

HDRUK
Health Data Research UK



DATA MIND
The Health Data Research Hub for Mental Health

Alleviate
The Advanced Pain Discovery Platform
(APDP) Data Hub

Data Access and Discovery Webinar

Data journeys from two Health Data
Research Hubs

Tues 6 Feb 2024, 14:00 - 15:00

Online



House Rules

Welcome!

- **Transparency:** Anyone is free to use information from our discussion, particular comments will not be attributed to individuals
- **Optimism:** Providing contributions that are positive and solutions-focused
- **Respect:** Promoting a culture of tolerance and inclusivity
- **Courage:** Be prepared to try new things and challenge
- **Humility:** Learning and respecting others and their diverse views

To read our meeting guidelines and etiquette in full visit our website:

www.hdruc.ac.uk/news-opinion-events/events/

Agenda

- 14:00 – 14:05: Hello and welcome by **Alison Elderfield**, Programme Manager, HDR UK
- 14:05 – 14:10: A brief history of the health data research hubs, **David Seymour**, Director of Infrastructure and Services, HDR UK
- 14:10 – 14:15: A patient perspective on health data research by **Antony Chuter**, PPIE Lead for Alleviate and Trustee of PainUK
- 14:15 – 14:30: Spotlight on Alleviate, **Gordon Milligan**, Deputy Director of Alleviate and **Chris Cole**, Director of Alleviate and Senior Lecturer, Health Informatics Centre at the University of Dundee
- 14:30 – 14:45: Spotlight on DATAMIND, **Ann John**, Co-Director of DATAMIND and Professor of Public Health and Psychiatry at Swansea University
- 14:45 – 15:00: Q&A with speaker panel, chaired by **Alison Elderfield**
- 15:00: Close

A Q&A with...

David Seymour

Director of Infrastructure and Services, HDR UK

Antony Chuter

PPIE Lead for Alleviate and Trustee of PainUK

Chris Cole

Director of Alleviate and Senior Lecturer, Health Informatics Centre, University of Dundee

Gordon Milligan

Deputy Director of Alleviate

Ann John

Co-Director of DATAMIND and Professor of Public Health and Psychiatry at Swansea University

**Thanks for attending.
We hope to see you again soon!**





An introduction and brief history of the health data research hubs

Data Access and Discovery Webinar

6th February 2024

David Seymour, Director of Infrastructure & Services, Health Data Research UK

Our mission & vision



HDR UK's mission is to unite the UK's health data to enable discoveries that improve people's lives

Our 20-year vision is for large scale data and advanced analytics to benefit every patient interaction, clinical trial, biomedical discovery and enhance public health.

Core funders 2023-28



The scale of the ambition

67 million
people

Across the lifespan

Diversity and detail






COALESCE: A UK whole-population analysis 2 of 2

How did we do it?

1 Performed parallel analyses in each of the 4 UK nations

Datasets held in national Trusted Research Environments (TREs), containing linked general practice (GP), hospital, prescribed medicines, COVID-19 vaccination and testing data

No. anonymised individuals

 1.9M		 5.0M
 2.4M		 58.9M

2 Harmonised data meta-analysed across all 4 UK nations

Completed the first epidemiological study using individual-level health data for the entire UK population
What did we find? Scan the QR code or visit <https://edin.ac/422Njsl>

Insights gained

In-depth, instructive results
Created a detailed picture of COVID-19 vaccination uptake across the whole of the UK, which can support all levels of decision-making

Difficulties in data harmonisation

- Each nation records data differently
- Data availability can vary between nations
- Challenging to write code that is 100% compatible with each of the national TREs

Difficulties of scale
Needed to use special techniques to run analysis on massive English datasets

Read paper at: [https://doi.org/10.1016/S0140-6736\(23\)02467-4](https://doi.org/10.1016/S0140-6736(23)02467-4)

We have demonstrated that the UK's health data environment has the potential to support whole UK population analyses.
These approaches could be refined and extended into other areas of medicine, to help drive better understanding, prevention and treatment of disease.

This work was done by the HDR UK COALESCE Consortium, led in partnership between:




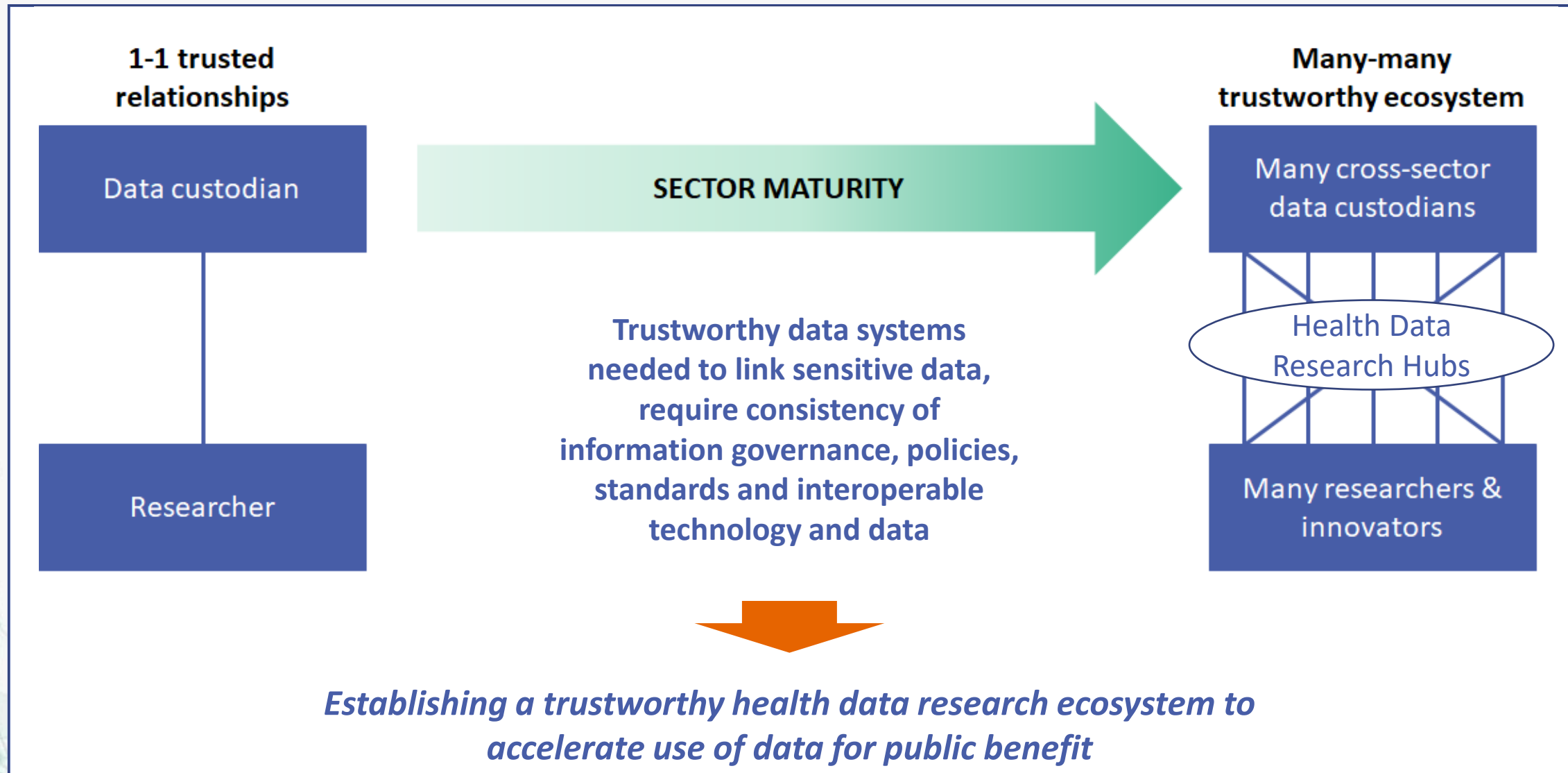
 THE UNIVERSITY OF EDINBURGH |  Usher Institute |  HDRUK Health Data Research UK

Image credit to Usher Institute, the University of Edinburgh

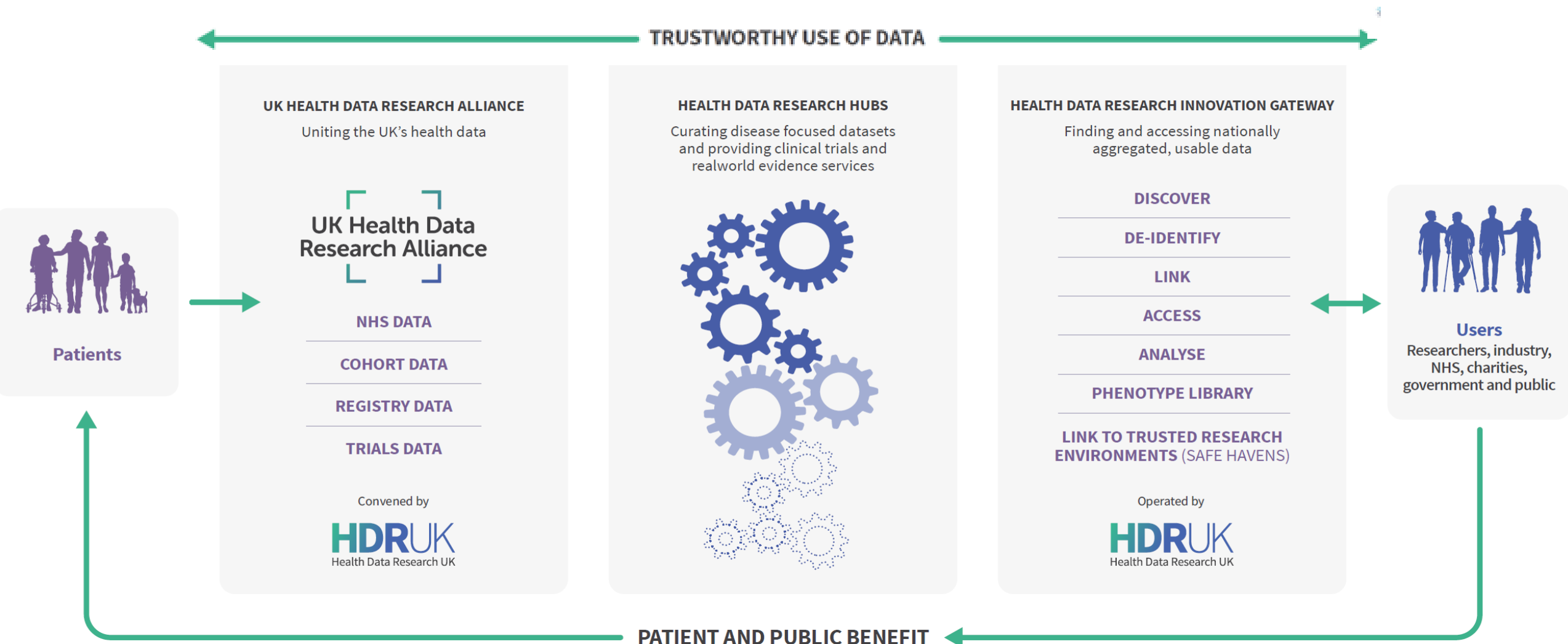
We need a *trustworthy* health data research ecosystem to translate the potential of health data research at scale requires



Where it all began...the Digital Innovation Hub Programme



Part of the Industrial Strategy Challenge Fund (ISCF) Data to Early Diagnosis and Precision Medicine challenge



Read more about the Digital Innovation Hub Programme and its evaluation, published August 2023



[Visit the Gateway](#) [Visit the Alliance](#) [Visit HDR UK Futures](#)

[About](#) [Advancing Health Research](#) [Access Health Data](#) [Helping with Health Data](#) [Study and Train](#)

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News

A pioneering programme to establish a national infrastructure for health data science

12 September 2023 | Author: Ruth Milne, Communications Manager, Infrastructure and Services

The Digital Innovation Hub Programme represents a defined period of funding but was delivered to support the advancement of a much wider agenda – to harness the power of UK health data for public benefit. The programme’s instrumental effort has reshaped the health data research landscape and created lasting impact.



