

CLOSER – UK LLC webinar: a step-by-step guide to applying and accessing linked data in the UK LLC Trusted Research Environment

Introduction

Robin Flaig
Deputy Director
5 April 2022

AGENDA

Introduction
Application process
Data Request

Robin Flaig
Stela McLachlan
Sammy Berman

Break for questions

Data Access
Public Involvement
Legal Documentation

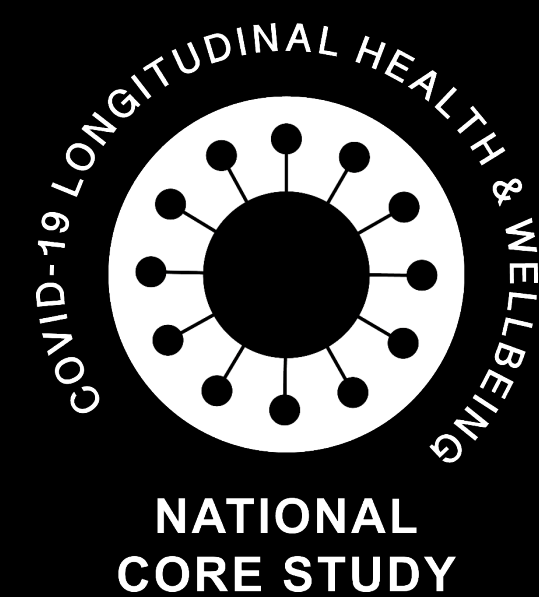
Rich Thomas
Kirsteen Campbell
Jacqui Oakley

Break for questions

Conclusions and summary

Robin Flaig

A collaboration to benefit public health



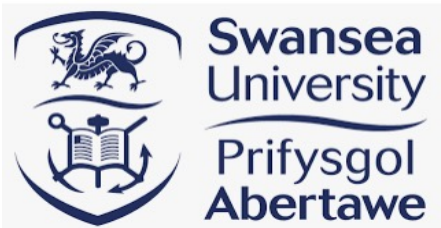
UK LLC led by the Universities of Edinburgh and Bristol



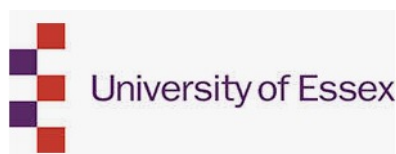
THE UNIVERSITY
of EDINBURGH



In collaboration with



A work package in the COVID-19 Longitudinal Health & Wellbeing National Core Study



UK Longitudinal Linkage Collaboration



A four-nations infrastructure for secure cross-cohort analysis

Align complex and divergent governance frameworks into a streamlined and predictable linkage/access route

Develop a sustainable four-nations data science infrastructure

A new way of working for record linkage

Watch our animation: <https://youtu.be/zFkvpKD3jvs>

UK LLC Design Decisions:

Interdisciplinary

Four nations approach

Pre-pandemic & pandemic data

Trusted Research Environment

Five Safes access model

De-personalised data only

Distributed governance

Transparent in its operations

Public Involvement programme

A globally unique cross-cutting resource



20+ Longitudinal Population Studies

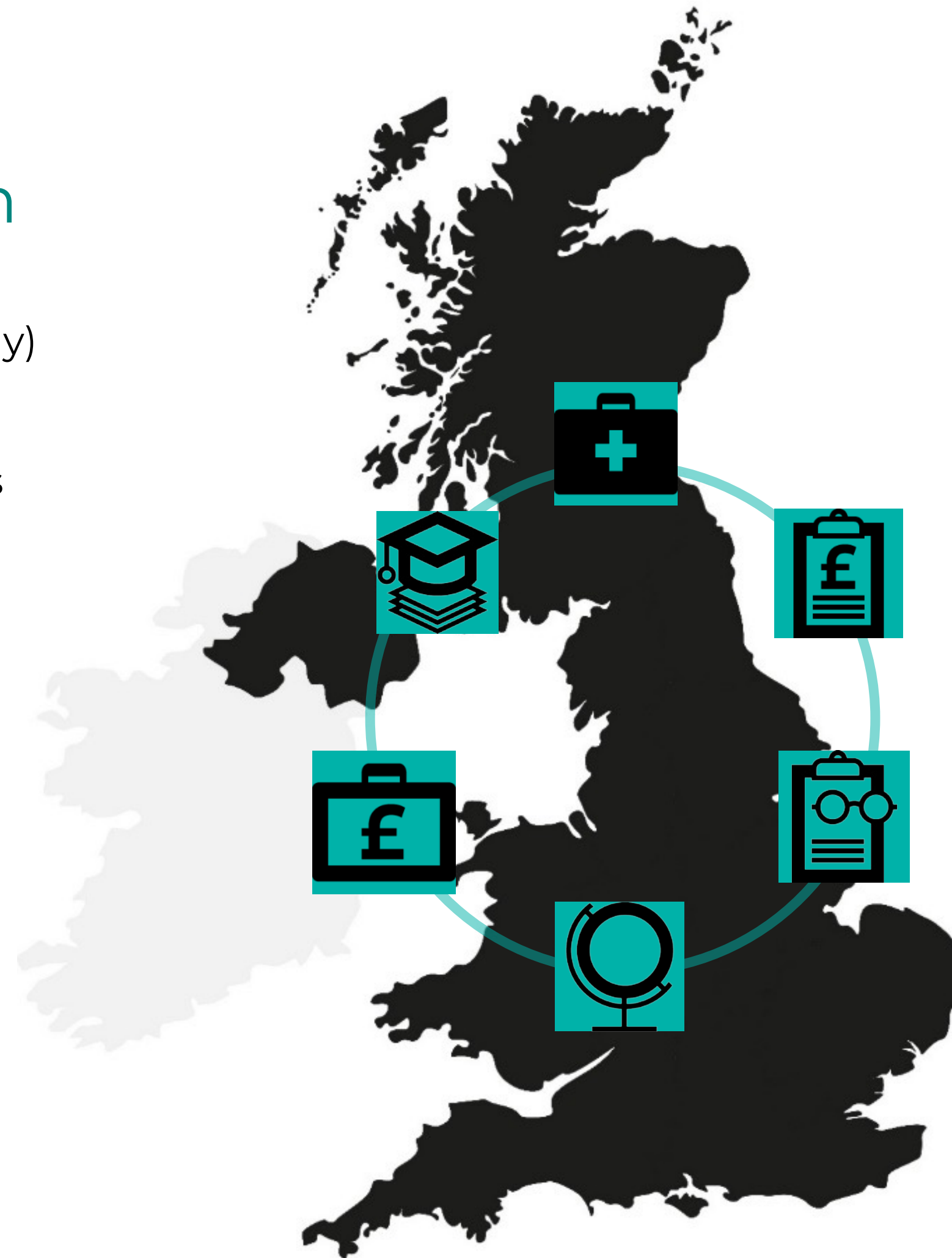
- COVID-19 collections (Questionnaires, Serology)
- SES & demographic
- Baseline physical & mental health
- Baseline family, SES and life-course indicators
- Genetics

NHS COVID-19 datasets

- GP Data
- Vaccinations
- COVID-19 test data (Pillar 1-3)
- Accident & Emergency
- CHES

Wider NHS datasets

- Hospital Inpatient data
- Cancer & mortality registers
- Community Mental Health (MHSDS, IAPT)
- Prescribing data



Administrative records

- HMRC
- DWP
- DfE

} **Negotiating data access**

Environmental & neighbourhood

- Air pollution
- Noise
- Greenspace
- SES & demographic
- Service provision

} **Being modelled**

Public Involvement



4 touchpoints for involving study participants and members of the public:

Strategic Advisory Committee

Data Access Public Review Panel

Public Advisory Group

Public Involvement Network

- Strategy and future collaborations
- Involve in data access process
- Assess remit and scope of public involvement
- Public involvement policy development
- Mutual ways of working
- Access wider public involvement networks
- Acknowledge and communicate public involvement
- Measure impact
- Training and guidance



