faculty members, usually on a project-by-project basis.

Core functions such as HR, Finance and Facility maintenance will be provided by TAU and UOL

- Two initial meetings have been held.
- Development of mutual understanding underway (example "ICU")

- First collaborative grant application in progress.
-  Editorial being written
- Workshop on current research planned

# Focus of work – detection of deterioration

- Validation of current Apollo illness severity score.
- Comparison of Apollo score and NHS EWS
- Integration of EPR with severity score (already underway in Apollo hospitals).
- Potential future areas:
  - General score v Condition specific scores.
  - Individualisation of risk scoring (a precision medicine approach).
  - Ethnic differences in accuracy of scoring.
  - Benchtop exploration of population variation and scoring accuracy.
  - Implementation science of scoring systems.
  - Clinical trial methodology for testing impact of scoring systems.
  - Limits of generalisability of scoring systems.

# Governance Structure

**The Executive Group**

**Joint Oversight Group**

**The Management Team**

**Sub Committees**

- Data Governance Committee
- Clinical & AI Ethics Committee
- Infrastructure Committee
- IP & Commercialization Committee
- Communication Committee

**External Scientific Advisory Group (ESAG)**

**Partner's Network Forum**

- Founding Partners
- Network Members
- Affiliate Members



Apollo Research Academy Board
And
University of Leicester Research Institute Oversight Board

Joint Oversight Group

External Scientific Advisory Group

Executive Group

Partners Network Forum

Management Team

Sub Committees
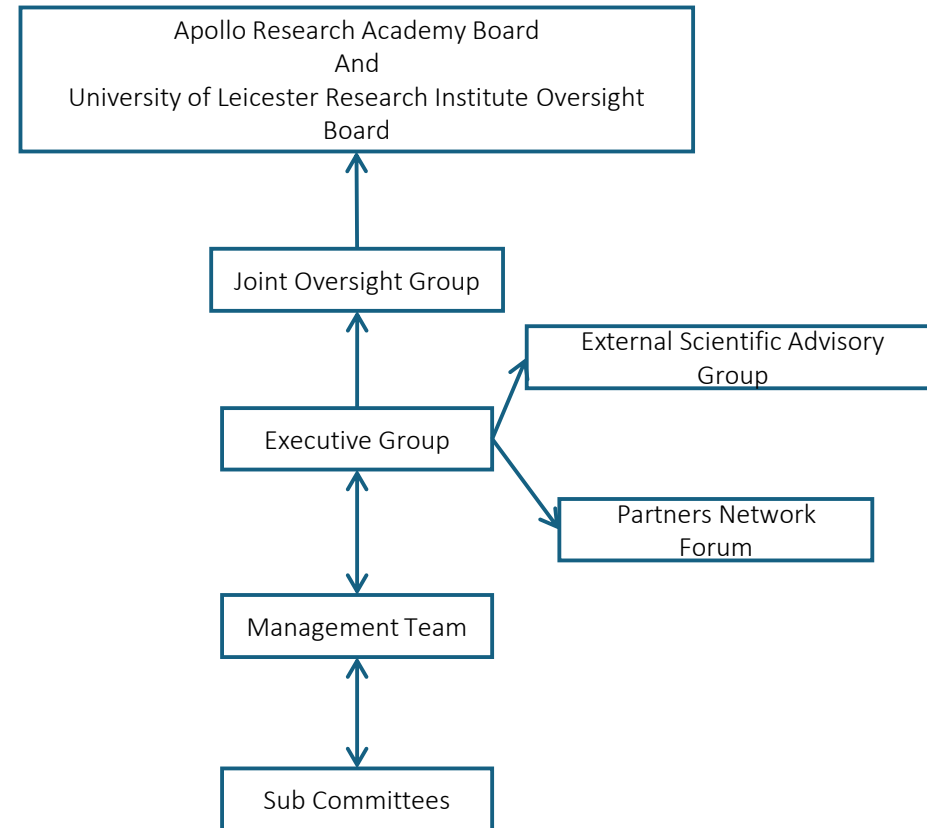
# Data Privacy & Security : Centre's Computing Architecture