[Visit the Gateway](#) [Visit the Alliance](#) [Visit HDR UK Futures](#)

[About](#) [Advancing Health Research](#) [Access Health Data](#) [Helping with Health Data](#) [Study and Train](#)

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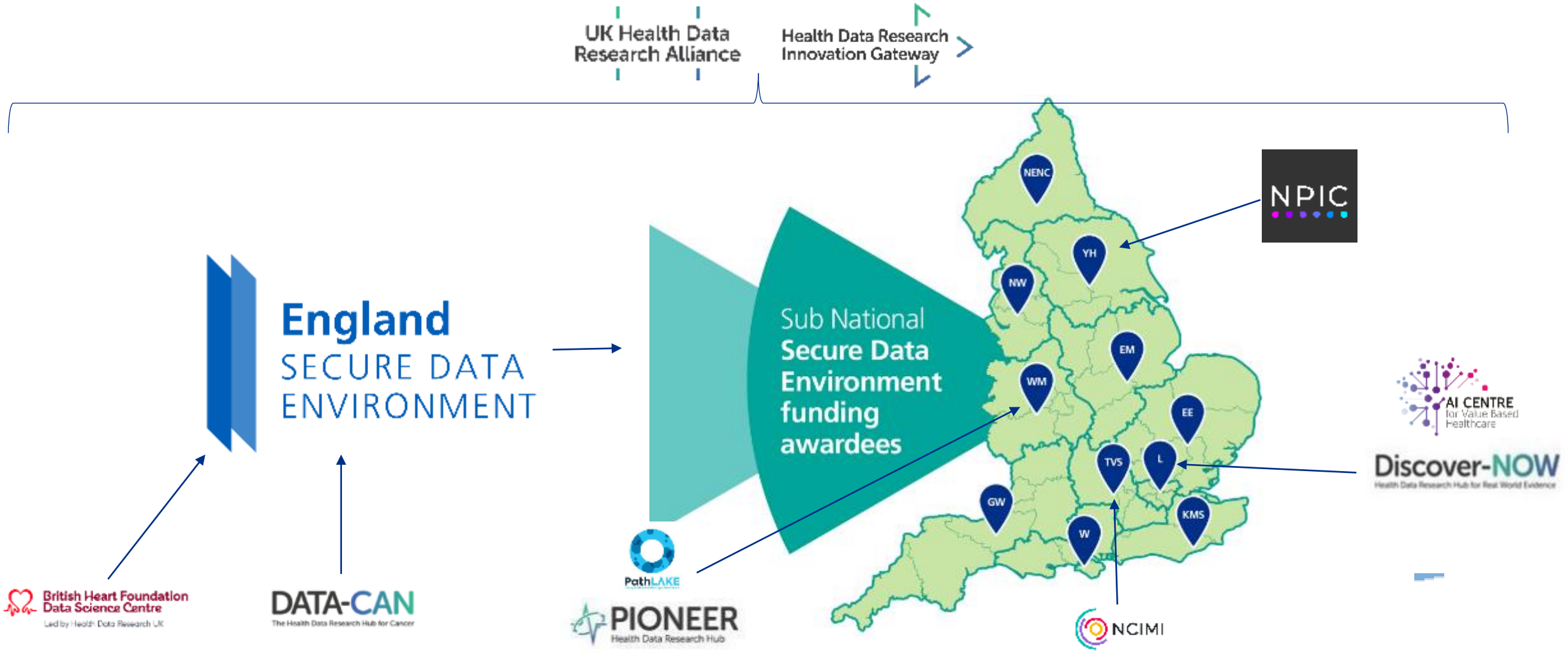
Opinion

Celebrating impact from our Health Data Research Hubs

31 August 2023

Since the Hubs were set up in 2019 as part of the Digital Innovation Hubs Programme, they have developed a long way. Here, we look back to see how they’ve evolved and how they’re enabling impactful research in a safe and secure way.

Helping to shape and deliver the NHS Data for R&D Programme - NHS Research SDE Network + NHS DigiTrials



Condition specific Hubs, Platforms and Data Science Centres



Centres of excellence with expertise and tools enhancing data foundations and providing FAIR data & services



**British Heart Foundation
Data Science Centre**
Led by Health Data Research UK

Cardiovascular & Diabetes (HDR UK)



PIONEER
Health Data Research Hub

Acute Care (Birmingham)



Gut Reaction
Health Data Research Hub

Inflammatory Bowel Disease (Cambridge)



**Dementias
Platform** UK

Dementia (Oxford, SeRP/Swansea)



BREATHE
Health Data Research Hub

Respiratory Health (Edinburgh, SeRP)



DATA-CAN
The Health Data Research Hub for Cancer

Cancer (Leeds, National SDE)



INSIGHT
Health Data Research Hub

Eye Health (Moorfields)



Alleviate
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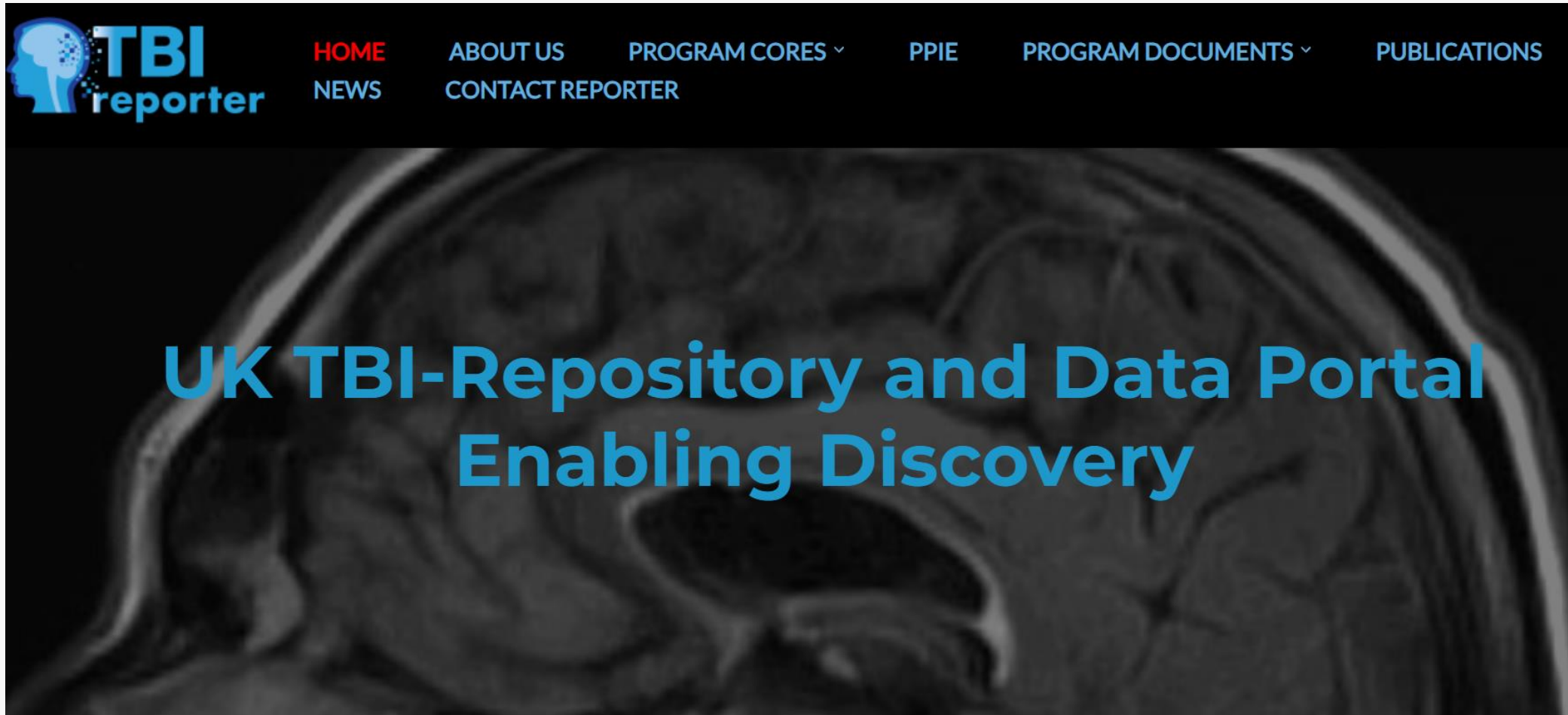
Pain (Dundee)



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Mental Health (Swansea, Maudsley)

Latest addition, focused on Traumatic Brain Injury

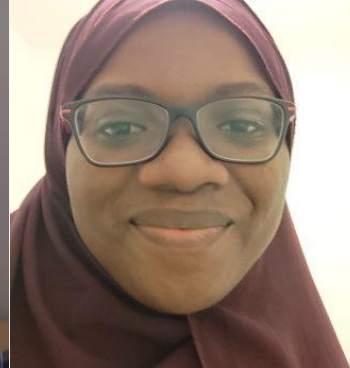


Jointly funded by the Medical Research Council (MRC), the National Institute for Health and Care Research, the Ministry of Defence, Alzheimer's Research UK

Why the Data to Early Diagnosis and Precision Medicine challenge still matters

HDRUK
Health Data Research UK

UKRI
UK Research
and Innovation



“Patients want their data to be used to improve care. In fact, they’re often surprised it’s not used already.”