The Minimum Viable Product



20+ longitudinal studies
Novel NHS Digital data pipeline
Public contributors & application panel
Nine applications through beta-testing phase

Year 1

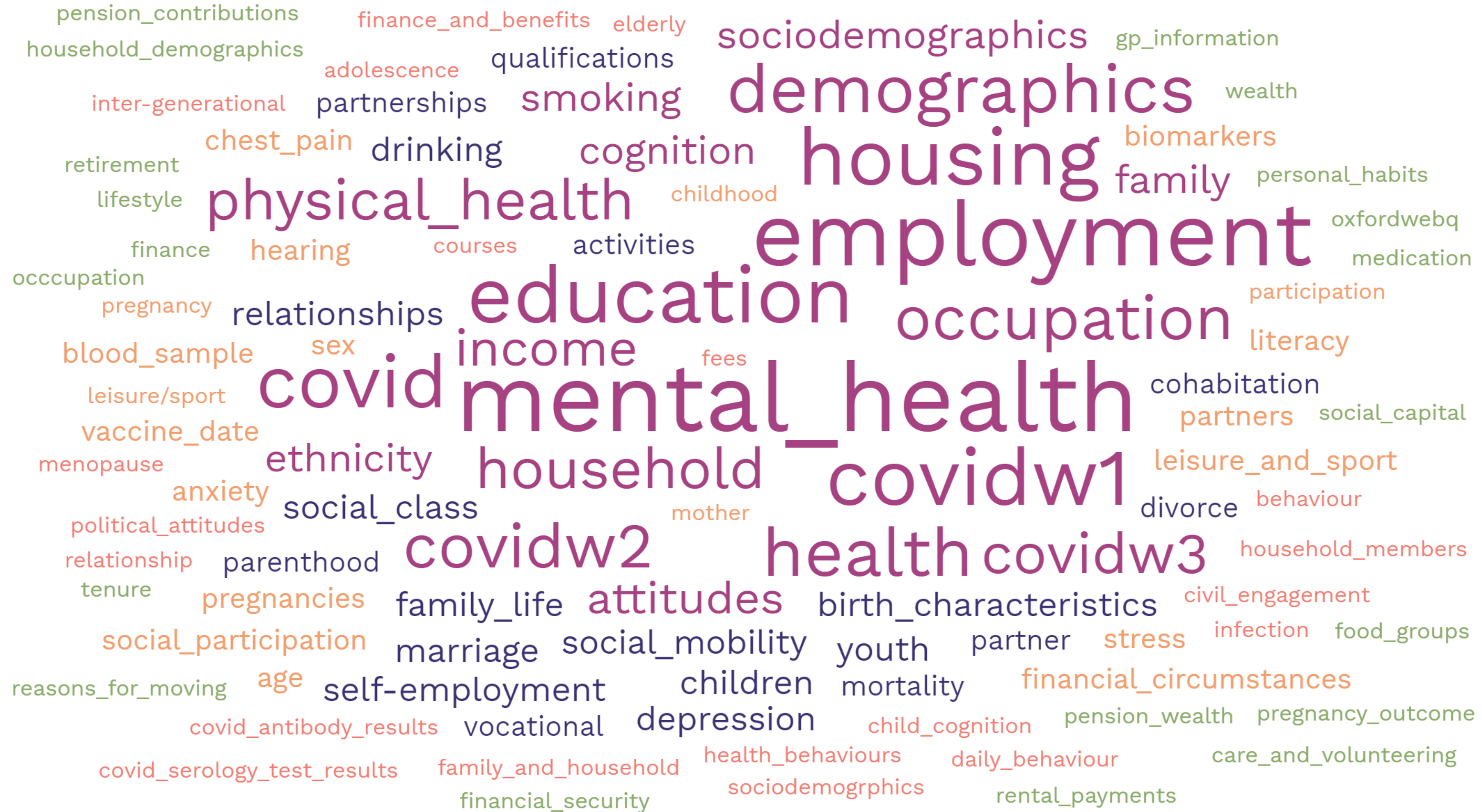
Accessible data from:

ALSPAC: Avon Longitudinal Study of Parents and Children
1970 British Cohort Study
Born in Bradford
ELSA: English Longitudinal Study of Ageing
EPIC-Norfolk: The European Prospective Investigation into Cancer (EPIC) Norfolk Study
EXCEED: Extended Cohort for E-health, Environment & DNA
The Fenland Study
Generation Scotland
GLAD: Genetic Links to Anxiety and Depression Study
The Millennium Cohort Study
NCDS58: 1958 National Child Development Study

Next Steps

NICOLA: Northern Ireland Cohort for the Longitudinal Study of Ageing (no linked data)
NIHR BioResource_COPING: National Institute of Health Research BioResource, COVID-19 Psychiatry and Neurological Genetics Study
NSHD46: MRC National Survey of Health and Development Cohort/1946 Birth Cohort
SABRE (no linked data)
TRACK-COVID Study
TwinsUK
Understanding Society - the UK Household Longitudinal Study

Keywords most commonly used to describe the LPS data



Linked Data – currently available



NHS Digital

- Primary Care GPES: Data for Pandemic Planning and Research
- COVID-19 Vaccination Status & COVID-19 Adverse Reaction
- NPex (pillar 2) Mental Health Services Data Set
- Medicines Dispensed in Primary Care (NHSBSA data)
- Hospital Episode Statistics: Admitted Patient Care, Critical Care, Outpatients, A&E
- Demographics data set
- COVID-19 SARI-Watch (formerly CHES) COVID-19
- Second Generation Surveillance System (Pillars 1 & 2)
- COVID-19 UK Non-hospital Antibody Testing Results (Pillar 3)
- Civil Registration – Deaths (England & Wales)
- Cancer Registration Data (England & Wales)

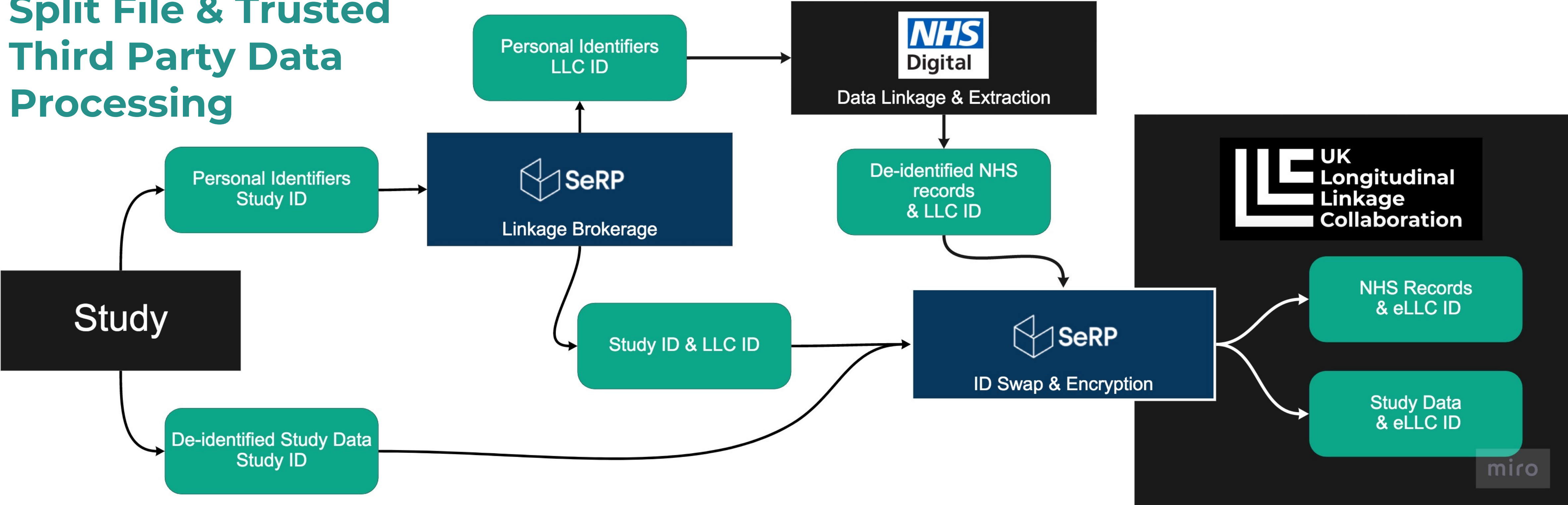
Generation Scotland

- PHS - NHS Vaccination data
- Electronic Communication of Surveillance in Scotland - testing
- PHS - NHS Prescription data
- PHS - Acute Inpatient and Day Case
- Civil Registration - Deaths