# Trusted Research Environment (TRE)



**Data Partner Tenant**

Key + policy

mHSM

**Data Provider**

Storage with encrypted training data

Apollo Hospital's Anonymized Processed Data

**TRE**

Model Training/Fine-tuning

Storage and Identity

Remote Attestation

Secure Key Release

**Confidential Containers based constrained environment**

Key + policy

**Model Partner Tenant**

mHSM

**Model developer**

Storage

Input model & Training parameters

Storage

Fine-tuned model

Advantage –
- ❖ Secure Data Collaboration
- ❖ Anonymized Patient Privacy
- ❖ AI tools IP Protection
- ❖ Collaborative Cyber-defence
- ❖ Better Computing abilities

Researchers from CDHPM

**Reuse – Recombination -- Redesign**

# Examples of Modelling, Data science and AI research at the University of Leicester

**Prof Simon Gill**

**Dean of Research & Enterprise for the College of Science and Engineering**

# Research Themes in the College of Science and Engineering

UNIVERSITY OF LEICESTER

**Space**
- Institute for Space
- Centre for Exoplanet Research
- National Centre of Earth Observation
- Space Park Leicester

**Environment**
- Institute for Environmental Futures
- Centre for Paleo. & Biosphere Evolution
- Environmental Health & Sustainability

**Sustainable Technology**
- Centre for Sustainable Materials Processing
- Centre for Sustainable Resource Extraction
- Centre for Digital Manufacturing

**Health**
- Institute for Precision Health
- Institute for Structural & Chemical Biology
- Biomedical Research Centre

**Culture & Heritage**
- Institute for Digital Culture
- Centre for Critical & Creative Geographies
- Heritage Hub

**AI & Data Science**

**UNDERPINNING CAPABILITY**
Turing University Network / Centre for AI, Data Analytics & Modelling (AIDAM)

**Digital Twins for Tropical Wetlands (UKRI FLF)**

Robert Parker (Physics - EO)



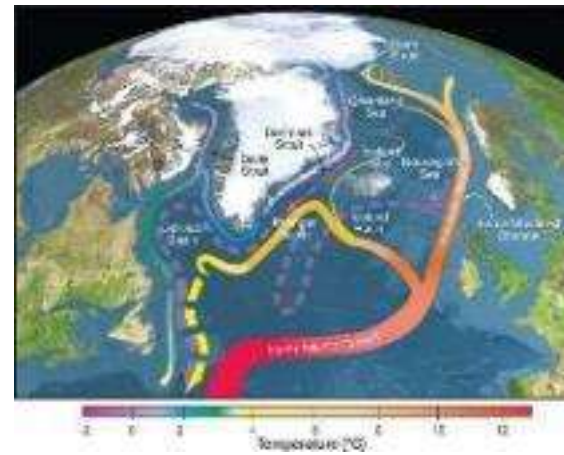**Digital Twins for Sustainable Land Management (EPSRC – UKRI AI for Net Zero hub)**

Heiko Balzter (GGE) Ashiq Anjum (CMS)



**Climate Tipping Points (ARIA)**

Valerio Lucarini (CMS)



**Digital Twins for Ceramic Manufacturing (EPSRC)**

Jingzhe Pan (Engineering)





**IGNITE Manufacturing Hub (UKRI)**

Hongbiao Dong (Engineering)

New research hubs to cut carbon and reshape UK manufacturing

University of Leicester and The Apollo University launch global research centre for digital health and precision medicine

20 January 2025

**Self-learning AI-based digital twins for accelerating clinical care in respiratory emergency admissions (EPSRC)**

CMS/Respiratory/Cardiovascular/Media & Comms/Population Health Sciences

**PRE-ACT : Prediction of Radiotherapy side effects using Explainable AI for patient Communication and Treatment modification (Horizon Europe/Innovate UK)**

Christopher Talbot (GGB)
Tim Rattay (Cancer Research Ce...

NIHR | Leicester Biomedical Research Centre

Kamlesh Khunti (Leicester Diabetes Centre)
Laura Grey (PHS)

Data Innovation for Multiple Long-Term Health Conditions and Ethnic Health

University of Leicester

DIRAC HIGH PERFORMANCE COMPUTING FACILITY
Supporting the STFC Theory Community

Mark Wilkinson (Physics)