Jacqui, cancer survivor and patient advocate

Alleviate

The Advanced Pain Discovery Platform
(APDP) Data Hub

Dr Christian Cole
and
Gordon Milligan



Background

- Chronic pain is defined as Pain lasting for three months or longer
- According to 2016 research by the British Pain Society around **28 million adults** in the **UK** are living with **Chronic pain**
- Chronic pain is poorly captured in health data
- Chronic Pain first recognized as a condition under ICD-11 by WHO
 - Improved evaluations
 - Better treatment decisions

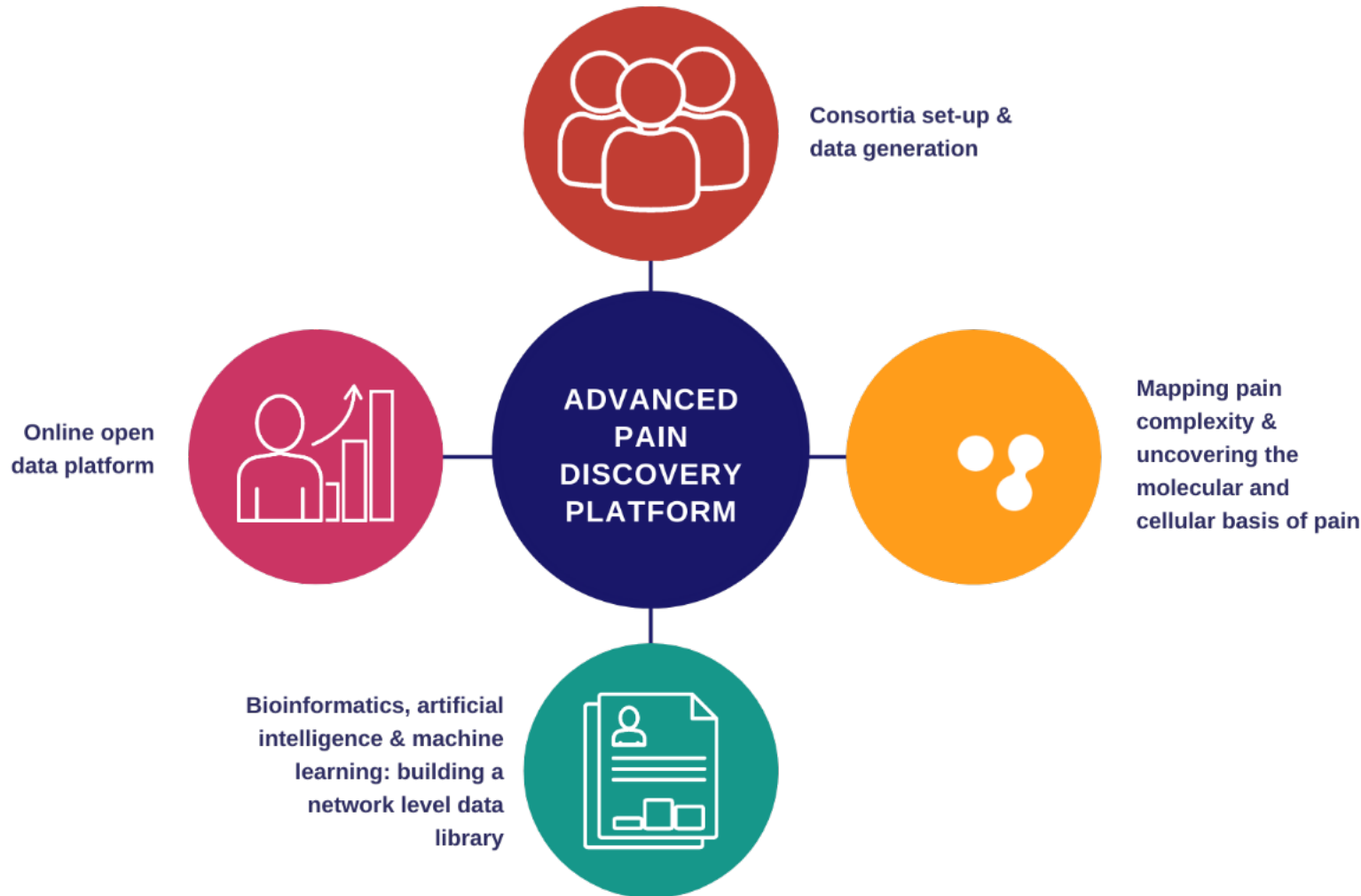
Feedback and opinions of people who live with pain is invaluable for pain related research



The Advanced Pain Discovery Platform (APDP)



The Advanced Pain Discovery Platform
(APDP) Data Hub



- Five year programme initially
- £34m from MRC, ESRC, BBSRC, Versus Arthritis and Lilly



Medical
Research
Council



**VERSUS
ARTHRITIS**



APDP Consortia



The Advanced Pain Discovery Platform
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Neuropathic Pain

ADVANTAGE

Visceral Pain



Adverse Childhood
Experience & Pain

CRiSP

Consortium to Research Individual,
Interpersonal & Social influences in Pain

Alleviate is the data hub of the APDP, and will collaborate with the consortia to streamline access to data and on-board data into the Alleviate federated platform where appropriate



FAIR Principles

Findable

Metadata and data should be findable for both humans and computers

Accessible

Once found, users need to know how data can be accessed

Interoperable

Data needs to work with applications or workflows for analysis, storage and processing

Reusable

The goal of FAIR is to optimise data re-use via well described metadata

Solution to a Common Problem

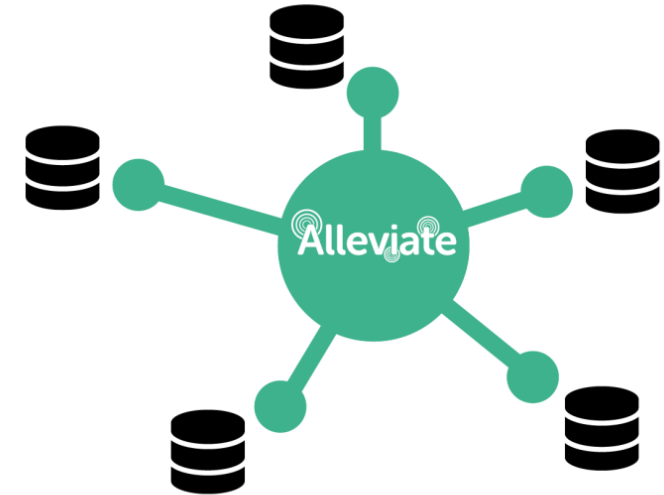
- Pain datasets are in silos
- Hard to find
- Even harder to query
- Datasets are in different formats

Data Silos



OMOP Mapping
CaRROT Tools

Data Discovery



HDR UK Metadata Catalogue



- Registered 20 Pain datasets with HDR UK's Metadata Catalogue
 - Available in the [Alleviate Collection](#)
- Currently added three Pain specific data sets to HDR UK Cohort Discovery Tool
 - Many further datasets in the pipeline for CDT

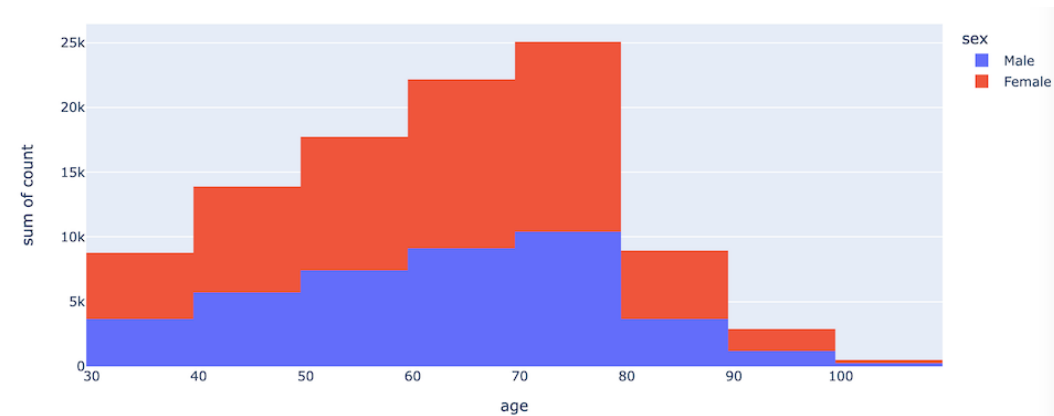
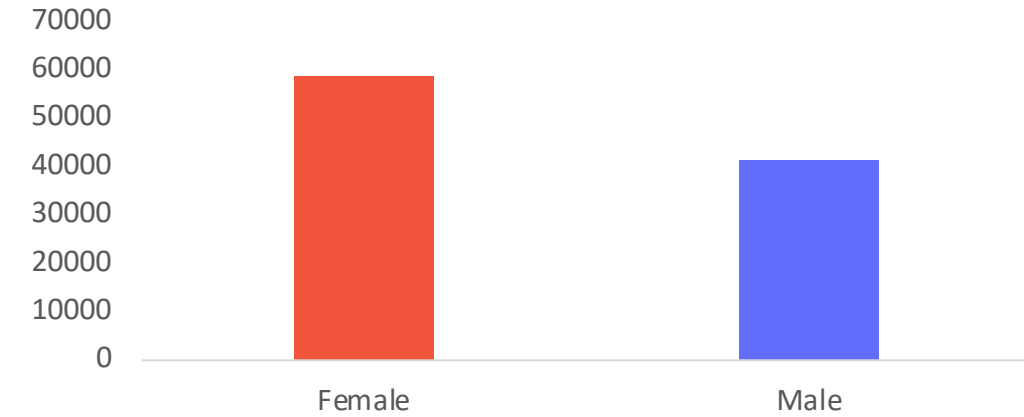
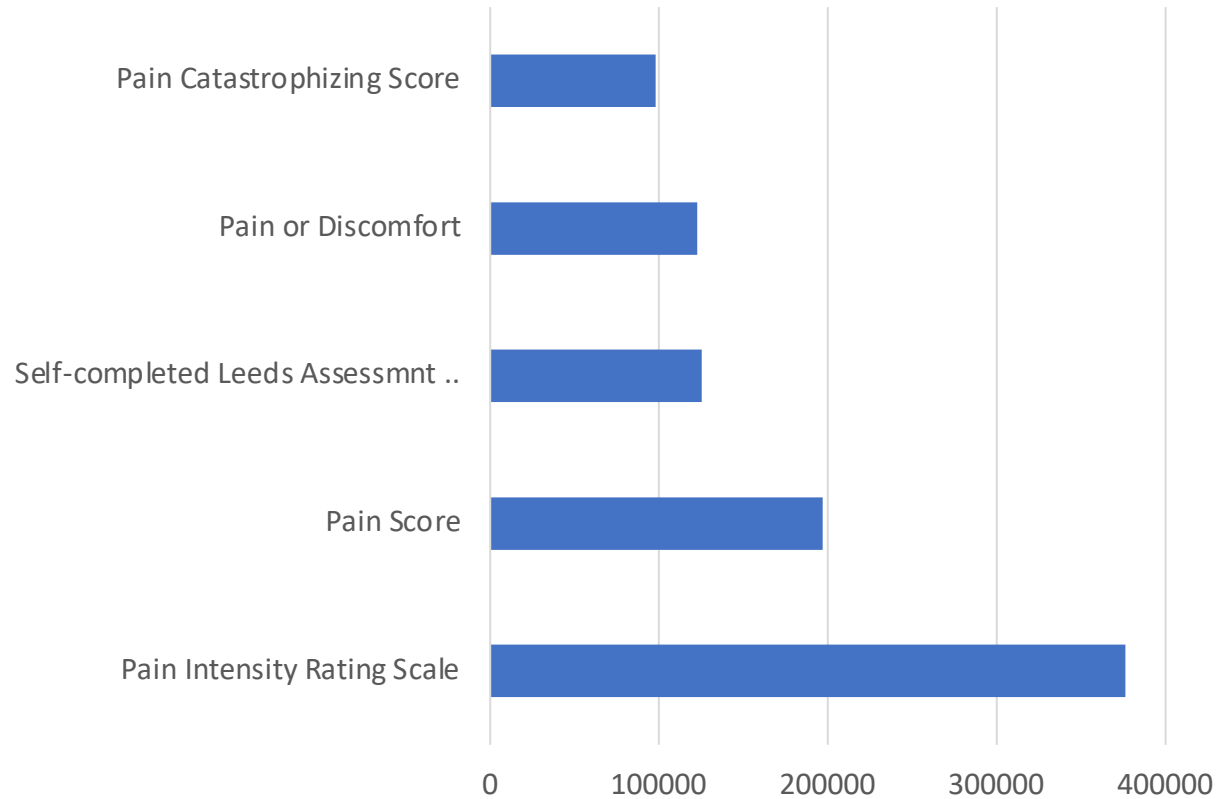


