South West
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data Environment Network

NHS

South West Secure Data Environment

Enabling research that's faster, fairer and safer.

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The Power of Partnership

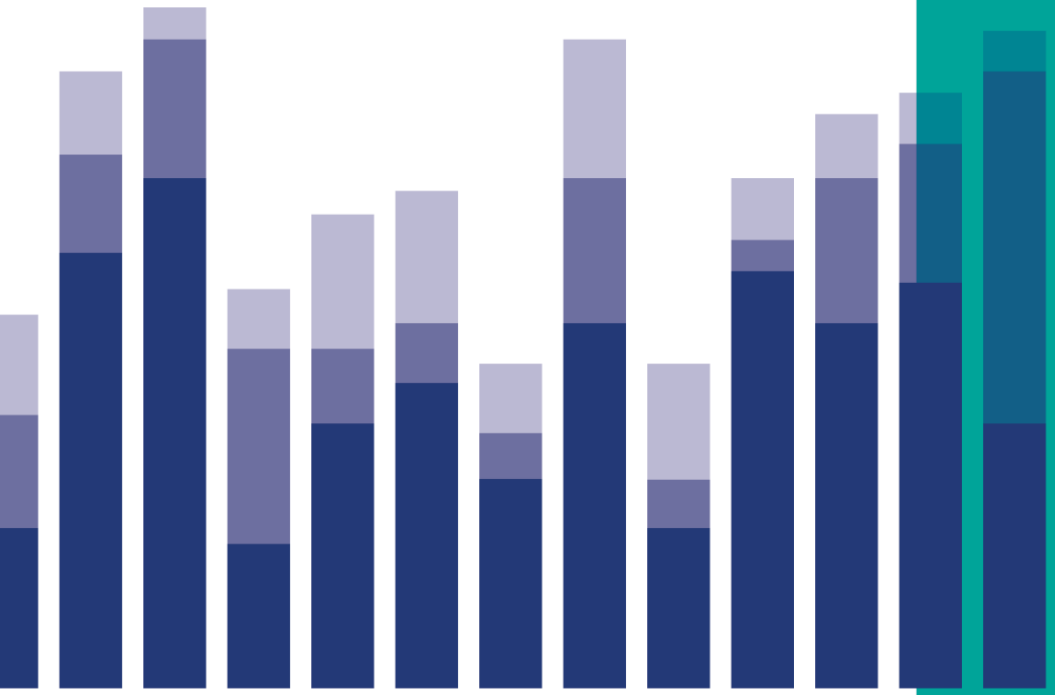




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Chrissie Walker

Senior Research Manager
South West Secure Data Environment

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Scene Setting

"…healthcare is more suited to data and the innovation that follows than almost any other sector - with the depth and coverage of NHS data providing unique opportunities."

*"The rewards of getting it right are profound, with not just lives saved but **longer, healthier and happier lives** too."*

Better, Broader, Safer introduction, 2022

*"…the system remains **slow and fragmented** which means that safe and secure research using the data is delayed or prevented for months and years."*

Health Data Research UK, April 2025

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What is the Secure Data Environment?



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This is our programme.



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Nobody is THE expert

Everybody is AN expert

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Different worlds

Challenges

NHS

Benefits often feel indirect or slow

Research funding process unclear

Rarely dedicated research time

University research

No clear route into the NHS

Little understanding of NHS data

Funding cycles/processes

Success metrics

NHS

Actionable insights quickly

Onward funding to implement change

Measurable impact

University research

Published papers in good journals

Onward funding to continue research

Measurable Impact

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Partnerships need:



- Trust and understanding
- A shared vision
- Time to learn from each other

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Why partnership working matters

- Project ideas ready for funding calls
- Stronger, collaborative proposals
- Trusted teams in place
- Early public involvement



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How do we build these partnerships?

What can we offer?





What do we need?

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South West Analytics and Infrastructure in Healthcare

SWAIH: over 620 members – for people working with healthcare data for research in the South West

Annual Meeting	Insight Talks	Newsletter
150 attendees *Invited speakers* *Focus on celebrating local and national progress*	*Online talks on a range of topics.* *30 minutes from the speaker, 30 minutes informal Q&A*	*National and Regional news* *Funding updates* *Regional Research*

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South West Data Science Hub

A focused group for NHS data professionals from Cornwall, Devon and Somerset

Skills Training

Has included:

Network analysis; discrete event simulation; data visualisation; process mining

Problem solving

Members can share and present current technical challenges for others to help work through.

Resource sharing

Open Source tools and models developed and trialled in different NHS organisations can be shared and refined collaboratively.

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We are a people programme, not a data programme.



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Embedding the public voice in the South West SDE

Digital Critical Friends





My experience

- 2018 – Co-development Panel member for Digitrials with NHSE - Trusted Secure Environment (TRE)
- 2022 – OpenSafely – Digital Critical Friend (DCF)
- 2023 - GW Secure Data Environment - SW SDE

Being a DCF with the South West SDE

- Training - what is a Secure Data Environment, the Five Safes, the secondary uses of data, including research, and the ethical questions raised by using unconsented health care data for research.

- Attended
  - Leadership Board meetings
  - Management Meetings
  - NHS England Audit
  - Technical meetings with Simpsons
  - Development of PPIE Strategy, Information Governance

- Represented South West SDE in PPIE consultation conferences

- Participated in Public participation workshops within various communities

What we learnt from the public?

Public Awareness

- Inform the public about the new Secure Data Environment (SDE) and the national opt-out option.

General Support with Conditions

- People generally agree if:
  1. Confidentiality is protected.
  2. Data Security is assured.
  3. Research serves the public good not private profit.
  4. Opt-out options are clearly communicated



Desire for Transparency

- Participants want to know how their data is used and access resulting research

Charging for access

- Acceptable if it is to cover costs/benefits the NHS

.

The role of DCFs today

- Number of DCFs expanded from 3 to 14 bearing in mind the Diversity of gender, ethnicity and geography

- Training was provided to the new DCFs and 2 to 3 DCFs are embedded in each work stream of the SW SDE.

- 6 DCFs are part of SWSDE Data Access Committee (DAC) - Public presence. They make up a minimum of 1 third of our Data Access Committee (DAC)

DCFs ensure that all South West SDE projects benefit the public, and patient data is used ethically and safely

Building public trust to enable research

Co-designed with trust

Built alongside patients and professionals, with security and confidence at its core.

Ongoing engagement

Through national deliberations and regional work we have engaged with over 21,000 members of the public.

Transparent governance

Clear principles guide data access, security, and opt-out choices.





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Using NHS data

Andy Mayne, Chief Data Officer, Somerset NHS Foundation Trust







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Introduction to Health Data in the NHS

Andy Mayne

Chief Data Officer
Somerset NHS Foundation Trust

Kindness, Respect, Teamwork
Everyone, Every day

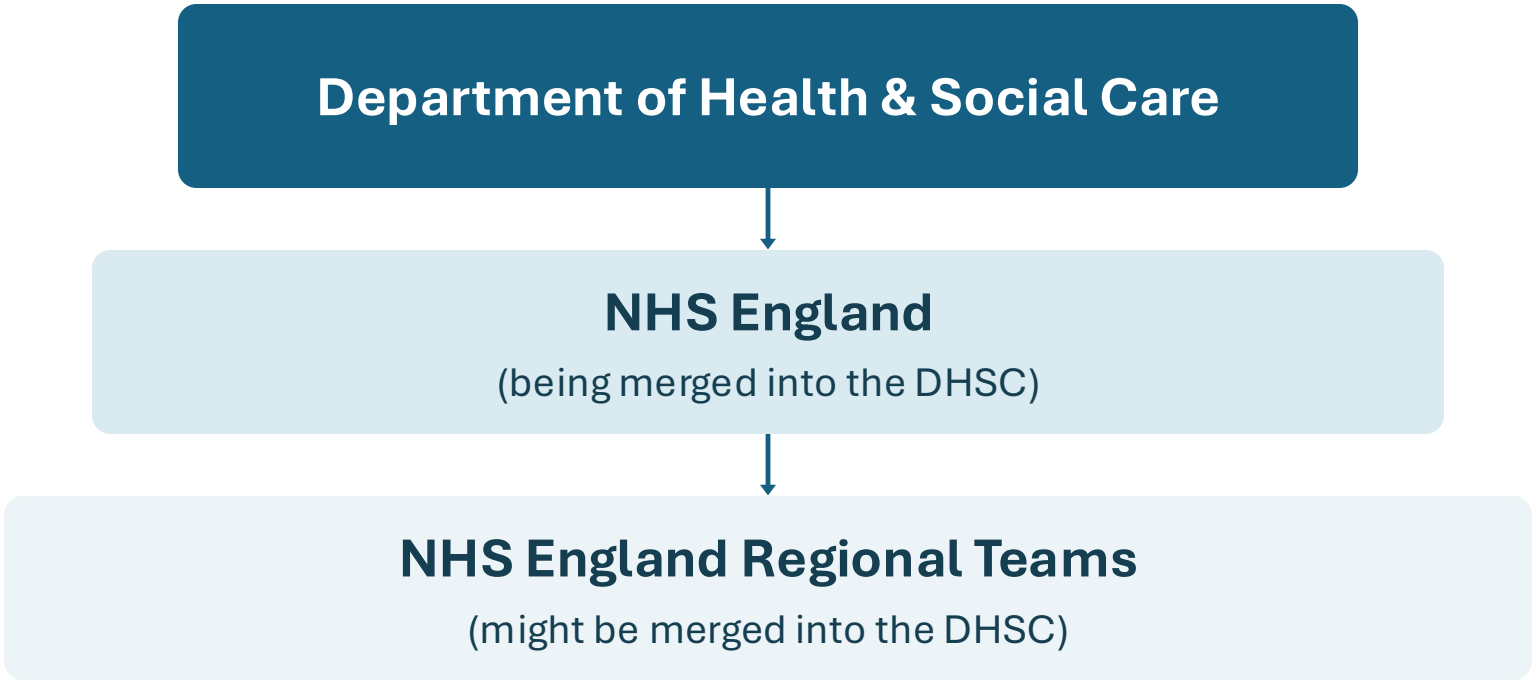
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Data in the NHS