**A new light on Jupiter's auroral processes with James Webb, Hubble and Junon (STFC)**
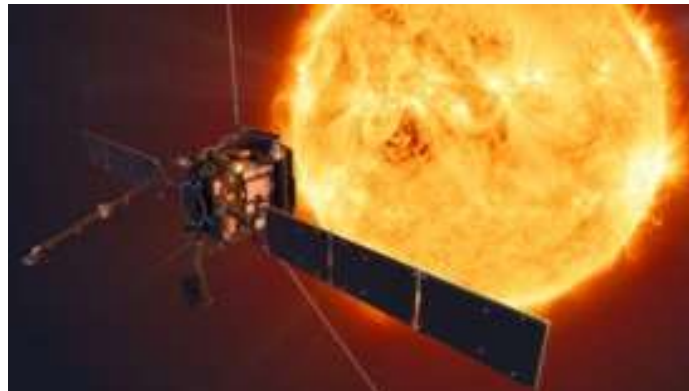
Jonny Nichols (Physics)

**ALICE HCP (4000 cores)**

**Thermal digital twin of Solar Orbiter (ESA Airbus)**

Ashiq Anjum (CMS)

**Space**

**Novel probes of the distant universe using Gamma Ray Bursts (STFC)**

Nial Tanvir FRS (Physics)

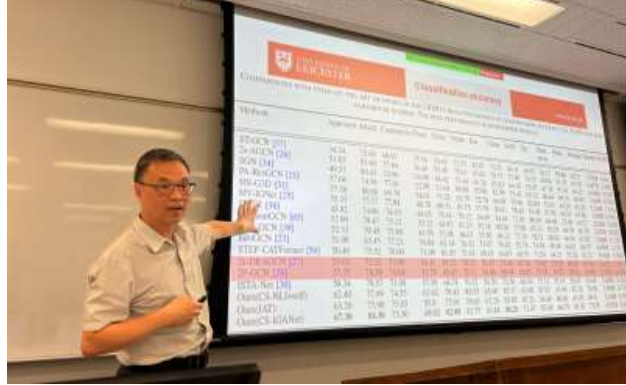Leicester cosmic explosion expert among exceptional scientists elected as Royal Society Fellows
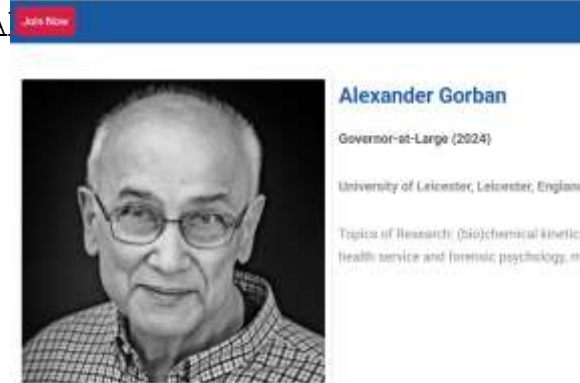
**Distinguished Artificial Intelligence Scholar Award for 2025 from the**

**US National Academy of Artificial Intel**

Huiyu (Joe) Zhou (CMS, co-director AIDA)



INTERNATIONAL NEURAL NETWORK SOCIETY

Join Now

**Alexander Gorban**

Governor-at-Large (2024)

University of Leicester, Leicester, England

Topics of Research: (bio)chemical kinetics, health service and forensic; psychology; mut

**ULTRACEPT: Ultra-layered perception with brain-inspired information processing for vehicle collision avoidance**

Shigang Yue (CMS)



EU Horizon 2020    ULTRACEPT(778062)

**Sustainable Data Centre Digital Twins (CGI)**

Ashiq Anjum (CMS)



**ENERGY FORECAST**
Widely cited forecasts suggest that the total electricity demand of information and communications technology (ICT) will accelerate in the 2020s, and that data centres will take a larger slice.

20.9% of projected electricity demand

- Networks (wireless and wired)
- Production of ICT
- Consumer devices (televisions, computers, mobile phones)
- Data centres

2010 2012 2014 2016 2018 2020 2022 2024 2026 2028 2030

**Personality Traits and Drug Consumption**

Elaine Fehrman; Vincent Egan (Psychology)
Alexander Gorban; Evgeny Mirkes (CMS)