Generation Scotland



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108 Pain OMOP Concepts

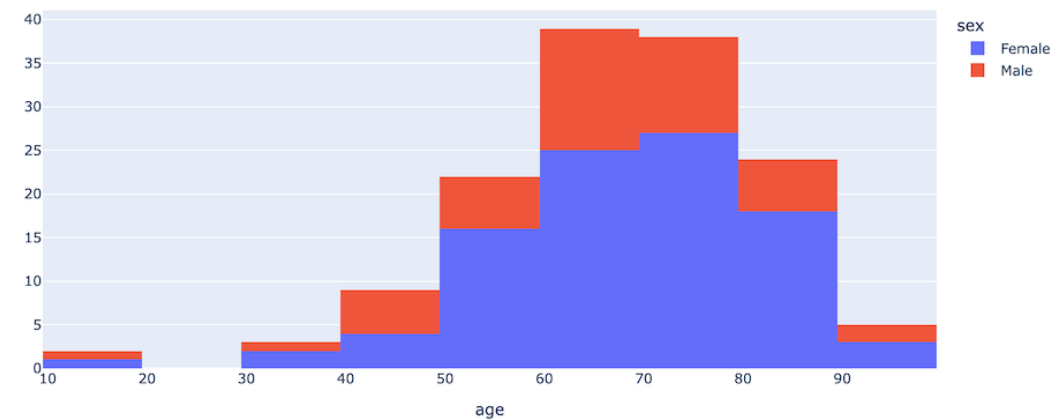
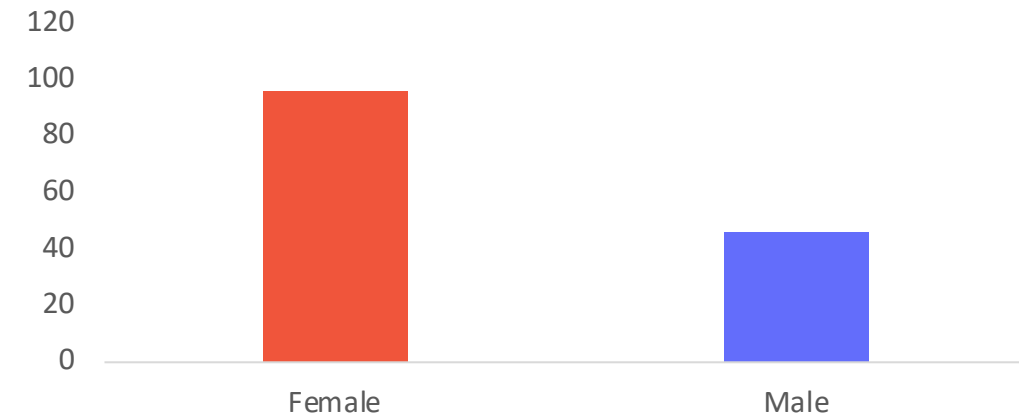
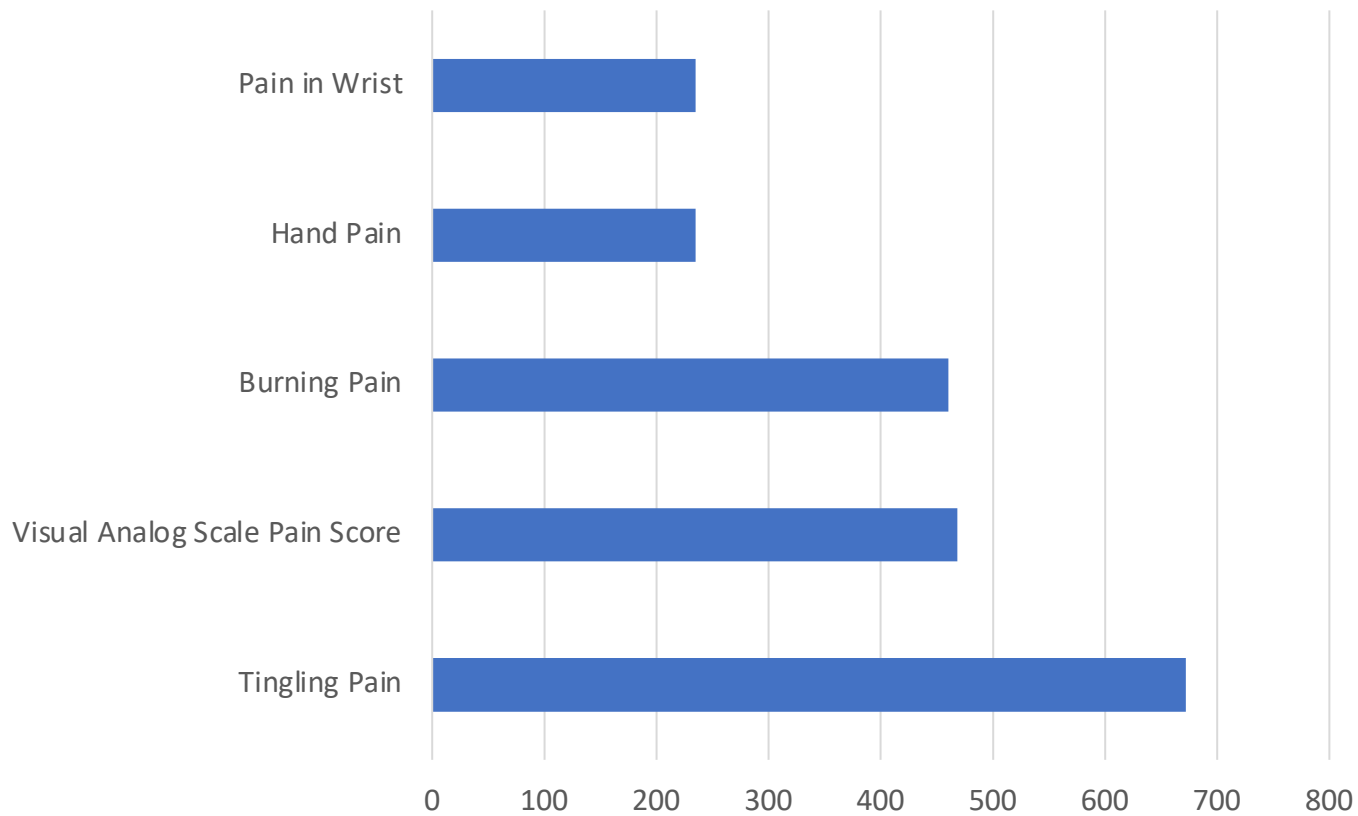


Oxford Carpal Tunnel Syndrome



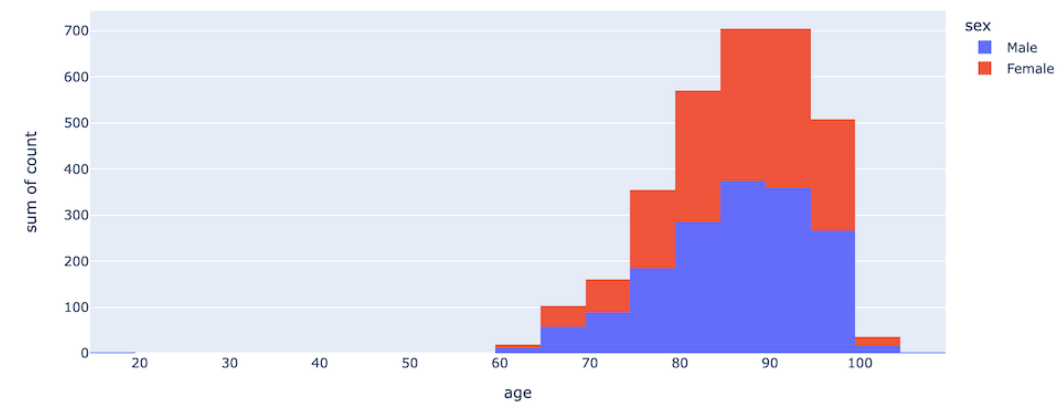
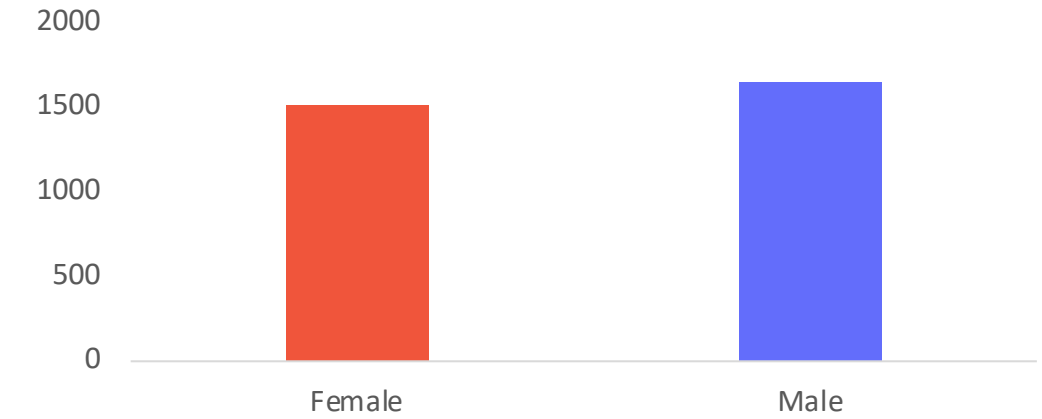
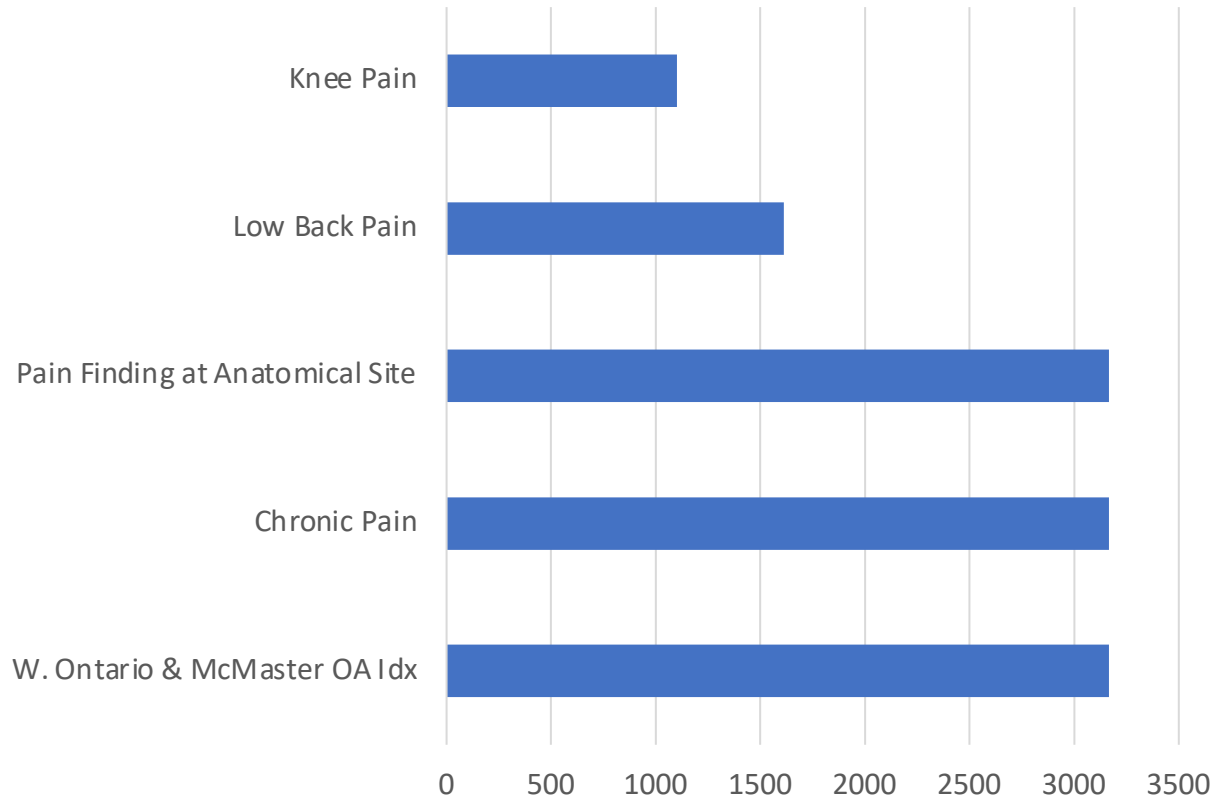
The Advanced Pain Discovery Platform
(APDP) Data Hub