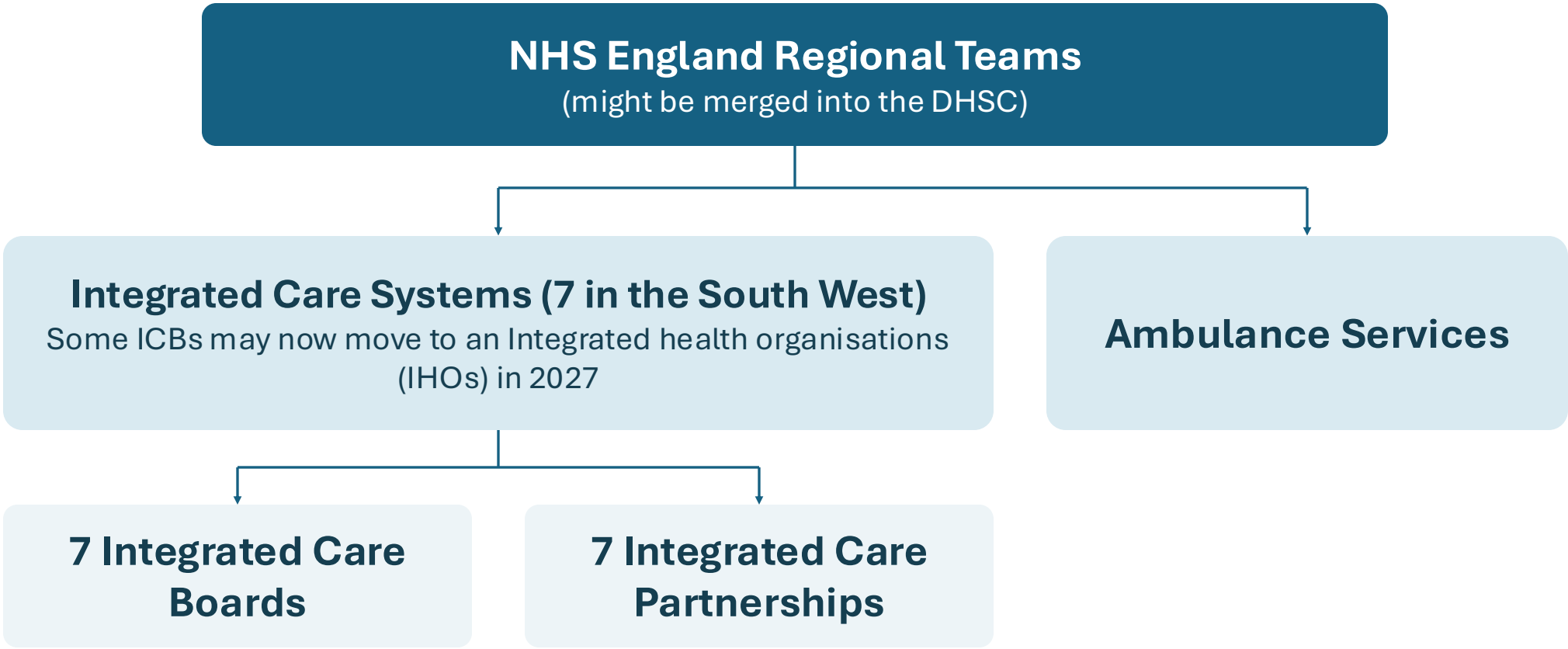
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Structure of the NHS - National

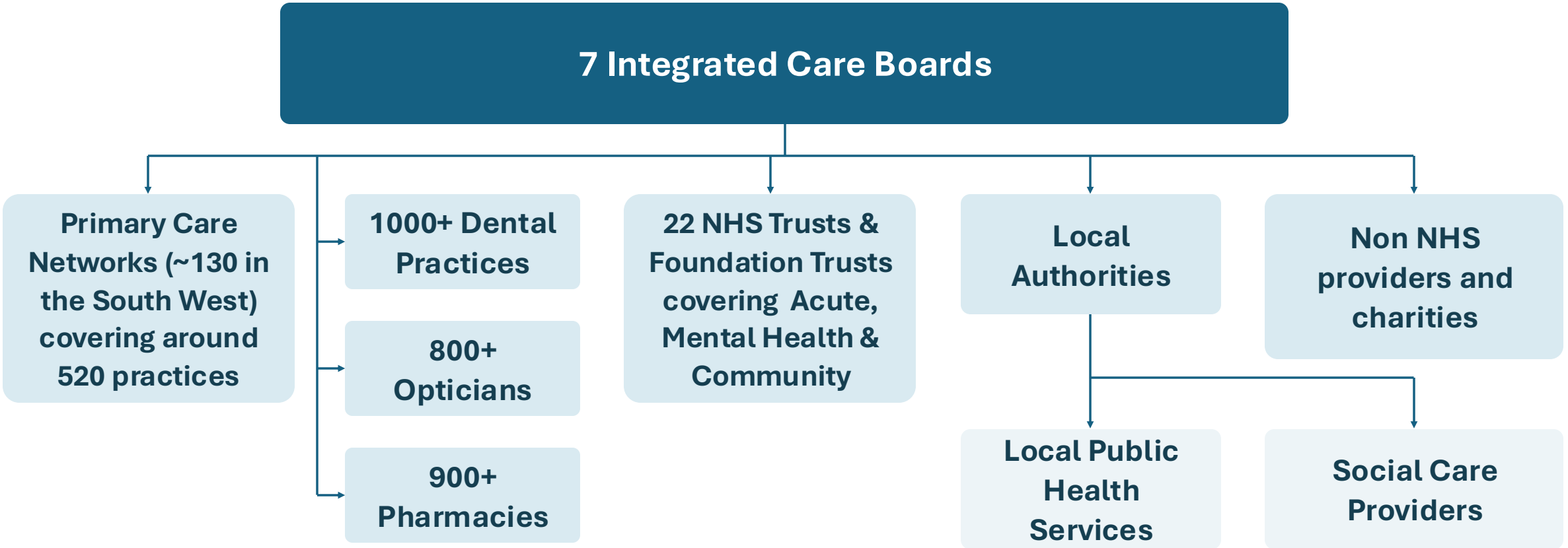
This is a common misconception around the structure of the NHS, and it's commonly referenced as a single company, in fact the NHS is made of thousands of GP Practices, Acutes, Community Hospitals, Pharmacies, Care Boards, Charities, NHS Trusts and Foundation Trusts that in many cases have their own governance, regulators, structures and priorities.



Structure of the NHS – Integrated Care Systems & Regional bodies



Structure of the NHS – Local / Integrated Care Systems



Somerset NHS Foundation Trust

Structure of the NHS – One Trust

22 NHS Trusts & Foundation Trusts in the SW covering Acute, Mental Health & Community

Somerset NHS Foundation Trust

100 + sites	**100 + Specialities**
629 Digital systems	**13,000 + staff**

Health Data

NHS Somerset NHS Foundation Trust

Why is it so difficult to get clinical research data

Data extraction follows service needs

Deliver Patient Care	Direct patient care uses the clinical system, there is no reason to extract most of this data for any other purpose
Run Our Services	Support day-to-day operations and meet regulatory performance requirements.
Keep the lights on	Extract the information needed to support payment for the care we provide.

Why research data is harder to obtain

Without a direct patient care, operational or payment need, the extraction of this information has no funding. Most healthcare data stays outside our data warehouses.

In addition, most of our clinical systems our third party owned, and few allow us a way to extract the data from them, outside of direct patient care.