Openness    Conscientiousness    Extraversion

The Big Five Personality Traits

Agreeableness    Neuroticism

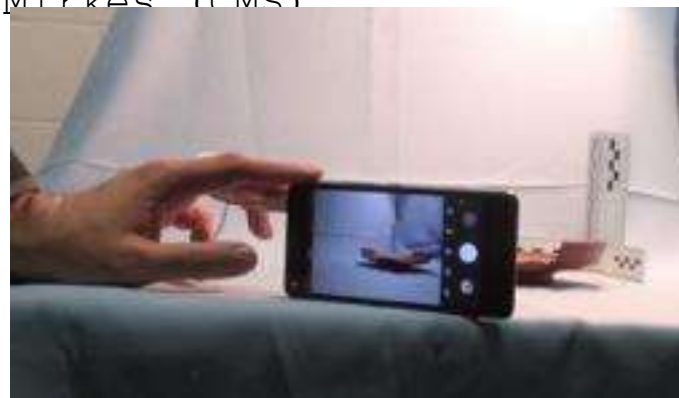**Society, Heritage & Culture**

**Breaking the Dickens code (AHRC)**

Claire Wood (English)
Huiyu (Joe) Zhou (CMS)



**Arch-I-Scan (AHRC)**

PI: Penelope Allison (Archaeology)
Co-I's: Alexander Gorban; Evgeny Mirkes (CMS)



**Museum Data Service (AHRC)**

Ross Parry (Museum Studies)

Access to UK's cultural heritage is revolutionised by Museum Data Service launch

13 September 2024



Professor Ross Parry, Director of the University's Institute for Digital Culture at the London launch. Photo: James Winspear

**Business, Finance & Economics**

**Development of AI software for a credit-chasing tool with financial software company Draycir (Innovate UK)**

Will Darler (College of



FINTECH

**Professor Xue Zhou**
Professor in AI in Business Education

School/Department: Marketing and Strategy, School of
Email: xue.zhou@le.ac.uk

**The Impact Of Technological Transformations On The Digital Generation (Horizon)**

Athina Karatzogianni (Criminology, Sociology and Soci



DigiGen

The impact of technological transformation on the digital generation
- policy recommendations
Policy brief November 2022

www.digigen.eu

**Development of Customer Intelligence software with The Audience Agency (Innovate UK)**

Will Darler (College of Business)

# Rutland

# (Primary Care) Data for Research

**Anthony Brookes**
**(for Nigel Brunskill)**

# The Aim

To make primary care data available for research purposes

# The Problems

- Each general practice is data controller for its own practice data

- ICB has access to aggregated anonymised PC data for service planning but not for research

- Individual agreements needed with each practice to process their data for research

- Need to be accompanied by substantial assurance about data governance

# The Solution



Leicester, Leicestershire & Rutland

# Data for Research

Information for GPs and practice managers about the work of the Primary Care Data for Research Forum and what we want to achieve for Leicester, Leicestershire and Rutland (LLR).

# The Solution

- GDPR compliant data transfer from SystmOne

- Local NHS data processor – LHIS

- PRIVITAR as secure data privacy solution for LHIS

- Only for approved research studies subjects to some form of institutional review