24 Pain OMOP Concepts



GOAL

12 Pain OMOP Concepts



Data Harmonisation & Standardisation



The Advanced Pain Discovery Platform
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- Data harmonisation across data sources
 - Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM)
- Using CaRROT Mapper and CDM Tools
 - Initially developed during CO-CONNECT
 - Continued development by Alleviate Team, Digital Research Services, University of Nottingham and HDR UK



Visit <https://carrot4omop.ac.uk> for more information on these tools

What Data is Being Mapped?



Alleviate Strengths



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Data Services

- Advice on mapping to OMOP
- End to end service to map your data to OMOP
- Guidance on setting up studies for efficient data management
- OMOP Data Linkage
 - Clinical Data
 - Genomics Data
- Trusted Research Environment (TRE)



Public and Patient Engagement

- Access to an active patient group for input on e.g. academic proposal
 - Time needs to be remunerated
- Awareness and visibility of Chronic Pain and its impacts
- Raising awareness of chronic pain through marketing campaigns
- Ran UK National Pain Survey



Data Sharing

- Data sets standardised to OMOP
- Data sets discoverable through HDR UK Gateway
- Data access requests through HDR UK Gateway
- Data extracts available via Alleviate TRE

Data Mapping Experience

- Data Discovery and Re-use (FAIR)
- Data Team through Alleviate (+CO-CONNECT) have been involved in mapping >10 million health records:
 - Research cohorts
 - Population scale clinical datasets
- All 19 datasets currently in HDR UK Cohort Discovery Tool

<https://www.healthdatagateway.org/about/cohort-discovery>

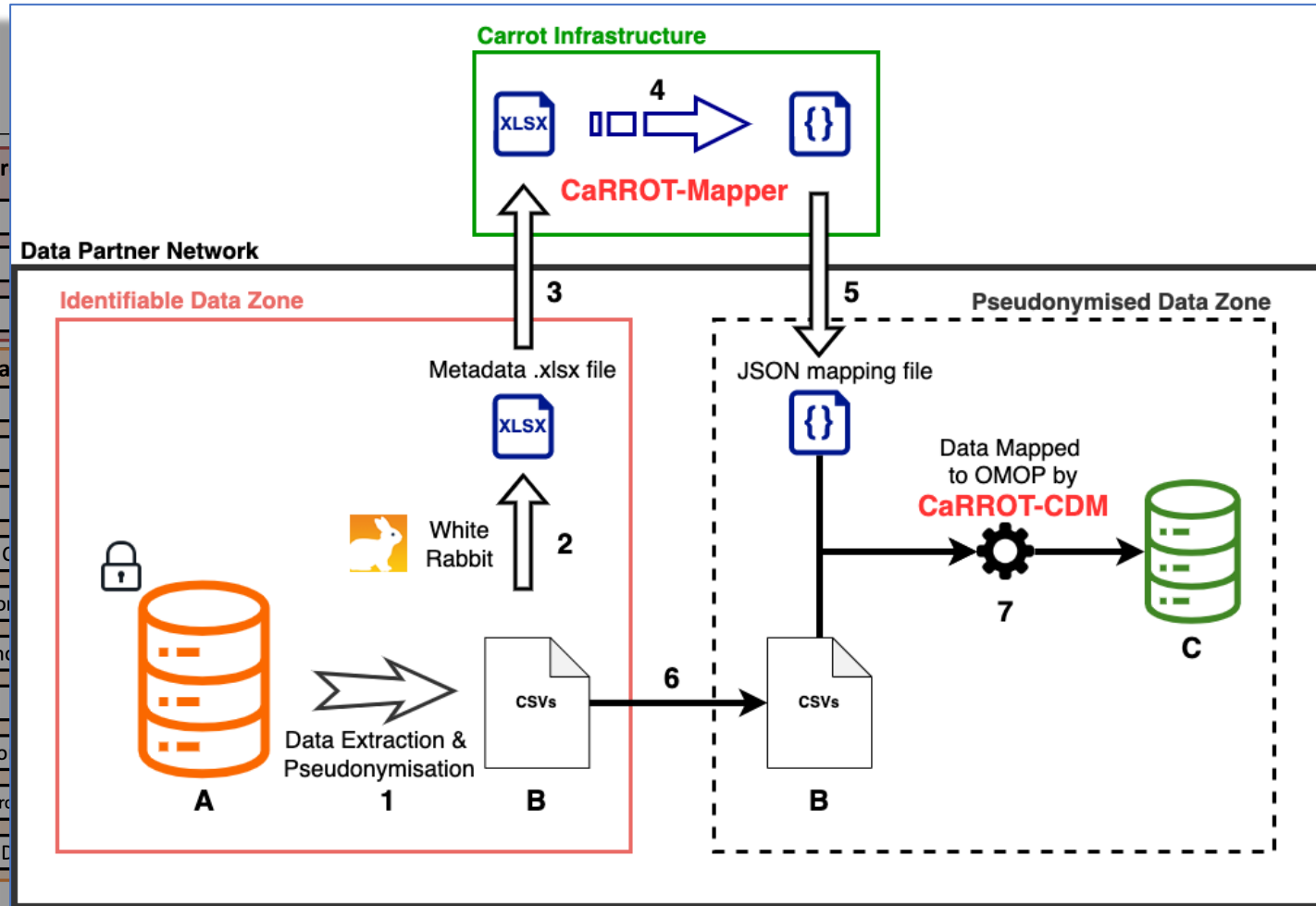
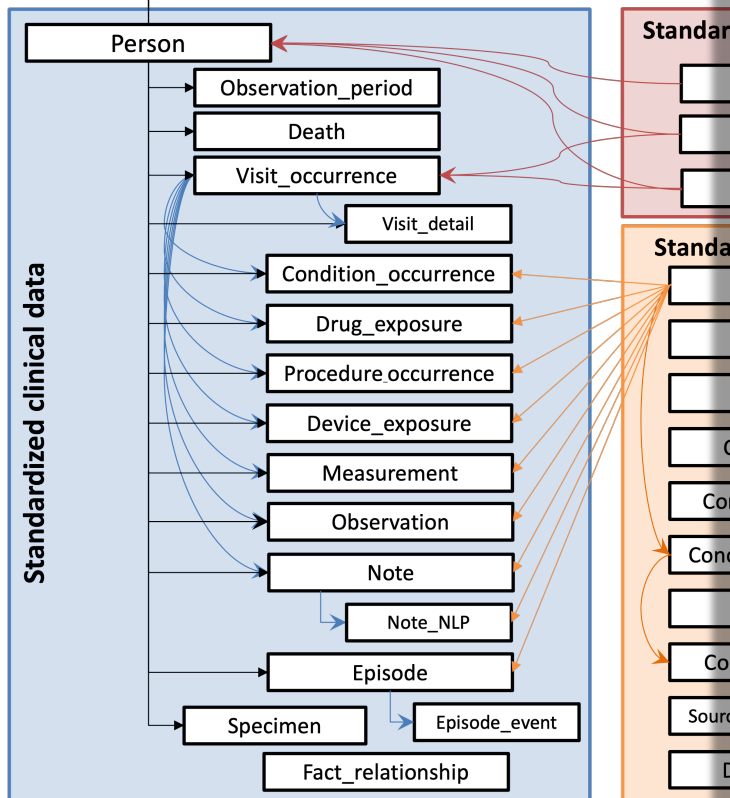


Data Mapping Experience



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OMOP Common Data Model



Our Data Mapping Service

- Mapping health data to the OMOP CDM
- Review mappings to provide advice
- Provide guidance on your OMOP health data journey
- Provide training on best practices for OMOP use
- Review existing plans for implementing OMOP and providing feedback on improvements
- Including OMOP as part of a research collaboration