UK LLC Trusted Research Environment (TRE)



Split File & Trusted Third Party Data Processing



Functionally Anonymous TRE

UK LLC: efficient and predictable data access for analysts



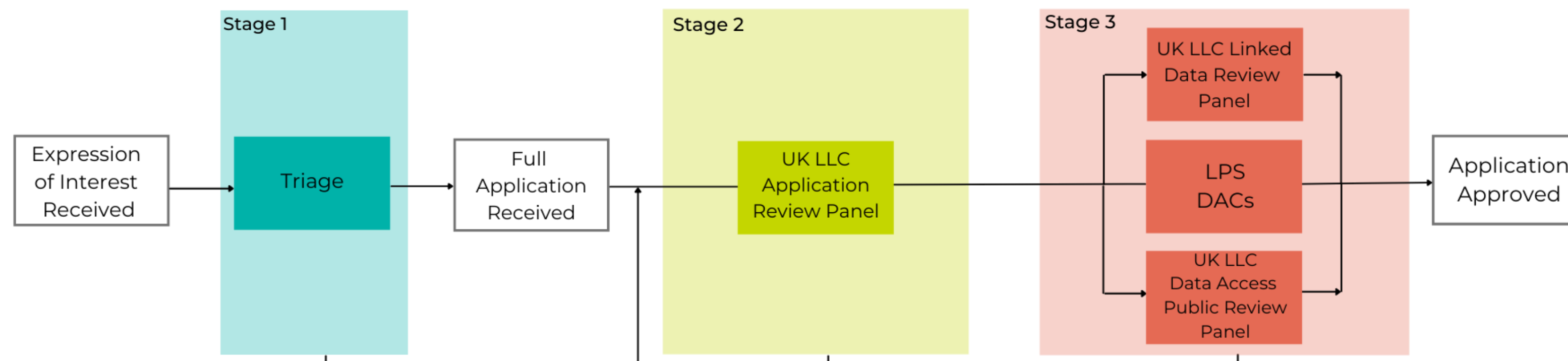
Data linkage made easy and predictable

UK LLC 'Five Safes' Application Framework

- UK LLC distributes applications to contributing studies
- UK LLC has delegated review authority from NHS Digital
- COVID-19 research only, UK based analysts
- Public benefit with public review
- Requirement for reproducible research