- No patient identifiable data

- Secure processes needed for anonymised data transfer

# 11.0 - Schedule 1– Data Items

| Table Name | Table Description |
|---|---|
| SRActivityEvent | The SRActivityEvent file records the specific consultation activities associated with an event. These are entered via the Event Details dialog within the patient record. They can also be automatically entered when performing a care plan.<br><br>Each SRActivityEvent will have a corresponding row within the SREvent table. A row in SREvent may not have a corresponding row within the SRActivityEvent table. |
| SRAppointment | The SRAppointment file lists all appointments for all organisations. |
| SRAppointmentAttendees | The SRAppointmentAttendees file lists all the attendees recorded against a patient's appointment.<br><br>This table has been superseded by SRAttendee and will be removed in the 09/05/19 release. |
| SRAppointmentVisitOutcomes | The SRAppointmentVisitOutcomes file lists the information recorded when entering outcomes for appointments and visits. |
| SRCode | The SRCode file shows the Read codes recorded for a patient including the CTV3 Read code and the numeric value for that entry, if appropriate. |
| SRCtv3Hierarchy | Provides the hierarchical relationships between CTV3 Read codes.<br><br>Each CTV3 Read code is listed against all of its parent CTV3 Read codes including the level at which the relationship exists (e.g. parent, grandparent etc). |
| SRGPPracticeHistory | The SRGPPracticeHistory file shows the practice history for each patient. |
| SRImmunisation | The SRImmunisation file shows the details of immunisations for patients including the immunisation name and dose. |
| SRImmunisationContent | The SRImmunisationContent file shows the details of immunisations including the immunisation name and its contents. |
| SRMedicationReadCodeDetails | The SRMedicationReadCodeDetails file allows users to map a Read code to a Multilex drug. NB - This is a deprecated table and will be removed in a future release. This is not SystmOne data (no drug Read Code is being recorded in the front end), and the mappings from IDMultiLexProduct to DrugReadCode are one to many. Please use SRPrimaryCareMedication for associated data analysis. |
| SRPatient | The SRPatient file provides a list of the patients registered at the organisations included in the extract. |
| SRPatientContactDetails | The SRPatientContactDetails table shows all current contact details and types for each patient. |
| SRPatientContactProperty | The SRPatientContactProperty table contains information recorded against a visit or diary entry. For example, the purpose of the contact being made. |
| SRPatientGroups | The SRPatientGroups file shows all the patient groups recorded against the patient. Patient groups can be used to make multiple SystmOne patients members of the same group or family within the system. This is often used to create a list of patients who are cared for in the same residential or nursing home, for example. |
| SRPatientRegistration | The SRPatientRegistration file provides registration details for patients registered at the organisations included in the extract. |
| SRPrimaryCareMedication | The SRPrimaryCareMedication file shows the details of medication for patients including the Multilex name of the medication and dosage. This is mainly used in the GP and community modules, but can also be used in Palliative Hospitals. |
| SRReferralIn | The SRReferralIn table shows the details of referral ins for patients including the referral category and reason for referral. |
| SRReferralInIntervention | SRReferralInIntervention provides the list of interventions set against a referral. |
| SRReferralInReferralReason | SRReferralInReferralReason provides the list of reasons entered against a Referral In when making the referral. |
| SRReferralInStatusDetails | The SRReferralInStatusDetails file shows individual status updates for a referral in. |
| SRReferralOut | The SRReferralOut table shows the details of referral outs for patients. |
| SRReferralOutStatusDetails | The SRReferralOutStatusDetails file shows individual status updates for a referral out. |
| SRRepeatTemplate | The SRRepeatTemplate file shows the details of medication repeat templates for patients including the Multilex name of the medication. |
| SRServiceDeliverySchedule | The SRServiceDeliverySchedule file contains all the details about each service schedules recorded for a client at a social care organisation. |
| SRVariableDoseCDMedication | The SRVariableDoseCDMedication file shows details for medication recorded as variable dose controlled drugs. |

**NHS**

Leicester, Leicestershire & Rutland
**Data for Research**

# Data Processing Agreement

Between LLR GP Practices (acting as Joint Data Controllers for the LLR DfR database) and Leicestershire Health Informatics Service (Data Processor)

---

Leicester, Leicestershire & Rutland
**Data for Research**

### Message for Patients about the LLR Data for Research Project

This local project is led by a forum of both NHS and University of Leicester academic staff and includes representatives from local clinical commissioning groups, the Local Medical Committee, GPs and Information Governance.

The GPs in this practice look after your medical records and data. They have agreed to NHS Leicestershire Health Informatics Service (LHIS) legally extracting and processing data from the practice so that it can be held and then released in an anonymous way for research purposes. 'Anonymised' means that you will not be identified. Researchers' requests for use of this data will be made via an application form, and the LLR DfR Forum members, together with a GP representative, will decide whether data requests for anonymous should be granted.

Safe and secure software technology is being used and all the work will comply with the existing data protection legislation (GDPR/DPA 2018).

This practice has reviewed and signed a Data Processing Agreement (DPA) with LHIS and also has a Data Protection Impact Assessment (DPIA) in place which covers any risks to the data associated with LLR Data for Research.

We are supporting the project because the data being collected can make a huge contribution to the way research is conducted in and beyond our area; research which aims to advance future treatment and care for you and for other patients.

Our Privacy Statement about this project provides more information and is on our practice website.