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How most NHS data for research is created

1	**The Patient Encounter**	When a patient is admitted, stays in a ward, and undergoes surgery or treatment, every detail is documented in their medical notes by doctors, nurses, and allied health professionals. This includes the primary diagnosis, secondary comorbidities, procedures performed, etc.
2	**Clinical Coding**	Once the patient is discharged, their physical or electronic medical record is passed to the hospital's Clinical Coding team.
3	**HRG Grouping**	Because there are tens of thousands of individual ICD-10 and OPCS-4 code combinations, it is impractical to price each one individually. Instead, the codes are processed through a piece of specialised software called a Grouper.
4	**Costing & Tariff Mapping**	Once an HRG code is assigned, it maps directly to the NHS Payment Scheme (NHSPS)
5	**Commissioning & Payment**	The hospital compiles these HRGs into an electronic dataset called a Secondary Uses Service (SUS) submission and invoices the local Integrated Care Board (ICB).

The data required for payments is a fraction of the data we store!

NHS Somerset NHS Foundation Trust

Variety of data in the NHS – statutory reporting

National datasets and reporting collections

Area	Dataset or route	What it covers
Hospital care	**CDS / ECDS via SUS**	Admissions, outpatients and emergency care
Mental health	**MHSDS**	Mental health, learning disability and autism services
Community	**CSDS**	Community care contacts and interventions
Maternity	**MSDS**	Pregnancy, birth and maternity care
Cancer	**COSD via NDRS**	Cancer diagnoses, treatment and outcomes
Operations	**RTT / DM01 / AmbSYS****	Waiting times, diagnostics and ambulance performance
Primary care	**GPES collections***	GP extracts for specified national purposes

* GPES is an extraction service. **AmbSYS is only submitted by Ambulance Services

OUR ACCESS AS A PROVIDER

We cannot see other providers' patient-level data. Meaning you would need to contact every provider who could have been involved in a patients care to get the full story.

Data in the NHS

Just one of our clinical systems has over 32,413 fields of data in it!

NHS Somerset NHS Foundation Trust

Breaking down all our data

45
Specialist systems or tools that support care delivery

32
Acquire, view, report, store or exchange diagnostic images.

29
Hold core patient, encounter and longitudinal clinical-record information.

18
Manage specimens, analysers, laboratory workflows and test results.

16
Support maternity, newborn, neonatal and children's pathways.

15
Support prescribing, medicines supply, tracking and pharmacy services.

13
Receive, assess, route and coordinate referrals and transfers of care.

13
Capture or analyse measurements from specialist diagnostic equipment.

12
Support cardiovascular investigations, imaging, monitoring and stroke care.

Data in the NHS

Somerset NHS Foundation Trust

Breaking down the “other” data

11
Support cancer tracking, treatment planning, radiotherapy and oncology.

10
Track screening, surveillance, statutory audit and registry datasets.

10
Record observations, acuity, handovers, tasks and care activity.

4
Create, store and distribute clinical notes, letters and documents.

5
Support mental-health records, assessment, treatment and referrals.

4
Enable patients to submit data, access their care or manage conditions remotely.

2
Capture referrals, assessments, outcomes, feedback and consent.

1
Provide clinical guidance, knowledge or care-team communication.

Breaking down a research data request

This is an example data request that has been made for a typical research request, however within the NHS very little of this information is readily collected or stored in a single area, system or report.

Data	Description
PERSON	**Patient demographics and identifiers.**
CONDITION_OCCURRENCE	Diagnoses and clinical conditions
DEATH	Death information
DEVICE_EXPOSURE	Medical device use and exposure
DRUG_EXPOSURE	Medication exposures, prescriptions and administrations
MEASUREMENT	Clinical and laboratory measurements
OBSERVATION	Clinical information not represented as conditions or measurements
OBSERVATION_PERIOD	Periods during which patient data are available
PROCEDURE_OCCURRENCE	Clinical procedures
PROVIDER	Healthcare providers and specialties
SPECIMEN	Biological specimens
VISIT_DETAIL	Detailed components of encounters, including movement within an admission
VISIT_OCCURRENCE	Hospital encounters and admissions

We need to combine a wide range of clinical systems to ensure we have accurate demographic information. Every interaction the patient can give different information across any health setting.

Data in the NHS

Somerset NHS Foundation Trust

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Requires manually clinically coding the patient episode to obtain diagnosis, co-morbidities and procedures through our APC (Admitted Patient Care) dataset

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We only store information on patients who died whilst in our care, to obtain this information fully we need to perform an external “death check” using the national tool.

Data in the NHS

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Can come from a wide range of third-party systems who provide the particular medical device, each system will have an entirely different data model. For example, Ultrasound, Pacemakers, Radiotherapy are all completely different systems.

Data in the NHS

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This information is stored within a separate pharmacy system or within specialist third party systems that deal with administering drugs like chemotherapy.

Data in the NHS

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Stored in a separate systems, data models or in some cases this work is performed by a third party to the organisation for Microbiology, Radiology, Pathology etc.

Data in the NHS

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Can be stored in any of the 100s of systems in use depending on the type of care the patient is receiving, in many case this information would be within a physical set of medical notes.

Data in the NHS

Somerset NHS Foundation Trust

Breaking down a research data request

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This data requires extracting information from four Electronic Health Record systems (until we migrate to EPIC)

However, it's the most accessible data in this list.

Data in the NHS

Somerset NHS Foundation Trust

How SDEs reshape this – the barriers

Governance

Every organisation is its own legal entity and requires its own governance to share data.

Funding

Hospitals are not funded to extract novel data from our systems

Mechanism

The controls required to share data safely requires meeting complex technical standards

Art of the possible

There is no single way of knowing what data the NHS holds, which makes it very difficult for researchers to ask for data

How SDEs reshape this – the solutions

Governance

Every organisation is its own legal entity and requires its own governance to share data.

SDE Solution

A large portion of South West NHS Organisations are signing or have signed a Data Sharing Agreement (DSA) with the South West Secure Data Environment.

This DSA is flexible in covering a wide range of research studies reducing the need for new agreements to be agreed for each application.

For a researcher, they access the SDE, request information once, and the SDE handles the sharing agreements between the healthcare organisations.

Data in the NHS

NHS Somerset NHS Foundation Trust

How SDEs reshape this – the solutions

Mechanism

The controls required to share data safely requires meeting complex technical standards

SDE Solution

The SDE has built a platform that meets the highest standards in security and governance to safely ingest, process and make available the hugely sensitive information.

This platform is capable of joining and deidentifying complex datasets across the region, to create larger, richer and more meaningful datasets to support research.

We now have a mechanism to remove the high-risk direct sharing of information between Hospitals and Universities that does not meet the required standards of cybersecurity and governance required.

Data in the NHS

Somerset NHS Foundation Trust

How SDEs reshape this – the solutions

Funding

Hospitals are not funded to extract novel data from our systems

SDE Solution

The SDE has directly funded roles within the NHS to identify or extract novel information from our wide range of systems.

In addition, where funding is available to support this extraction through research grants, the SDE can coordinate this with the participating organisations to encourage them to be involved in the research.

However, the biggest barrier for providers to participate in research is the gap between the priorities of research and the NHS. The NHS needs more focus on research that addresses the operational pressures we have faced for decades.

Data in the NHS

Somerset NHS Foundation Trust

How SDEs reshape this – the solutions

Art of the possible

There is no single way of knowing what data the NHS holds, which makes it very difficult for researchers to ask for data

SDE Solution

This SDE has created a community of practice between researchers and the NHS. This includes our South West Analytics & Infrastructure in Healthset (SW.AIH) community and conference, our Peninsula Hub for Data Science and our links in with most NHS organisations across the South West.

There are several NHS colleagues in the room today that you can speak to, to enquire about the wide range of datasets we hold, and the mechanism for extracting it.

In addition, by 2028, three counties in the South West will be using the same Electronic Health Record (EHR) Epic, and therefore the same data model.

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Any questions?

Kindness, Respect, Teamwork
Everyone, Every day

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Lightning sessions:

HELP Flag
Chrissie Walker





University of Exeter Medical School

HELP Flag Study

The High or Elevated Level of Platelets (HELP) Flag Innovation: a primary care intervention for early cancer detection

Dr Raff Calitri
Senior Research Fellow

Background

University of Exeter Medical School

- HELP Flag sits in field of early cancer diagnosis - Improving early cancer diagnosis is a national priority
- Our team have created an innovation that flags patients with an elevated risk of cancer based on platelet count (a type of cell found in blood & measured as part of a Full Blood Count).
- We have identified new age-sex personalised upper platelet count thresholds
- Patients with platelet count above the threshold have 7+% risk of cancer

Female aged 60-69, Platelet count ≥550 x 109/L	Female aged 70+ Platelet count ≥500 x 109/L	Male aged 60-69, Platelet count ≥450 x 109/L	Male aged 70+ Platelet count ≥400 x 109/L

- Thresholds underpin the innovation, which has two parts….