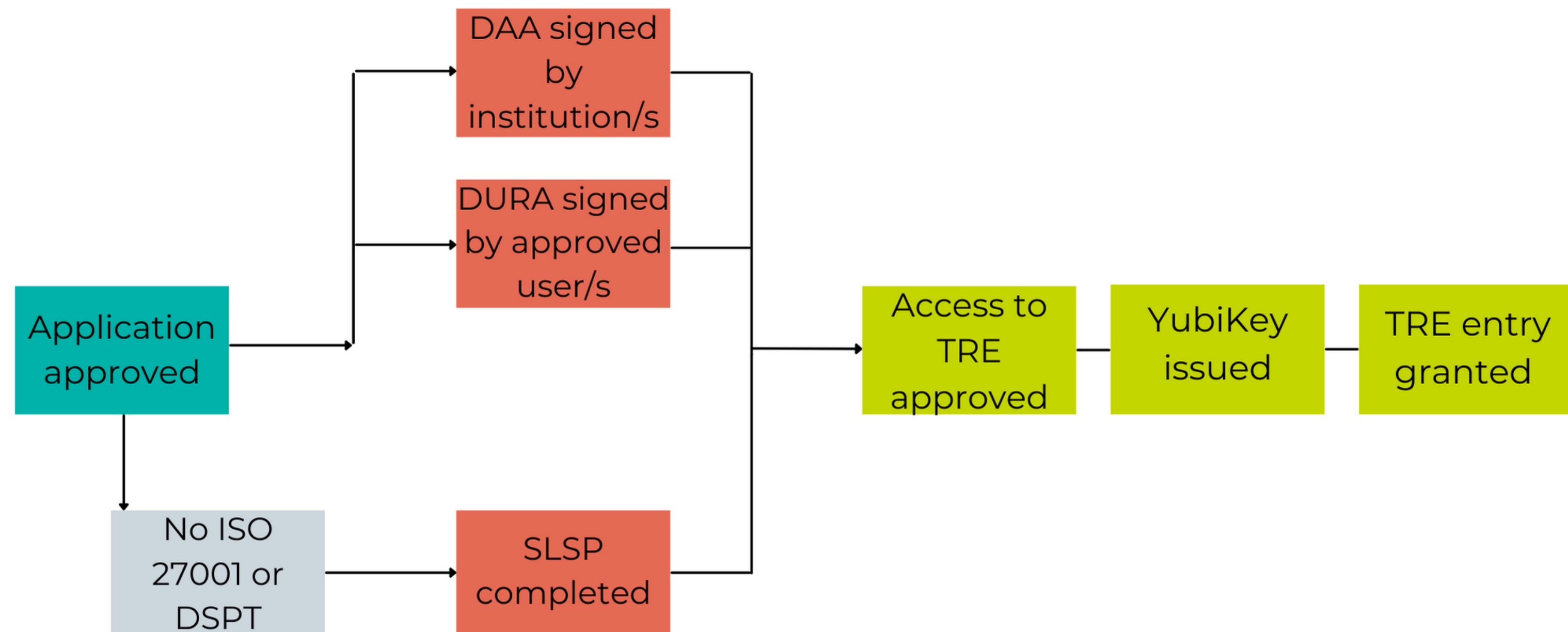
Apply for access via portal at the HDRUK Gateway
(<https://www.healthdatagateway.org/>)

- All researchers need to be ONS Approved Researchers & trained
- Data Access Agreement
- Light touch research user IT security framework as heavy lifting done at the UKLLC (ISO27001)