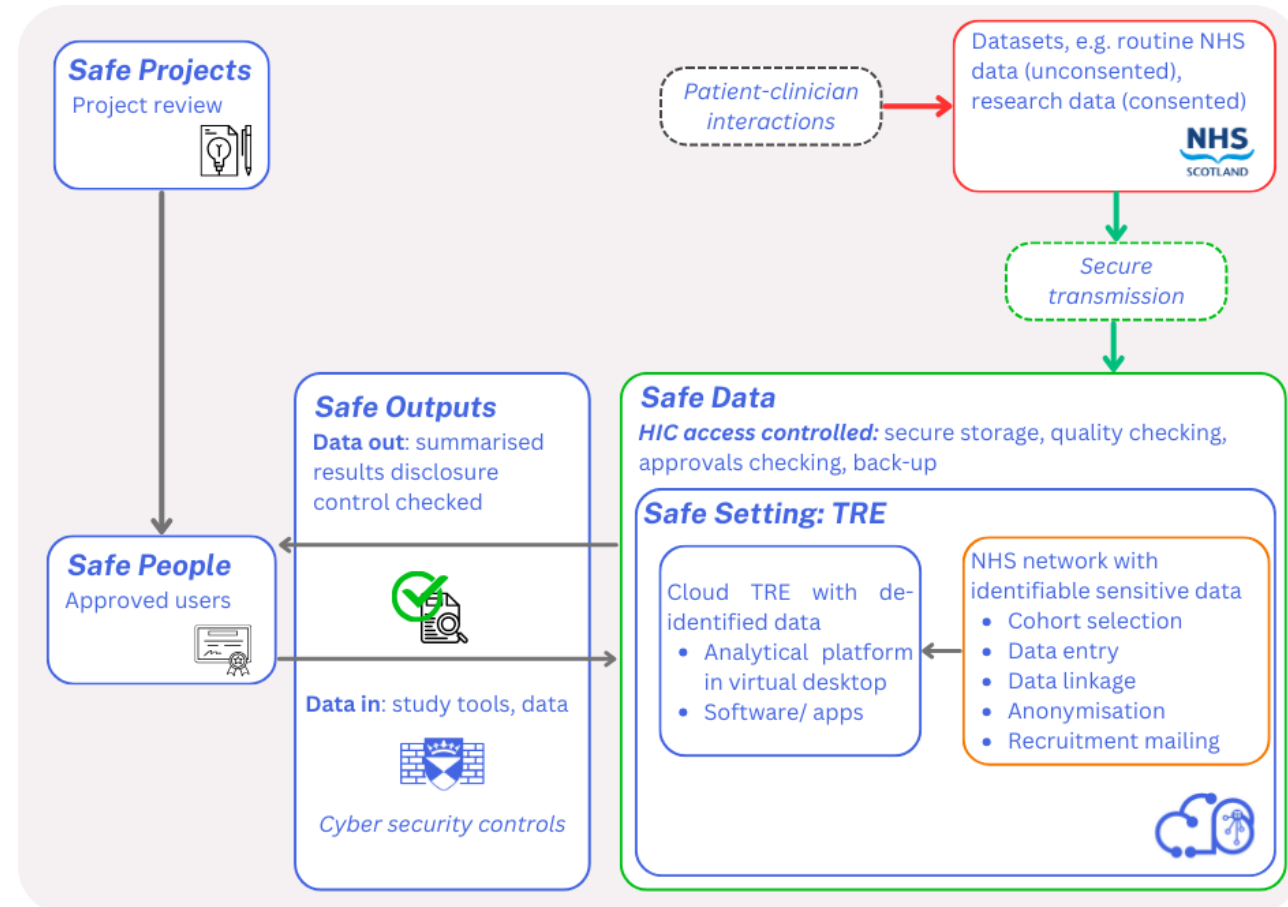


Trusted Research Environment



The Advanced Pain Discovery Platform
(APDP) Data Hub

- Hosted by HIC, University of Dundee
 - >10 years experience
 - Flexible cloud compute
- “Five Safes” compliant
- We provide access to project data (following approvals), which is always pseudonymised and provisioned in a segregated workspace (green box for TRE). Diagram shows 5 Safes in blue and colour coded traffic light system for risk.
- Strict monitoring and auditing capabilities



Collaborative Partners



The Advanced Pain Discovery Platform
(APDP) Data Hub



University
of Dundee



University of
BRISTOL



UNIVERSITY OF
CAMBRIDGE



UNIVERSITY OF
BATH



University of
Nottingham
UK | CHINA | MALAYSIA



Imperial College
London



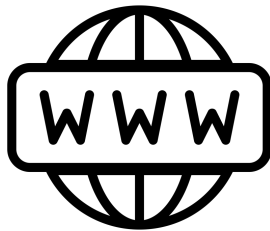
Questions?



@Alleviate_Data



@alleviate-hub



Alleviate.ac.uk



DATA MIND
The Health Data Research Hub for Mental Health

Ann John- Co-Director



Medical
Research
Council

HDRUK
Health Data Research UK



Research and data and MH

Studies face problems:

- People most likely to experience poor MH may be least likely to take part
- Many measures are self-reported and may be subject to bias and/or their clinical meaning may be unclear
- People are lost to follow up

These partly overcome through using linkage to routinely collected data

Real world data

Cohorts important but numbers

It speaks to policy makers, the public and practitioners

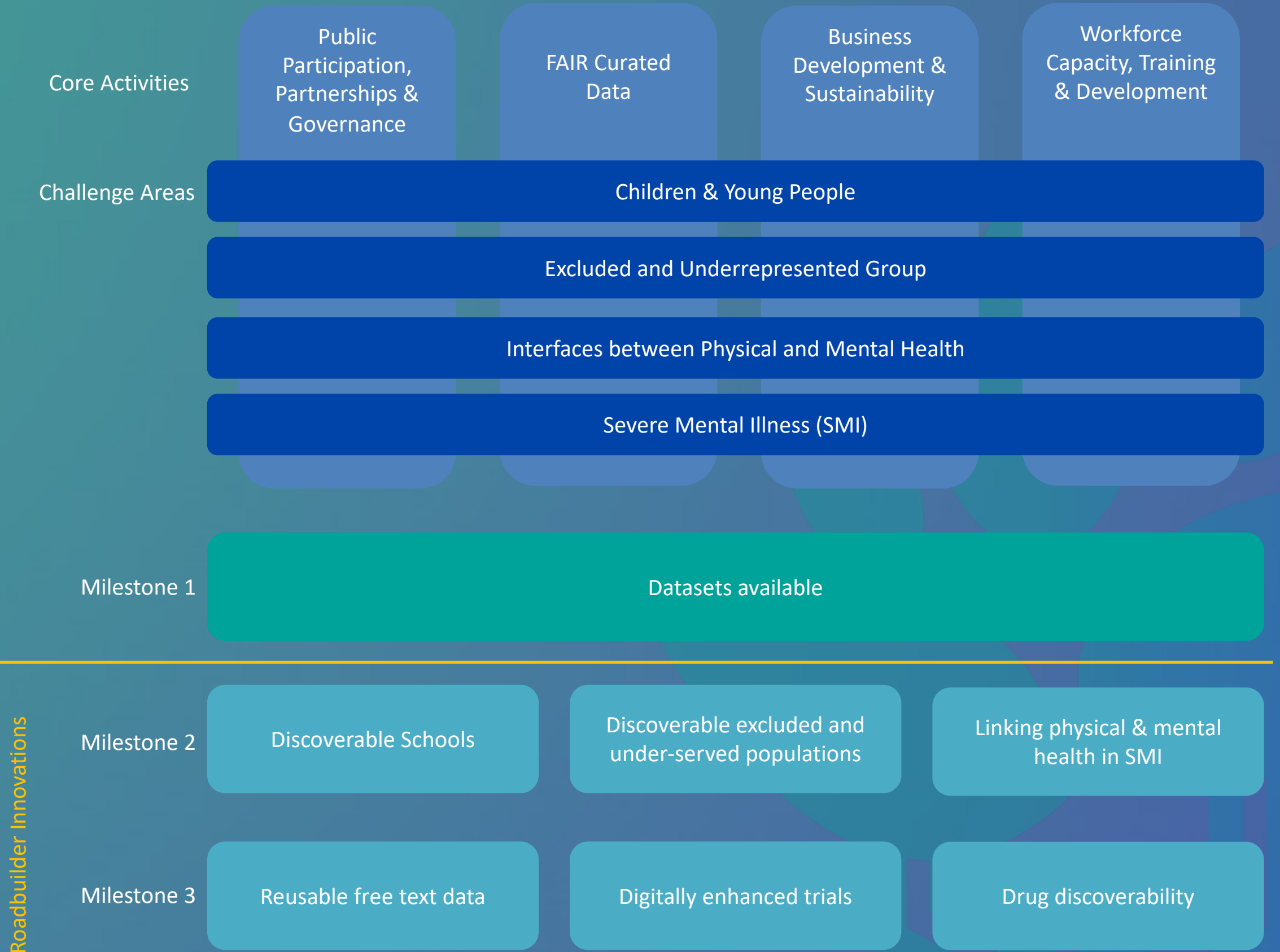
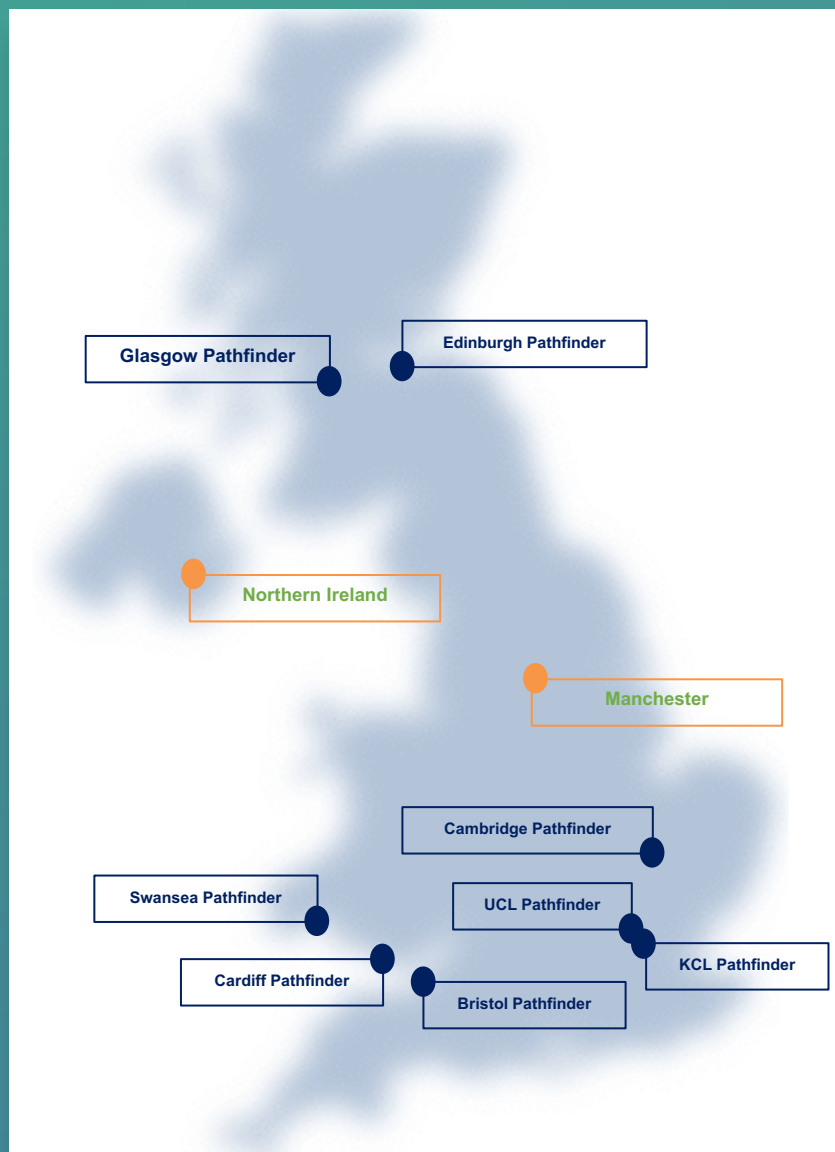
Issues re trust and innovation





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The Health Data Research Hub for Mental Health

Overview





DATA MIND
The Health Data Research Hub for Mental Health

Meet the Team

Leadership Team



Ann John
Principal Investigator
and Co-director



Rob Stewart
Co-director



Andrew McIntosh
Chief Scientific
Officer



Matthew Broadbent
Chief Operating
Officer



Dermot O'Reilly
Chief Data
Officer



Parisa Mansoori
Core Activity Lead



Rudolf Cardinal
Core Activity Lead



Louise Arseneault
Core Activity Lead

Management Team



Matthew Broadbent
Chief Operating
Officer



Dara Almeida Medina
Project Manager



Matthew Iveson
PM Business
Development &
Sustainability



Linda Jones
PPI Lead



Elena Triantafillopoulou
PM FAIR Curated MH Data



Hala Rachidi
PM Workforce
Capacity, Training &
Development



Claire McLoughlin
Roadbuilders
Innovations



DATAMIND
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Public Participation, Partnerships and Governance





Data Literacy Short Course Share



Data Literacy Short Course

Understanding Your Health Data and its Applications



Watch on  YouTube

SRAG

Shortlisted for HDRUK PPIE Award



winner to be announced

Industry Forum Contribution

SRAG shape guidelines on data sharing with industry



Opinion Article:

SRAG publish article in *Frontiers in Psychiatry* on AI and Mental Health

Empowering SRAG to Engage with Other Organisations

Collaboration with CRUK, HDRUK, HRA, MQ, McPin, and others





DATAMIND

The Health Data Research Hub for Mental Health



DATAMIND

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Super Research Advisory Group



Glossary  

[Our Focus](#) [Data](#) [Our Work](#) [Patients & Public](#) [About Us](#) [Newsroom](#) [Contact Us](#)

Home

Glossary

Welcome to the DATAMIND Glossary, an accessible tool created in partnership with the DATAMIND PPIE team. This user-friendly resource aims to make the complex language of mental health data science understandable to everyone, regardless of their level of knowledge or experience. In these pages, you'll discover straightforward explanations of important terms. Our aim is to help people communicate more easily and work together effectively within this field.