HELP Flag Study

HELP Flag – The Alert

University of Exeter Medical School

F, 60 yrs, 22/12/1963

Collected 11/12/2024 09:00
Container: 1 Purple top

Contacts

Specimen Tracking

24B-34600004.1 Purple top - FBC

Instrument ID: 100029490

Full Blood Count (FBC)

Result reported: Scattergram{1} + Auto diff{1}

Res	Component	Value	Units	!	Δ	L	IE	R	Ref. Range	Method	Chart	PV
1	Hb	140	g/L						120-160	Modulab-Manual		
1	WBC	[illegible]	10*9/L						3.6-11.0	Modulab-Manual		
1	Plat	575	10*9/L	^					150-400	Modulab-Manual		
	Comment: Raised platelet count: This may be reactive (e.g. secondary to infection, bleeding, malignancy, iron deficiency) or a primary thrombocytosis. If cause unknown suggest discuss with a haematologist. Platelet count is raised; consider investigating under the HELP Flag pathway.											
1	RBC	5.00	10*12/l						4.00-5.20	Modulab-Manual		
1	HCT	0.380	L/L						0.360-0.460	Modulab-Manual		
1	MCV	87.0	fL						82.0-100.0	Modulab-Manual		
1	MCH	30.0	pg						27.0-33.0	Modulab-Manual		
1	MCHC	325	g/L						320-357	Modulab-Manual		
1	RDW	10.5	%						9.9-15.5	Modulab-Manual		
1	Neutrophils	6.00	10*9/L						1.80-7.50	Modulab-Manual		
1	Lymphocytes	2.00	10*9/L						1.10-3.50	Modulab-Manual		
1	Monocytes	0.70	10*9/L						0.20-0.80	Modulab-Manual		
1	Eosinophils	0.30	10*9/L						0.04-0.40	Modulab-Manual		
1	Basophils	0.09	10*9/L						0.02-0.10	Modulab-Manual		
1	OPTICAL PLATELETS (10*9/L) IN BLOOD AUTOMATED COUNT		10*9/L						150-400	Sysmex SSP50		

Method: Modulab-Manual Last received: 11/12/2024 15:47 Last verified: 17/12/2024 12:46 by Lab, Background User

HELP Flag Study

HELP Flag – The Pathway

Liverpool Clinical Laboratories | Cheshire & Merseyside Cancer Alliance | NHS University Hospitals of Liverpool Group

University of Exeter Medical School

The Liverpool High or Elevated Level of Platelets (HELP) Flag pathway

This pathway aims to provide information to support GPs to triage patients with elevated platelet counts.

The HELP Flag pathway should not supersede current practice in seeking advice from haematology if there is sufficient clinical concern. Follow local procedures for routine and urgent haematology referrals and guidance.

HELP Thresholds (a)

Female aged 60-69, Platelet count ≥550 x 10^9/L	Female aged 70+ Platelet count ≥500 x 10^9/L	Male aged 60-69 Platelet count ≥450 x 10^9/L	Male aged 70+ Platelet count ≥400 x 10^9/L

Platelet count above thresholds (box a - above) with no adverse symptoms in (box b - below) or alternative explanation (box c - below)

Any of (b) present? — Yes → **Consider Urgent Suspected Cancer (2WW) Referral consistent with current guidance**

Any of (b) present? — No

Alternative cause (c)? — Yes → **Manage outside of pathway**

Alternative cause (c)? — No

Repeat FBC

Send text message to patient to arrange repeat FBC in 4 weeks. GP to safety net 5 weeks after high platelet flag

Platelet count now below thresholds in (a) or explained (c) — Yes → **No Further Action**

Platelet count now below thresholds in (a) or explained (c) — No

Consider the possibility of cancer

Likely cancers: lung, colorectal, kidney, ovarian, oesophago-gastric, endometrial

send text message to arrange F2F exam, check history (b), and request 'Non-Specific Symptoms (GPs) investigations' bundle on ICE and organise a urine dip:

Full Blood Count (FBC); C-reactive protein (CRP); Erythrocyte Sedimentation Rate (ESR); Renal Profile; Liver Function Tests (LFTs); Thyroid Function Tests (TFTs); HbA1c; Calcium profile; B12 and Folate; Ferritin; Myeloma Screen; CA-125 (female patients); PSA (male patients); Faecal Immunochemical Test (FIT), Chest x-ray (CXR),

NG12 Tumour site identified? — Yes → **Urgent Suspected Cancer (2WW) Referral - Refer to relevant speciality**

NG12 Tumour site identified? — No → **Refer to Non-Specific Symptom Rapid Diagnostic Service (NSSRDS)**

(b) History – Check symptoms and signs to see if tumour specific Urgent Suspected Cancer pathways required, especially

- Haemoptysis
- Upper GI symptoms in over 55s
- Post menopausal bleeding
- Visible Haematuria – urology/gynaecology
- Vaginal discharge in women over 55
- Abnormal masses – Abdominal, pelvic, Ano rectal, Organomegaly, Splenomegaly, Lymphadenopathy
- Iron Deficiency Anaemia (may itself be a feature of malignancy)
- New unexplained and unintentional weight loss (either documented >5% in three months or with strong clinical suspicion)

(c) Alternative causes of thrombocytosis

Consider:

- Inflammation[1]
- Infection[1]
- Post-splenectomy and hyposplenism (e.g., Coeliac disease)[1,2]
- Post-operative[1]
- Inflammatory bowel disease[2]
- Rheumatoid arthritis[2]
- Giant cell arteritis[2]
- Segmental colitis associated with diverticulosis[2]
- Thromboembolic disease[2]

Helpflag@Exeter.ac.uk

HELP Flag Study

Implementing HELP Flag

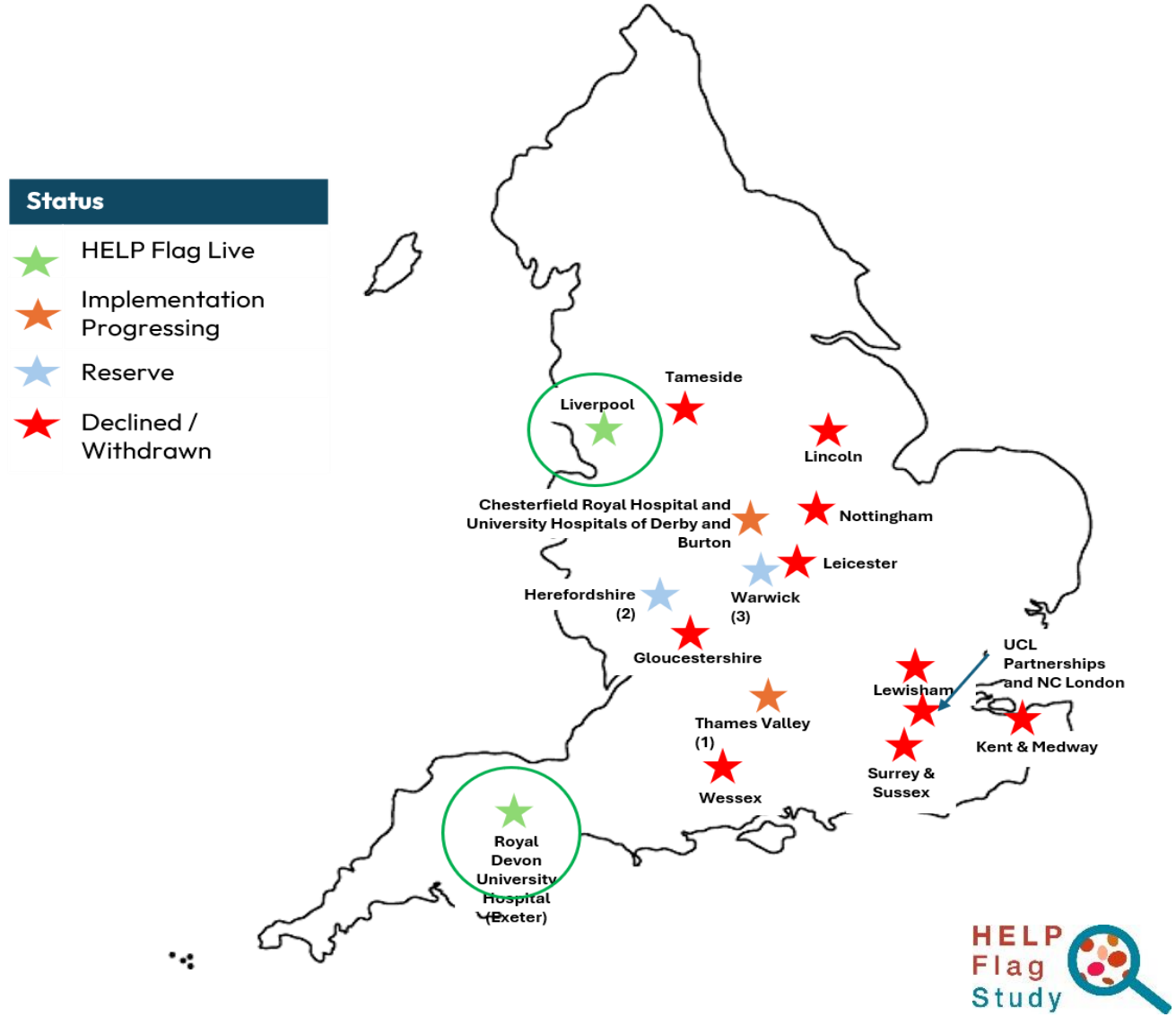
NHS England have awardee us £2.5m to implement and evaluate HELP Flag

HELP Flag has been Implemented in Devon & Liverpool

~70 GP practices are receiving the alert

It will be implemented in up to 2 other regions in England

University of Exeter Medical School



HELP Flag Study

Real-World Evaluation

University of Exeter Medical School



Clinical Impact

Aim: to establish the impact of HELP Flag on clinical outcomes.