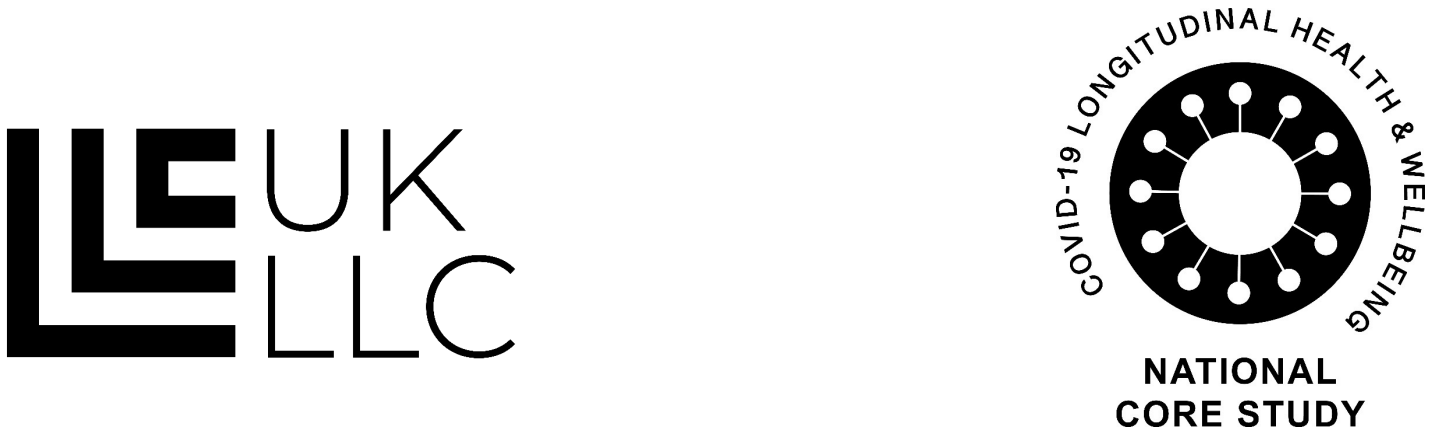


UK LLC Access – after approval

- Each research institution must sign the Data Access Agreement (DAA) and have IG covered
- Each researcher must sign a Data User Responsibilities Agreement (DURA)
- Once one institution and researcher have signed the DAA and DURA data can be provisioned
- Amendments to approved applications can be made

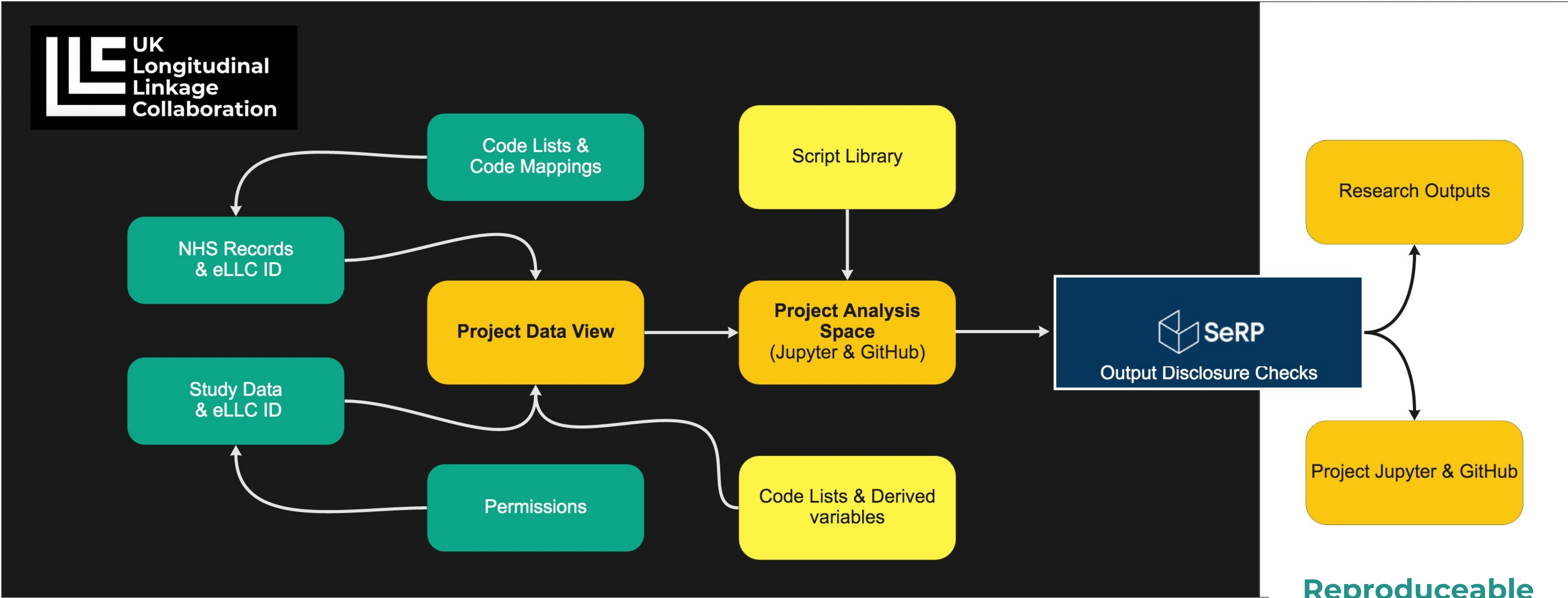


User experience & reproducible research



All processing *within* the TRE

Safe Outputs



Future plans

(above consolidating minimum viable product)



User experience & reproducible research

Enhance with administrative records

Efficient and predictable data access for analysts

Expanding beyond Covid-19 research to become a general research resource.