---

### Data Protection Impact Assessment for GP Practice Use

| | |
|---|---|
| DPIA Title: | Leicester, Leicestershire & Rutland Data for Research Projects. (LLR DfR) |
| Data Protection Officer consulted (date): | 30/02/2020 |
| Data Protection Officer comments: | Validated by MLCSU. Please keep a copy in your records -Approved by DPO 30/02/2020 Reviewed and approved by Umar Sabat, IG Health 01/06/21 |
| Data Protection Officer signature: | |
| Caldicott Guardian consulted (date): | |
| Caldicott Guardian comments: | |
| Caldicott Guardian signature: | |
| SIRO approval (date): | |
| SIRO comments: | |
| SIRO signature: | |

# LLR-DfR Website -
https://brookeslab.le.ac.uk/llr-dfr/



**PRIMARY HEALTHCARE DATA FOR RESEARCH**

Home    About    Access Process    Help Desk    Acknowledgements    Get Started

Anonymous data from 30 GP practices in Leicester, Leicestershire and Rutland, have been pooled and made available for use in ethically-approved healthcare research. A support team and an **online tool** are provided to enable bona fide researchers to safely explore and profile this *Leicester, Leicestershire and Rutland Data for Research (LLR-DfR)* dataset, in advance of seeking secure access via an assisted and responsible access request process.

## ABOUT

The LLR-DfR dataset is securely managed by the non-profit Leicester Health Informatics Service (LHIS). They will provide customised portions of the data for approved research, for a minimal fee, with this process being facilitated by the research group of Professor Anthony Brookes. This team also provides a **dedicated interface** and support service via which the dataset can be initially profiled to evaluate its suitability for use in addressing specific research questions.

# LLR-DfR Exploration Tool – https://fair-hd4r.ca:



**Cafe Variome Central**

Discover    Hello Anthony ▾

## Discover - Query Builder

### PATIENT INFORMATION

Age:    58 - 99

Gender:    **Male**    Female    Any

### SNOMED CT

Q  Start typing and a list of relevant items will populate...          Q  filter by keyword

Add          Remove

### MEDICATION

Q  Start typing and a list of relevant items will populate...          Q  filter by keyword
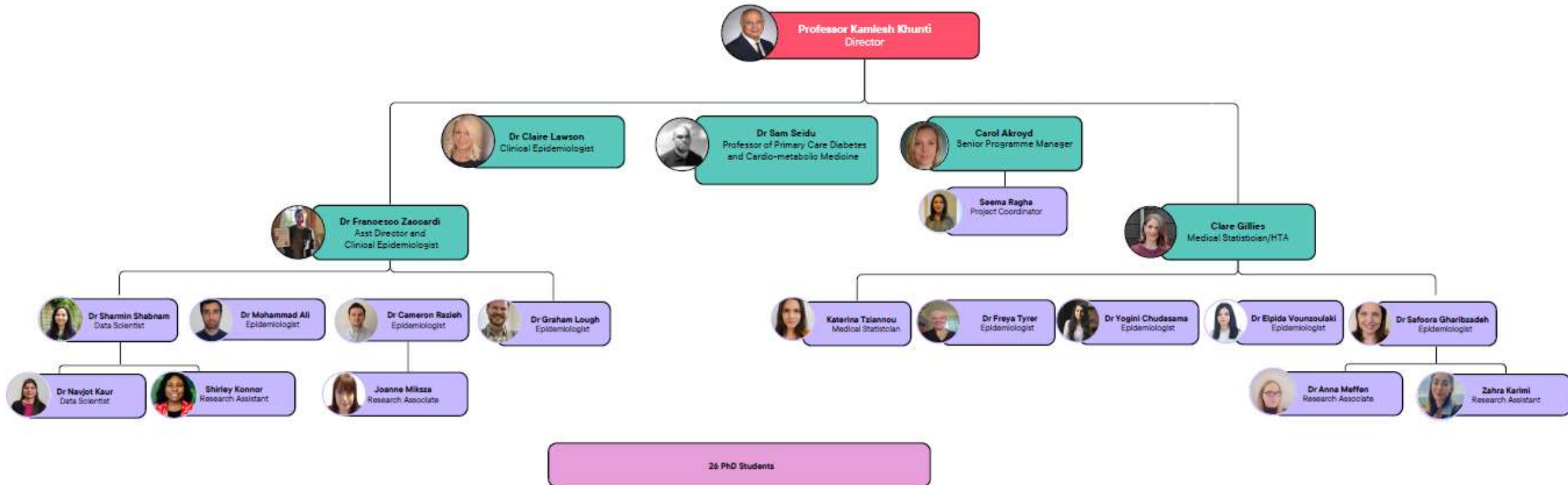
Add          Remove