Health economics

Aim: to assess the economic impact of HELP Flag.



Acceptability

Aim: to understand the acceptability of implementing and using HELP Flag

HELP Flag Study

University of Exeter Medical School

Working with SW SDE



Preparing for the SDE Recipe for Success…

University of Exeter Medical School

- Prepare a clear Research Question
  - Understand how you are going to implement this question
    - You looking for proportions or differences in means?
- Prepare clear data specification
- Prepare to work closely with the data specialists
- Prepare for iterative data extracts and refinements

HELP Flag Study

Data requested

First high platelet count	Patients' characteristics	Cancer diagnosis tests and referrals	Cancer Outcomes	Cancer Treatment
How high was the count? Date of test	Age at platelet test and sex (to check they meet the flag criteria) Ethnicity, local deprivation, live in urban or rural setting? (These help us know if some groups get worse outcomes) GP practice (so we know if their GP gets the Flag)	Any further platelet count tests Further full blood count tests "Non-specific symptom" pathway tests (e.g. chest x-ray, urine tests) Any referrals from the GP to investigate for cancer These help us know whether the HELP Flag Pathway was followed.	Site of cancer (e.g. lung, breast) Date diagnosed Early or late stage at diagnosis? Diagnosed from an emergency hospital admission? (This tends to indicate the cancer was not picked up by the GP)	Was there cancer progression? Treatment start / end dates Drug treatment used? (type and dosage) Radiotherapy treatment used? (type and dosage) Any information on costs (so we can calculate if the HELP Flag is cost-effective). Without this data we can use estimates.

HELP Flag Study

Challenges

University of Exeter Medical School

- Working with multiple SDEs… federation of data
  - DSAs might need to be arranged between Trusts and SDE
    - Account for time in project planning
- Limited statistical packages
- Front end interface could be more intuitive (designed for data scientists not researchers)

HELP Flag Study

University of Exeter Medical School

HELP Flag Study

www.helpflag.com
helpflag@exeter.ac.uk

Acknowledgements

Funded by: NHS Cancer Programme – Innovation Open Call 3, supported by SBRI and Accelerated Access Collaborative

Collaborators: University of Manchester, National University of Singapore

Pathway Contributors: Peninsula Cancer Alliance; Chesire & Merseyside Cancer Alliance

University of Exeter Medical School

HELP Flag Study

www.helpflag.com
helpflag@exeter.ac.uk

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South West SECURE DATA ENVIRONMENT

Part of the **NHS Research Secure Data Environment Network**

NHS

Lightning sessions:

DAFNEA introduction
Henry Ireland





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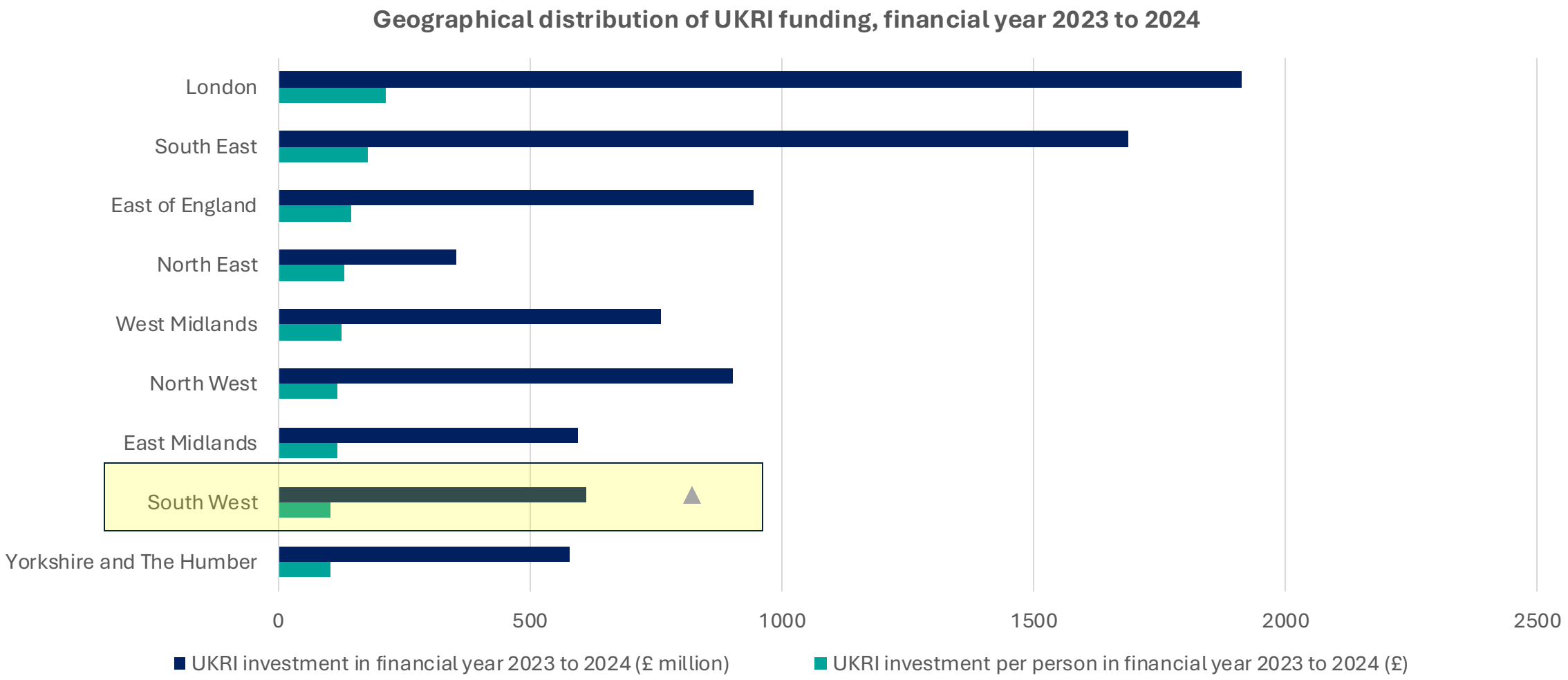
NHS



D Data
A Accelerator
F Fund for
N Novel
E Emerging /
A Assets

Research Investment

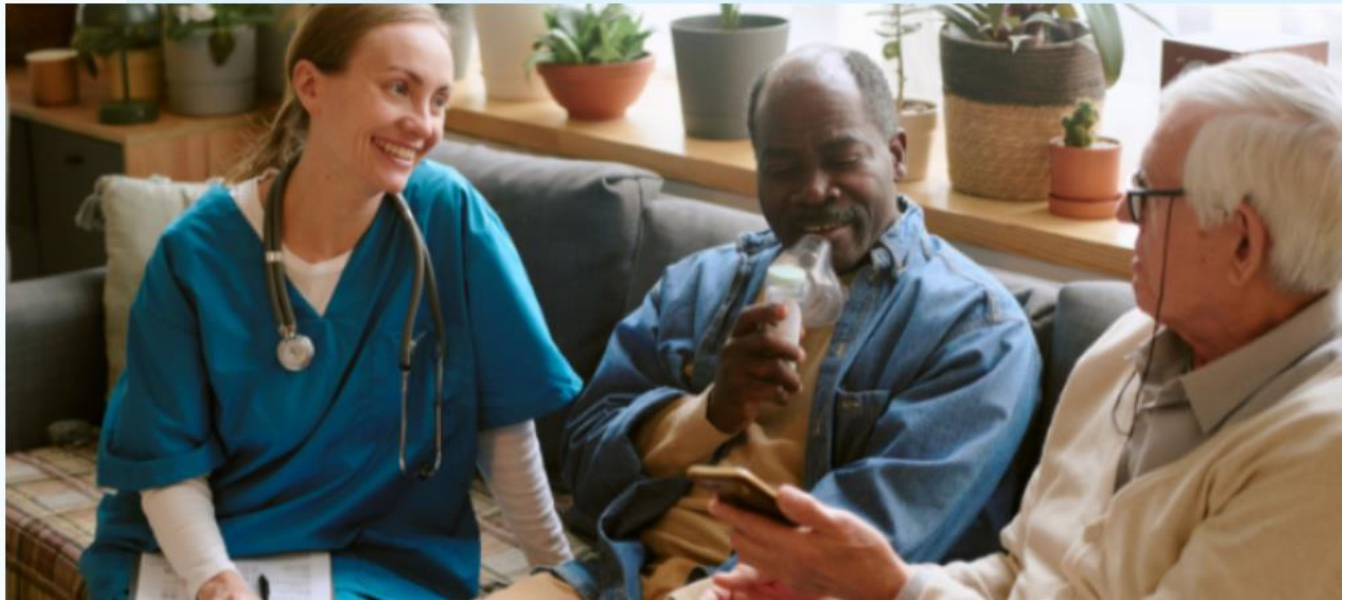
Regional UKRI funding, how does the SDE stack up



From: UKRI (Geographical distribution of UKRI funding, financial years 2022 to 2023 and 2023 to 2024 – UKRI), **Published:** 10 March 2025, Accessed 7 July 2026

New £1m South West SDE Fund to Accelerate Access to Health and Care Data for Research

December 5th 2025



South West SECURE DATA ENVIRONMENT | Part of the NHS Research Secure Data Environment Network

NHS

NIHR Biomedical Research Centre: Exeter

About | Events | News

The #KMSSDE DAFNEA aims to make novel, unique, and multimodal data assets available to researchers.