If you would like us to consider adding a term or have any suggestions for improvement, please don't hesitate to contact us at datamind@swansea.ac.uk. Your input is invaluable as we strive to enhance, expand, and continually improve this resource.

Search Glossary Term:

Term **Category** **Definition**

Term	Category	Definition
Long-read sequencing	Health Research	Is a method used to read longer sections of a person's genetic code all at once. This technique provides more detailed information about complex parts of the genetic material, giving scientists a better understanding of the individual's genes. It's like reading a longer paragraph in a book, which helps us see the whole picture and discover more about someone's unique genetic makeup.

Search Glossary Term:

Term **Category** **Definition**

Term	Category	Definition
Linkage of data (data linkage)	Processes	Joining (linking) data from more than one source. For example, to study the relationships between mental and physical health conditions, it might be necessary to link data from NHS mental health services to primary care (GPs) or acute hospital data. To study the relationships between health conditions and education, it might be necessary to link data from health services and a government education department.

Linkage may be legally complex because it involves data from more than one data controller. Linkage may be based on straightforward rules ("two records with the same NHS number are from the same person") or based on probability ("if two records share the same forename, surname, and date of birth, they are more likely to be from the same person"). Links may be made using identifiable data (e.g. NHS number) or de-identified data (e.g. a research pseudonym).



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FAIR Curated DATA





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The Health Data Research Hub for Mental Health



SPECIALIST CATALOGUE AND ANNOTATION

The screenshot shows the DATAMIND website interface. At the top, there is a search bar with a magnifying glass icon and a 'Search' button. Below the search bar, there are navigation tabs: 'Datasets (0)', 'Tools (1)', 'Data uses (0)', 'Collections (1)', 'Courses (0)', 'Papers (0)', and 'People (0)'. The 'Tools (1)' tab is currently selected. Below the tabs, there is a 'Save' button with a dropdown arrow. The main content area shows search results for 'DATAMIND catalogue'. It displays the title 'The Catalogue of Mental Health Measures' by Elena Triantafillopoulou, Lily Strange, Louise Arseneault, and Clara Fennessy. Below the title, there are tags: 'Tool', 'Dataset discovery tool', 'Webpage', 'Data Discovery', 'Mental Health', 'Longitudinal', and 'DATAMIND'. The description below the tags reads: 'The Catalogue of Mental Health Measures is designed to provide easy access to information about the mental health measures included in UK cohort and longitudinal studies to maximise the uptake of existing data and facilitate mental health research. The C...'

Transparency **P**roject
DATAMIND and the team at KCL received MRC funding to improve health data transparency.
The SRAG and the team are creating plain language summaries of the studies on the Catalogue of Mental Health Measures, a longitudinal studies infographic, and identifying new terms for the DATAMIND glossary, to be shared across organisations

Updates

Added new studies: British Autism Study of Infant Siblings (BASIS), Longitudinal Outcomes of Gender Identity in Children (LOGIC), Edinburgh Study of Youth Transitions and Crime (ESYTC)

Collaborated with other discoverability platforms: The Catalogue of Social Care Measures, HARMONY, Center for Pediatric Traumatic Stress

Developed and embedded an API

55 UK-based longitudinal studies reviewed

Over **3000 mental health measures** from over **300 waves** of data collection

More than **30 mental health and wellbeing topics**





BCS70

1970 British Cohort Study

twinsUK

sabre



AESOP-10

E-RiSK

Environmental Risk Longitudinal Twin Study



logicQ

Longitudinal Outcomes of Gender Identity in Children

WHITEHALL II



BORN IN BRADFORD'S BETTER START

APMS

TEDS



Resilience, Ethnicity, and AdolesCent Mental Health



Edinburgh Study of Youth Transitions and Crime

75 YEARS

National Survey of Health and Development 1946 - 2021

biobank^{uk}

85+

generation scotland

ELSA

English Longitudinal Study of Ageing



HCS 3G

ncds

National Child Development Study



CHILD OF THE NEW CENTURY



gemini

growing up in Scotland

bib We are family BORNINBRADFORD

CFAS

E European Social Survey

NEXT STEPS

NICOLA

Understanding Today for a Healthier Tomorrow

LBC 1921 **LBC 1936**

SCAMP

Study of Cognition, Adolescents and Mobile Phones

MHCYP

Airwave Health Monitoring Study



ADVANCE

SUS

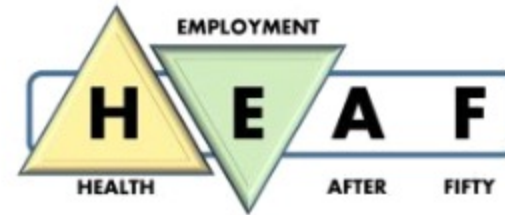
Southampton Women's Survey

PROTECT

CHILDREN OF THE 90s



SELCoH



KCMHR

KING'S CENTRE FOR MILITARY HEALTH RESEARCH

Eurofound Quality of Life Survey

Eurofound Working Conditions Survey

Harmonisation

Catalogue of Mental Health Measures

The Project Mental Health and Wellbeing Resources About Us Search Mental Health Measures

An interactive catalogue of mental health and wellbeing measures in British cohort and longitudinal studies

The UK boasts rich and world-renowned cohort and longitudinal studies which offer unique opportunities to answer key questions about mental health and wellbeing.

The Catalogue provides information about thousands of standard and non-standard measures of mental health and wellbeing collected in UK longitudinal studies.

Measures detailed in the catalogue include indicators of mental health problems, treatment, service use, impairment and psychological wellbeing.

Search Mental Health Measures

Other- annotation

Physical health data

MH across cohorts

Genetic summary tables

Data harmonization- HARMONY

Data from from third sector

UKLLC

New Data Utility Wizard Tool Try out our new tool which will help refine your search to only datasets that meet your data utility requirements- click the Advanced Search button back on the tool

Health Data Research Innovation Gateway Explore Help Usage Data About Us News Community

Gateway to health data and tools for research

Search, discover and request access to hundreds of datasets, tools and resources for your research. Join the thousands of researchers and scientists worldwide who are already using the Gateway for research and scientific discovery.

I'm looking for... Advanced Search





DATA MIND

The Health Data Research Hub for Mental Health

Phenotypes

My Collection →

View content owned by or shared with you.

Create a Phenotype →

Start here to contribute to the Library.

Reference Data →

Look up values for phenotype fields.

Filter By

Type

Date

Collections

- ClinicalCodes Repository
- CALIBER
- BREATHE
- DATAMIND
- Adolescent Data Platform (ADP)
- BHF Data Science Centre
- PIONEER

Tags

Results

1-20 of over 39

Order By: Relevance Results Per Page: 20

PH932 - Attention-Deficit hyperactivity disorder (ADHD)

A. John, Y. Friedmann, M. DelPozo-Banos, A. Frizzati, T. Ford, A. Thapar

Disease or syndrome · Last updated 2022-05-05

ICD10 CODES READ CODES V2 ADOLESCENT DATA PLATFORM (ADP) DATAMIND PHENOTYPE LIBRARY

PH933 - Autism Spectrum Disorder (ASD)

Underwood, J. F., DelPozo-Banos, M., Frizzati, A., John, A., Hall, J.

Disease or syndrome · Last updated 2022-05-05

ICD10 CODES READ CODES V2 ADOLESCENT DATA PLATFORM (ADP) DATAMIND PHENOTYPE LIBRARY

PH934 - Conduct Disorder

A. John, Y. Friedmann, M. DelPozo-Banos, A. Frizzati, T. Ford, A. Thapar

Disease or syndrome · Last updated 2022-05-05



DATA MIND

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Roadbuilder Innovations

Milestone 2

Discoverable Schools

Discoverable excluded and under-served populations

Linking physical & mental health in SMI

Milestone 3

Reusable free text data

Digitally enhanced trials

Drug discoverability

Children's Health & Wellbeing Dashboard

Local Authority	Gender	Value	2017	2019	2021
Monmouthshire	Persons	%	59.1	54.3	52.1
Newport	Persons	%	50.5	50.6	45.6

Show/hide technical info

Survey question: How often do you usually have breakfast (more than a glass of milk or fruit juice) on weekdays?

This indicator presents the percentage of children who eat breakfast every weekday (Monday-Friday). The data includes 11-16 year olds who answered that five days out of seven.

General Information

The School Health Research Network (SHRN) administers a Student Health & Wellbeing Survey within secondary schools in Wales every two years. Since 2017, all maintain secondary and middle schools in Wales are SHRN members. For further details on response rates and survey methodology [please see the SHRN website](#).

No weights were applied to the data presented in this dashboard as the demography of the survey sample closely matched the equivalent population of Wales due to the high response rates. Responses to the questionnaire item are presented and then a binary indicator is defined. For each indicator, results are presented by: gender, age (where age is defined), local authority & local health board. Confidence intervals have been calculated using the profile likelihood method (Venables & Ripley, 2002) to assist in identifying significantly different from one another.

In the data table, values are highlighted in dark or light grey in the data table where the selected breakdowns have a significantly higher or lower result than Wales, respectively. For example, if the 2021 Wales value is lower than the range for a local authority in 2021 then the local authority value is significantly higher than the Wales value, the converse is also true for significantly lower than Wales value. If the confidence interval overlaps with the Wales value, then the difference is not significant and therefore not highlighted in the data table. The HBSC Family Affluence Scale (FAS) has been used to measure young people's socio-economic status, based on a set of questions which measure the material conditions of the household in which young people live. A binary affluence score between 0 and 7, with high scoring between 6 and 7) has been used in place of the usual high, mid and low standard scoring system, due to one of the six questions making no longer being an appropriate measure as a result of pandemic restrictions (has your family travelled outside of Wales on holiday?). This method has been used across all SHRN reports. In this dashboard and is therefore not comparable with results in the SHRN National Reports. Those who did not provide a response to all of the questions which were not given a high or low result; meaning they have been excluded from FAS breakdowns. For each survey year: 4,644 (4.3%) responses were excluded in 2017/18, 5,333 were excluded in 2019/20, and 5,732 (4.7%) responses were excluded in 2021/22.