Q Build Query    🗑 Reset

# An Introduction the Leicester Real World Evidence Unit (LRWE) and the Clinical Practice Research Datalink (CPRD)

Joanne Miksza

# Leicester Real World Evidence Unit

# What is the Clinical Practice Research Datalink (CPRD)?



Longitudinal primary care records

Linkage to health datasets
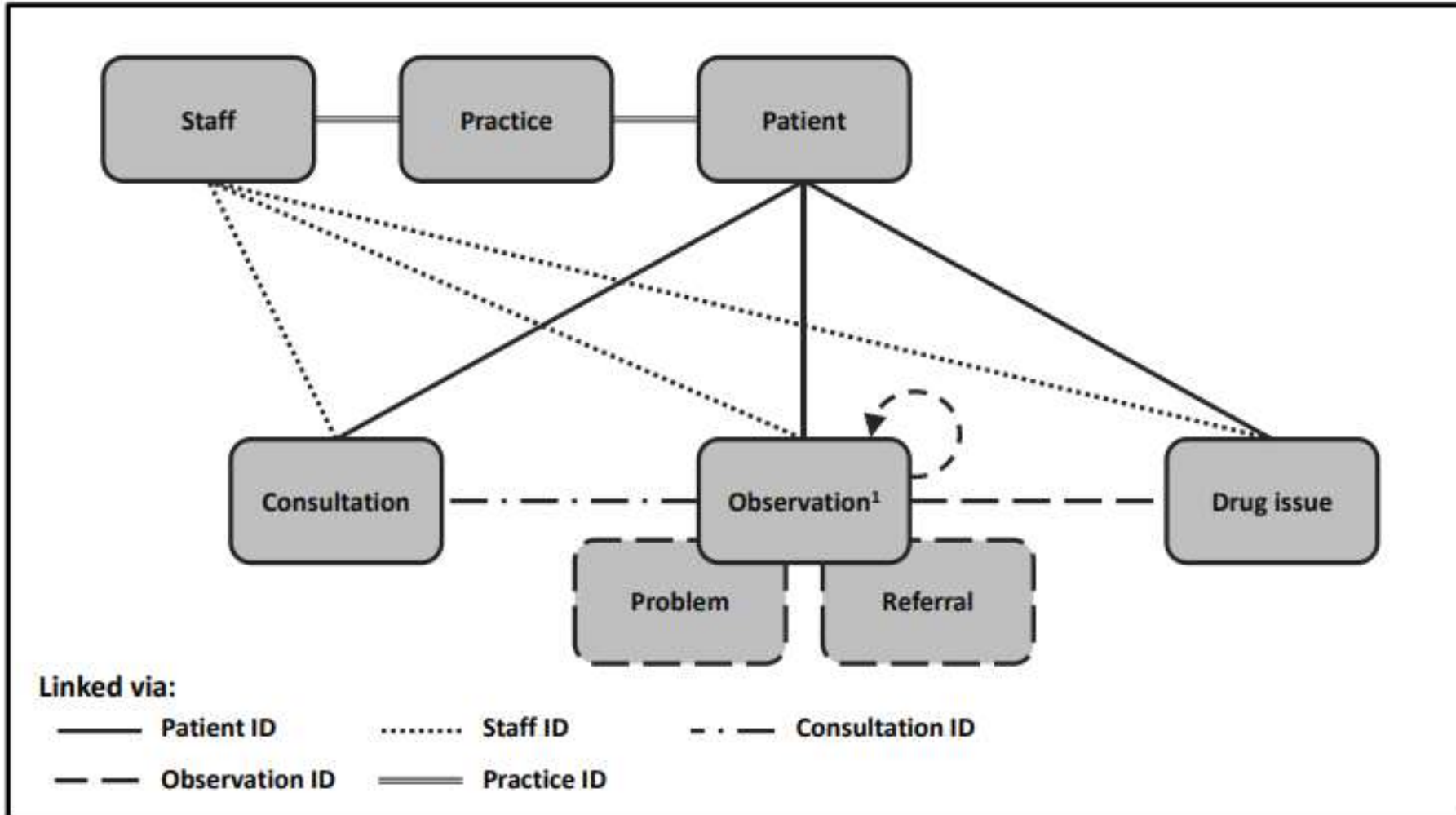
60 million patients
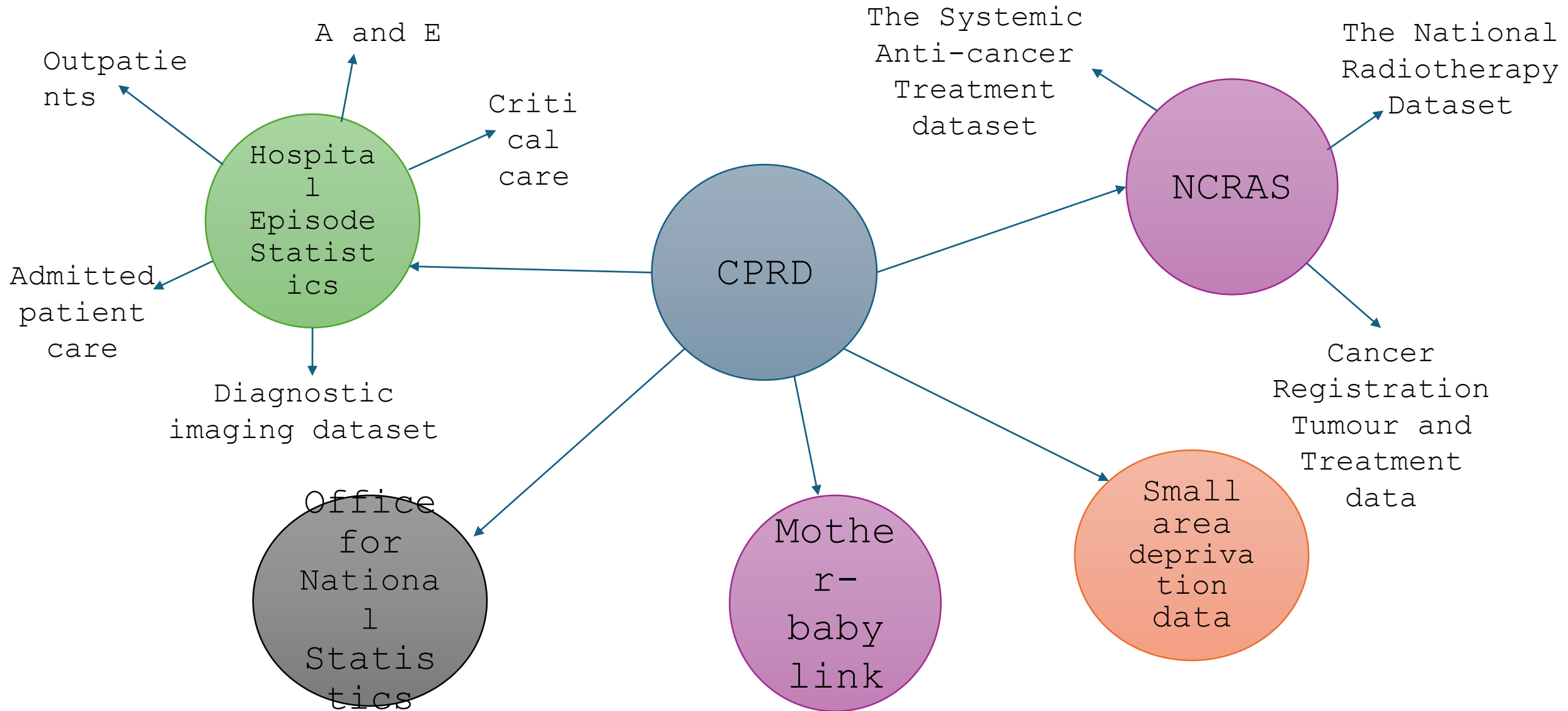
UK network of GP practices

16 million recruitment pool

Retrospective and prospective

# The CPRD Aurum data set

# Linked datasets

# Process for applying to use C data

- LRWE have a multi-study license
- A protocol for the study has to be submitted through eRAP system This must be approved by CPRDs ethics committee.
- Feasibility counts can be requested from CPRD fob holders
- There can be several rounds of amendments/approvals
- Data will be extracted by a fob holder
- Linkage datasets can be requested
- Data is ready to be cleaned and analysed

# Where to find out more

- Email the LRWE unit: Clare Gillies clg13@le.ac.uk, Sharmin Shabnam ss1279@le.ac.uk

- CPRD online training modules: http://learning.mhra.gov.uk/mhra/index.jsp

- https://www.cprd.com/

- enquiries@cprd.com