New £1m South We… Fund to Accelerate… to Health and Care… for Research

December 5th 2025

University of Liverpool Researchers Secure £375,000 to Develop Five Major Health Data Assets

Published on 29 July 2026

Researchers from the University of Liverpool have secured £375,000 through the North West Secure Data Environment's (SDE) Data Accelerator Fund for Novel and Emerging Assets (DAFNEA), supporting five projects that will create innovative research-ready data resources in partnership with NHS organisations and local authority collaborators across Cheshire and Merseyside.

Core Principles

Call: December 25 – January 2026
Delivery of data pipelines: December 2026

Robust
Two stage process with scoring and panel review

Equitable
Geography, point of care, population

PPIE Led
Chairing and panel

HDR UK strategic priorities
VSCEs

The Data

Successful awardees

Royal United Hospitals Bath NHS Foundation Trust

Rheumatology dataset; Bath **National Pain Centre** Complex Pain Outcomes dataset

Highly complete demographics/Diagnoses:/Clinical measures: BASMI, DAS28, joint counts and mobility assessments./Treatments: high-cost drugs including biologics and rehabilitation programmes./PROMs: such as pain scores, fatigue, function, quality-of-life measures./ Follow-up data 13,000+ patients

University Hospitals Plymouth NHS Trust

Multimodal stroke and control dataset – ABSTRACT project

9155 stroke/transient ischaemic attack (TIA) cases and 109,581 controls. Includes 22023 MRI brain, 47283 CT brain (reports and DICOM files), 16,247 ambulatory ECG (ISHNE files and reports), 35,553 echocardiogram (reports and DICOM), 100,331 laboratory results (CSV), 100,331 radiology/pathology reports (free text), and 100,331 GP records (SNOMED and ICD-11 codes, complete medication history, no free text).

Royal Cornwall Hospitals NHS Trust

Skin lesion imaging dataset; multi-**modal chest imaging** dataset

Chest X-rays for correctly placed and misplaced NGT and ETT, Pneumothorax, Pneumoperitoneum and negative controls. (14000 cases) 2) Chest X-ray: Covid-19 positive and negative controls. Extensive associated data inc. demographics, medical history, bloods, observations, survival. (2000 cases) 3) Chest x-rays: no specific pathology, collected for training. (3000 cases) 4) 2000 skin lesion images with detailed breakdown of case and type.

The Data

Successful awardees

University of BRISTOL

One in a Million: Telesafe, ***telephone appointment*** *cohort*

For each call, the dataset contains the audio recording and a written transcript. For most consultations, it also links to extracts from the patient's GP record from around one month before and three months after the call, plus short questionnaires from patients and clinicians.

NHS
Avon and Wiltshire Mental Health Partnership
NHS Trust

Eating Disorders *complete cohort*

Structured activity data, Unstructured progress notes , Coded diagnostic data, Coded PROMs, Coded PREMs, Coded prescribing data Service areas covered (e.g. hospital, mental health, maternity, housing), Mental Health community services, Mental Health inpatient services

CaafiHealth

Community health dataset *of Bristol's global majority communities*

The dataset contains clinical measurements and demographic information structured around individual health check events

The Data

Successful awardees

Royal Devon University Healthcare NHS Foundation Trust

University Hospitals Bristol and Weston NHS Foundation Trust

North Bristol NHS Trust

Diabetes genomics *datasets*

PeMCOD – ***Perinatal & Maternal*** *Care Outcomes Dataset*

Monogenic data: Currently 24687 UK individuals referred for testing from 17018 families; 7297 with a confirmed genetic diagnosis Exeter 10,000 data: We currently have SNP chip and TOPMed imputed data available on 10,163 participants. Monogenic data: Data available on all monogenic diabetes testing in the Exeter Genomics Laboratory since 1995. Testing will be ongoing as routine care. Exeter 10,000 data: Started in 2010 and still recruiting

The PeMCOD data asset population will include all births in the South-West region between 2015 and 2025, and then ongoing data from all completed pregnancies. The cohort will be approximately 450,000 births, of which 15% (67,500) will have been admitted to neonatal/transitional care units for specialised inpatient neonatal care. An estimated 8% (3,600) of the cohort will be in the high-risk preterm group, with high expected mortality and multi-morbidity rates

The Data

Successful awardees

Centre for Sustainable Energy

Energy and property *related data assets*

Housing and home environment; fuel poverty and energy affordability; financial wellbeing and debt; public health and prevention; hospital discharge and safe return home; mental health and wellbeing; community support services.

BrisDoc

Urgent care multimodal datasets including NHS 111 and ***GP Out-of-Hours*** *services*

Integrated Urgent Care services (OOH, NHS 111, weekday professional advice), Frailty/ACE, IAP Mental Health, and primary care across ~1m people

South West SECURE DATA ENVIRONMENT

Part of the **NHS Research Secure Data Environment Network**

NHS

Lightning sessions:

Centre for Sustainable Energy
Kate Thomas





Centre for Sustainable Energy

Fuel poverty and cold homes

Kate Thomas - CSE

Centre for Sustainable Energy

Vision: sustainability, reduced carbon emissions, fair access to affordable energy

Mission: share knowledge and practical experience, empower others

With over 150 staff we have up to 100 different, separately-funded projects at any one time

“Change the way people think and act around energy”

Centre for Sustainable Energy

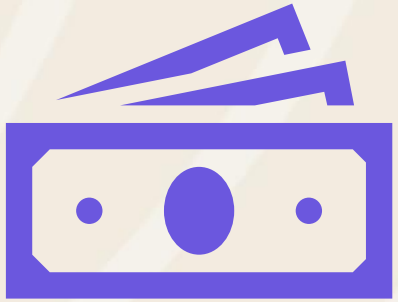
Understanding Fuel Poverty

Identifying individuals at risk of suffering

What is fuel poverty?



Inefficient property



Low income



High fuel prices

Heat or eat?

More likely to be fuel poor if:

- Living in privately rented property
- Unemployed
- Pre-payment meter
- Single-parent household
- Low energy performance rating

Estimated **6 to 7 million households** in England are defined as fuel poor (NEA 2023) – up from 4.5 million in 2021



Centre for Sustainable Energy

Housing conditions, energy affordability and fuel poverty data

DAFNEA project

Our data is a unique mix

- Household income
- Energy affordability
- Debt
- Heating behaviour (under and overheating)
- Housing circumstances
- Damp, mould and ventilation

Often absent in healthcare data, even though it influences whether people can remain warm, healthy and independent at home.



Beyond broad deprivation data

We can demonstrate how a household can afford to heat their home, whether the heating works, and how this interacts with their health and vulnerability.