Age was calculated using results provided for month and year of birth, which were then subtracted from month and year of survey being completed. If month of birth was not provided, age was calculated using year of birth and year of survey. Only 0.57% total results were given a proxy age from just year data across all three years of surveys.

2017/18 survey: From 103,971 records, there were 50,452 (48.5%) males, 51,458 (49.5%) females, and 2,061 (2.0%) "prefer not to answer" responses. For outputs at a person level, those who responded "prefer not to answer" were included. During the 2017/18, survey there was no option to choose anything other than male or female. Responses were expanded to include "neither word describes me". Exclusion criteria removed 1,997 (1.92%) results where they had an age outside of 11-16 or they did not provide enough data to calculate age. Authority breakdowns for Torfaen in 2017/18 have been removed from results due to <70% coverage of schools in this area. In 2018 Bridgend moved health boards therefore included historical labelling for this geography; Bridgend has been manually reassigned to Cwm Taf Morgannwg health Board in this survey year to aid with comparability between years.

2019/20 survey: From 119,288 records, there were 58,115 (48.7%) males and 58,610 (49.1%) females, with 1,472 (1.2%) choosing neither word describes me, and 1,191 "I do not want to answer". For outputs at a person level, those who responded "neither word describes me" and "I do not want to answer" were included. Exclusion criteria removed 2,147 where they had an age outside of 11-16 or they did not provide enough data to calculate age. "Neither word describes me" responses are not displayed as a single group within breakdown due to the small number of responses which could increase statistical variation and lead to highly uncertain results.

2021/22 survey: From 123,204 records, there were 60,315 (49.0%) males and 57,219 (46.4%) females, with 3,691 (3.0%) choosing neither word describes me and 1,979 "I do not want to answer". For outputs at a person level, those who responded "neither word describes me" and "I do not want to answer" were included. Exclusion criteria removed 2,147 where they had an age outside of 11-16 or they did not provide enough data to calculate age. "Neither word describes me" responses are not displayed as a single group within breakdown due to the small number of responses which could increase statistical variation and lead to highly uncertain results.

For presentational purposes, the scale of each figure's axis is variable and relative to the data being presented. Care should therefore be taken when reading the figures, as differences are not over-interpreted due to scaling.

Please note, data produced in this dashboard may not fully match the data found in the SHRN national reports due to extra exclusion criteria set by Public Health Wales. For example, rounding in SHRN reports may lead to small discrepancies in reported percentages. Similarly, numbers within SHRN's Local Authority reports may not match numbers in this dashboard due to different methods.

If you have any comments or feedback, then please get in touch with us by emailing: zoe.streeter@phwales.nhs.uk

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Mean mental wellbeing scores out of a total of 35 using SWEMWBS, persons, aged 11-16, local authorities, Wales, 2021

Produced by Public Health Wales Observatory, using SHRN data

Select a chart view

- 2017 data, all local authorities
- 2019 data, all local authorities
- 2021 data, all local authorities
- Custom view

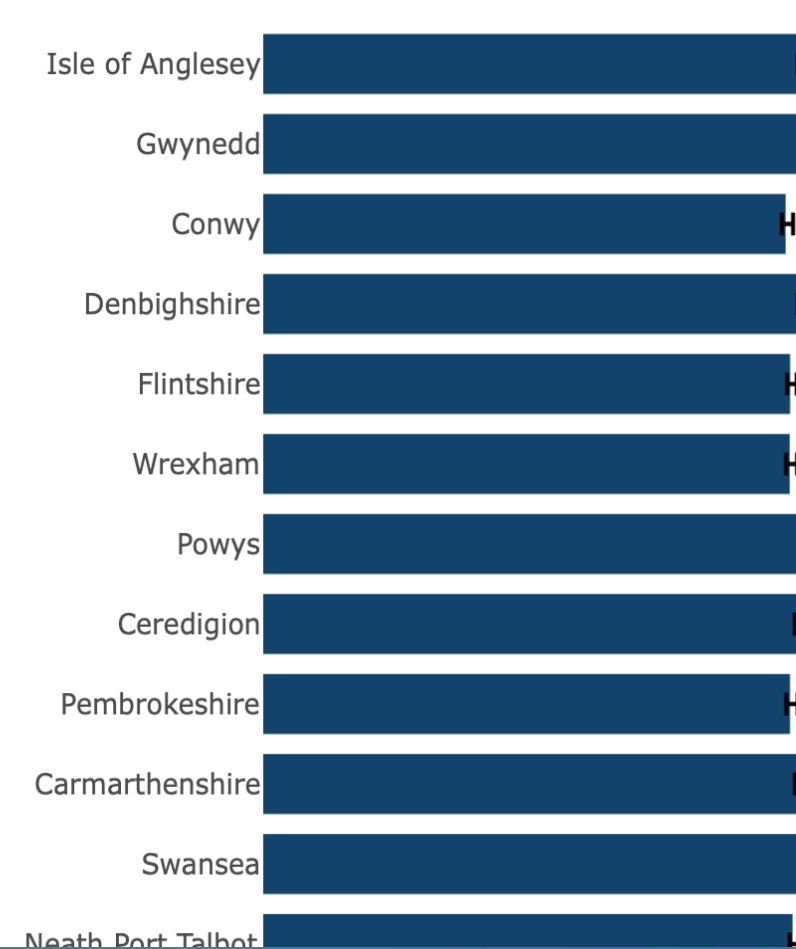
Select Gender

- Persons
- Female
- Male
- Male and female

Sort by value?

- On
- Off

95% confidence interval | Wales, 2021





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The Health Data Research Hub for Mental Health



Training and Capacity





DATA MIND
The Health Data Research Hub for Mental Health

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To support capacity development, including development of early career researchers



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Build capacity on research practices, Data Science methods, PPIE, Leadership



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MH DATASCIENCE COMMUNITY

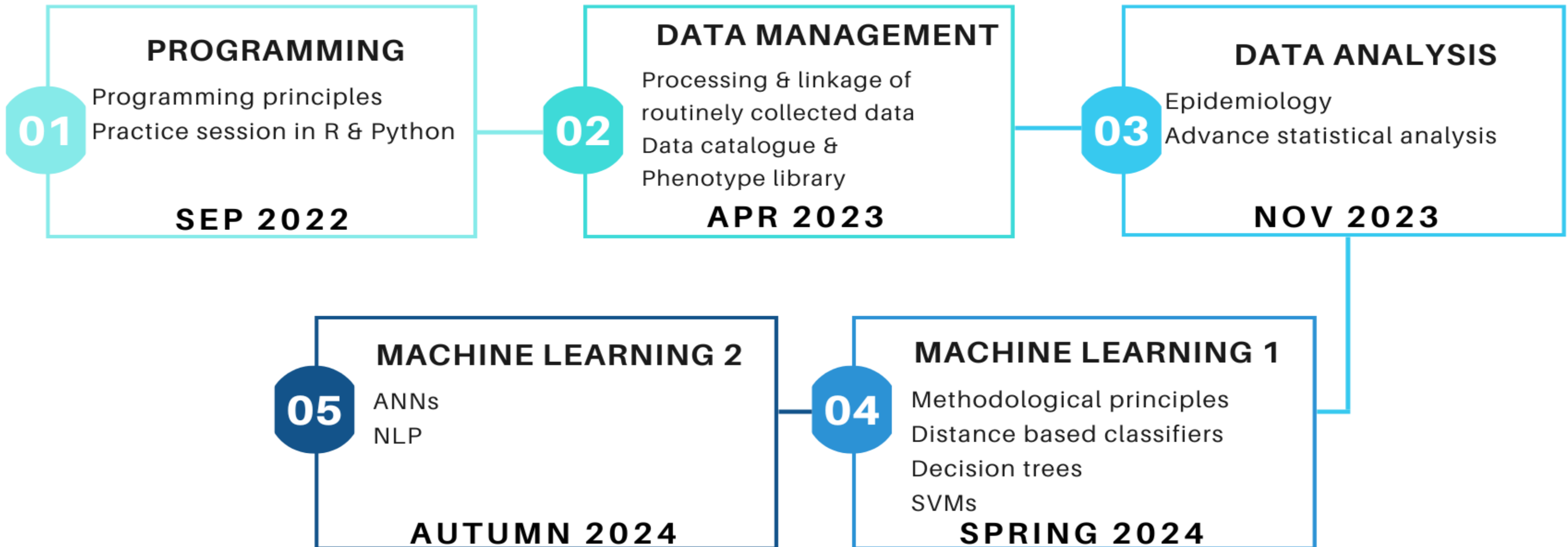
Convene ECRs to share career development and collaboration opportunities and experiences



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A Feasibility Study to Define and Embed a Core Mental Health Dataset in Physical Health Research Studies

An individual's mental and physical health are closely linked. However, this fails to be reflected in starkly disconnected mental and physical healthcare provision, or in the public health and research sectors (DoH, 2017). Enhanced understanding of the links between physical and mental health is now a priority for patients, research councils and the NHS. The Mental Health Research Framework highlighted the "need for securing closer integration of mental and physical health research to maximise research capacity" (DoH, 2017, p.5). Routine capture of mental health data in physical health studies was specifically identified as a critical area to address.

Our overarching aim is to create a seamless and widely acceptable mechanism to collect a common/core set of mental health data (the Core Mental Health Dataset - CMHDS) for all UK physical health study participants so that researchers can analyse the links between physical and mental health.

The NIHR Clinical Research Network (CRN) collects data on over 800 000 participants across its clinical portfolio every year in England and Wales. The vast majority of participants are from studies concerned with physical ill health. A significant gap in these data is information about participants' mental health and wellbeing. However, public data collection initiatives require substantial PPIE, as well as multi-organisation agreement about the content and format of the datasets collected. Moreover, the technical infrastructure to capture mental health data routinely within physical health studies needs to be designed.

This project aims to work with people across the UK to co-create an acceptable, safe and secure mechanism to collect a core set of mental health data for participants in physical health research projects. This involves workshops with the public and other researchers to understand the concerns people may have about sharing mental health data when partaking in a physical health study – ensuring mental health outcomes collected in the Core Mental Health Data Set (CMHDS) reflect what the public and researchers feel are important elements of mental health to be captured in all studies. This is in line with COMET's goal to create outcomes that are relevant to patients and health professionals.

We will then test the feasibility of embedding the CMHDS in 3 physical health studies. The ultimate aim of the research is to have a core set of mental health questions asked across all physical health studies, giving us consistent data which can be compared and analysed and providing a broader understanding of the mental health status of the population at large, as well as an insight into the links between mental and physical health.

The principal research question is: How can we safely, securely, acceptably and easily collect mental health information from participants in physical health research projects?

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Host organisation: Greater Manchester Mental Health NHS Foundation Trust

Linked Studies
No related studies

Related Links
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