Conditions frequently linked to cold homes and FP

- **Respiratory conditions**, particularly **asthma and COPD**
- **Cardiovascular conditions**, including heart disease and increased risk of **stroke**
- **Mental health conditions**, including stress, anxiety, depression and social isolation
- Many more long-term health conditions **affected by cold, damp or overheating**

Low temperatures, damp, mould and air pollution can mean increased and exacerbated **COPD**

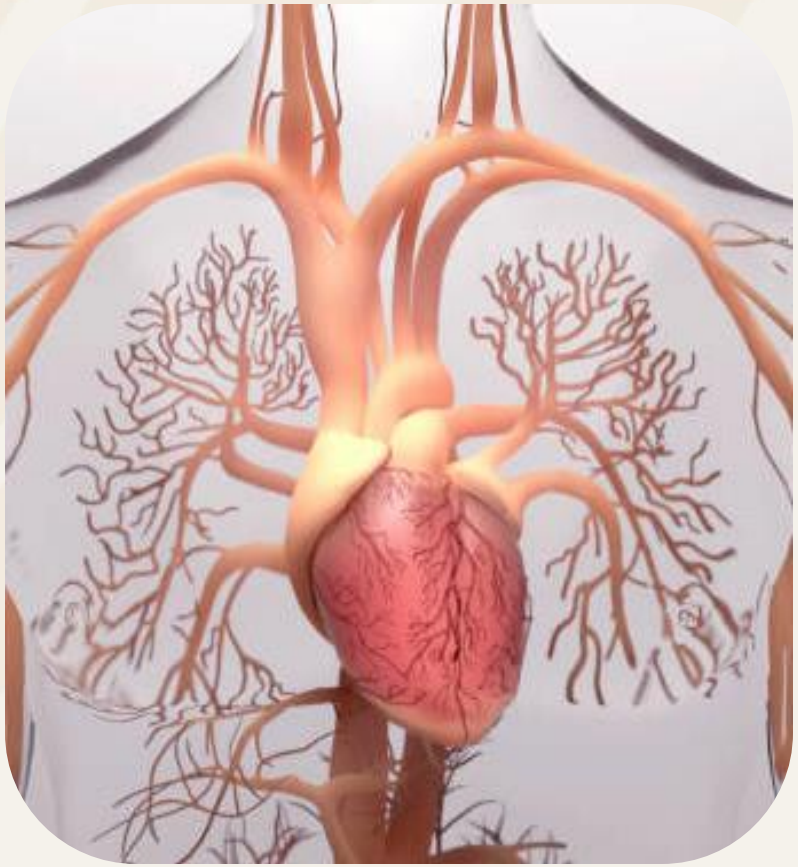
- Linking our dataset with health data could strengthen our understanding of health inequalities and support more targeted, preventative interventions.

- As an example - COPD and acute respiratory admissions rise from November-March and spike below 3 degrees, this group has a high re-admittance to hospital rate.

Practical support

- Health practitioners to reinforce message around dangers of cold and instruct patients to seek support

- We seek affordable, reliable heating first, then energy efficiency and healthier homes solutions later



Sharing health data means targeted support



- Primary care data helps identify risk
- Secondary targets acute need, identify need before discharge
- Opportunity to be connected and preventative through early assessment
- Affordably warm and healthy homes are the best places to live with a condition or to recuperate from one.

By the end of the project, we want to…

Enable trusted NHS research partners to build a better understanding of the links between fuel poverty, cold homes and health outcomes

Provide consistent, high-quality data to SWDE

Link this wider determinate of health to targeted future services

Centre for Sustainable Energy

Refer to us

How to access our support

Refer online
https://www.cse.org.uk/refer-a-patient-or-client/

Advice line
0800 138 0810 |
nationalenergyadvice@cse.org.uk

WhatsApp
https://wa.me/447514669219

Website
https://www.cse.org.uk/



The year in numbers 2024-25



22,593

People supported by our freephone energy advice service.



30,462

Survey responses received in our research to understand how people respond to electricity demand flexibility services.



£25 million*

Saved by our clients, through benefits claimed, insulation and new heating systems installed, fuel vouchers distributed, and much more.



755

Young people reached through our high-quality education and youth leadership programmes.



55

Climate action plans written for local authorities and community organisations.



£1,106*

Average saving per household for people who called our advice line. That's more than double the £525 average saving we achieved last year.

925

Community organisations supported to take action on climate change or tackling fuel poverty.





5,849

Energy efficiency measures installed as a result of our help – more than twice the number last year (2,400)

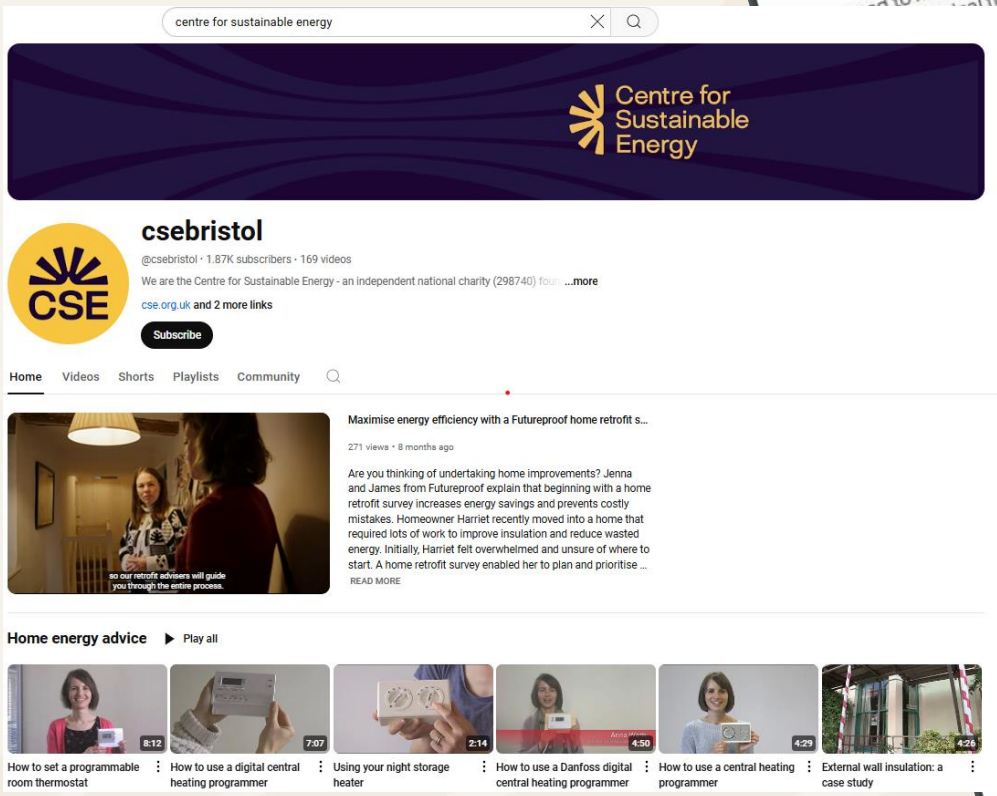
£1.9 million

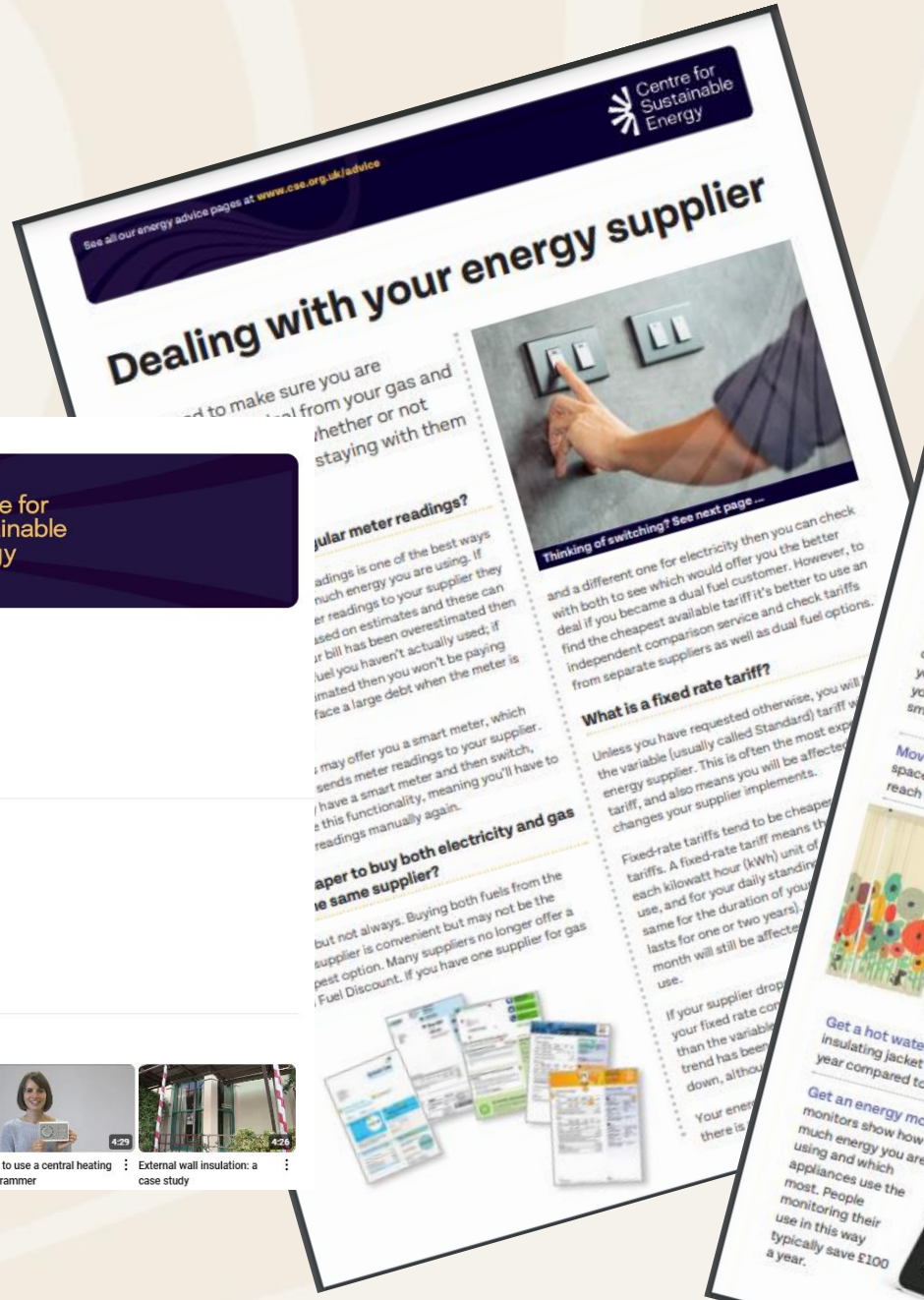
Value of grants distributed to 132 community organisations, enabling them to drive community focused energy projects reaching over 21,000 people.



Ref: https://www.cse.org.uk/news/cse-impact-report-2025/#numbers

Resources


centre for sustainable energy
Centre for Sustainable Energy
csebristol
@csebristol · 1.87K subscribers · 169 videos
We are the Centre for Sustainable Energy - an independent national charity (298740) ...more
cse.org.uk and 2 more links
Subscribe
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Shorts
Playlists
Community
Maximise energy efficiency with a Futureproof home retrofit s...
271 views • 8 months ago
Are you thinking of undertaking home improvements? Jenna and James from Futureproof explain that beginning with a home retrofit survey increases energy savings and prevents costly mistakes. Homeowner Harriet recently moved into a home that required lots of work to improve insulation and reduce wasted energy. Initially, Harriet felt overwhelmed and unsure of where to start. A home retrofit survey enabled her to plan and prioritise ...
READ MORE
so our retrofit advisers will guide you through the entire process.
Home energy advice
Play all
8:12
How to set a programmable room thermostat
7:07
How to use a digital central heating programmer
2:14
Using your night storage heater
4:50
How to use a Danfoss digital central heating programmer
4:29
How to use a central heating programmer
4:26
External wall insulation: a case study


See all our energy advice pages at www.cse.org.uk/advice
Centre for Sustainable Energy
Dealing with your energy supplier
Thinking of switching? See next page ...
What is a fixed rate tariff?


See all our energy advice pages at www.cse.org.uk/advice
Centre for Sustainable Energy
Tips for lower energy bills
We want you to be warm and comfortable in your home, but we know that cutting down on costs is important too. Follow our easy tips on using energy economically.
Turn your heating down by one degree.
Turn down your wash.
Move your furniture away from radiators.
Keep the heat in.
Set your hot water timer.
Dry your clothes outside
Draught-proof your home
Buying a new TV, washing machine or dishwasher?
Get a hot water cylinder jacket.
Use LED bulbs.
Get an energy monitor.
Be a friend to your freezer.
Turn down radiators in rooms you don't use much.

Thank you

Kate.Thomas@cse.org.uk

Centre for Sustainable Energy

We're a charity (298740) supporting people and organisations across the UK to tackle the climate emergency and end the suffering caused by cold homes.

South West SECURE DATA ENVIRONMENT

Part of the NHS Research Secure Data Environment Network

NHS

Lightning sessions:

Caafi Health

Emma Smith and Kevan Muhammad Akif







SOUTH WEST SDE CONFERENCE

Community clinics and health inequalities research

Caafi Health's DAFNEA project

- Emma Smith (Project Coordinator)
- Kevan Akif (Data Analyst)

Caafi Health and the communities we serve

A community interest company working in and around Bristol

Who we support

- Somali
- Sudanese
- Pakistani
- Roma
- Arabic
- Global Majority Communities (including people experience homelessness and refugees)

Barriers to care

- Language
- Low trust in health services
- Access to services
- Digital Exclusion
- GP registration

Our clinic data

49.46%

Need language support with 16.32% requiring additional interpreter

19.3%

Repeat visits with two or more clinic attendance

What happens at a community clinic?



Free, walk-in support

At community venues or the mobile clinic

Health checks

Blood pressure, blood sugar, cholesterol and more

Time to talk

Results, wellbeing, diet and exercise

Help with next steps

GP appointments, hospital letters, medication

Taking clinics to where people are

Community venues

- Easton Christian Family Centre, Stapleton Road (every other week)
- Stapleton Baptist Church
- The Vassall Centre
- St. Paul's Learning Centre
- Barakah Mall
- Wellspring Settlement
- and more.



Mobile clinic

Taking checks to people who may not come to a clinic

Case studies: why community clinics matter

1

A man with a family history of prostate cancer received support to follow up a raised PSA result despite mistrust of GP services. He reported that further investigation identified a benign prostate condition, and he began treatment.

WHY IT MATTERS

Reassurance and trusted support can help people engage with further investigation and care.

2

Clinic checks identified raised blood pressure and later raised blood glucose and cholesterol levels. During a prolonged pathway to cardiac treatment, the clinic team provided language support at his appointments and helped him understand his tests and results.

WHY IT MATTERS

Language support and continued follow-up can help people navigate care and understand their treatment.

3

A woman living with diabetes joined the fruit and vegetable project, receiving vouchers and healthy-eating education. She retuned 3 months later with improved weight management, blood sugar levels and healthier food choices across her family.

WHY IT MATTERS

Practical support alongside education can help families make changes to everyday eating habits.

Practitioner-reported cases. Identifying details omitted.

Our clinics in numbers

2,452

Total clinic records

1,844

Unique people seen

3+ years

of community clinics

Weekly

clinics running now

Data period: February 2023 to 14 October 2026 (analysis snapshot)

What we record

People

Demographics and GP practice

Health checks

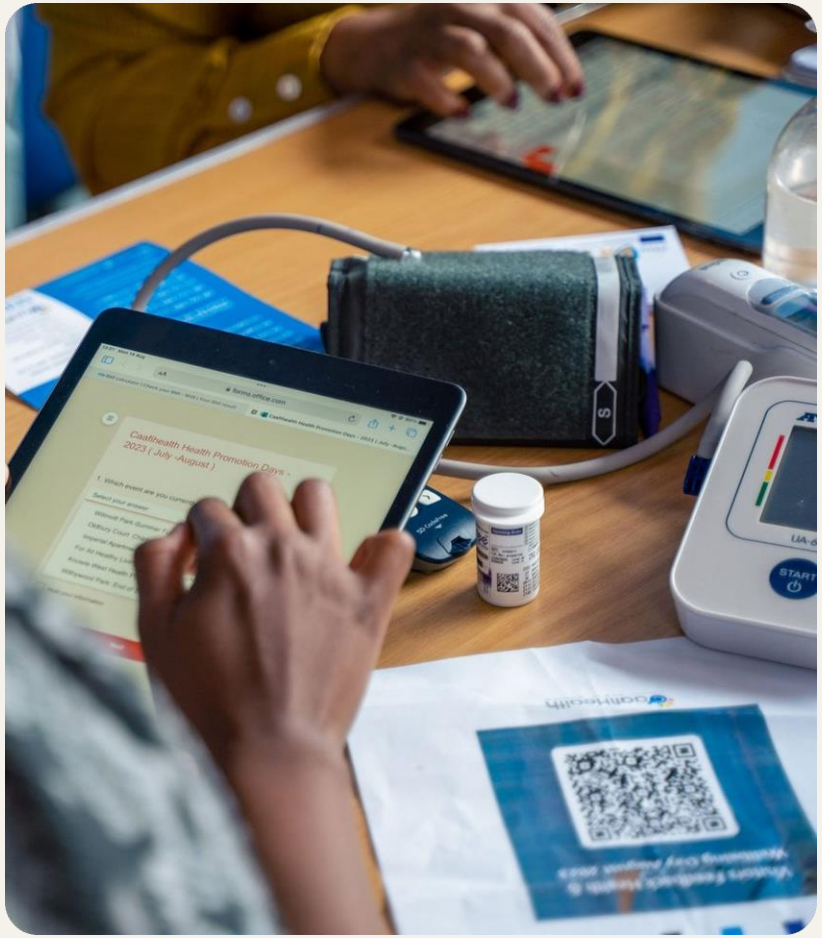
Blood pressure, glucose, cholesterol, BMI and more

Visits

Dates, clinic type and support given

Experience

Digital support and feedback



Keeping people's data safe



Before transfer

Quality checks, minimum data, national opt-out

Secure linkage

Identifiers used only for matching

Research access

De-identified data, approved researchers only

Safe outputs

Checked before any results leave the SDE

Set out in our signed data-sharing agreement with the South West SDE

What could this data tell us?

Who do community clinics reach?

Who attends, who comes back, and what support they need

What happens after a health check?

PROPOSED



Clinic visit	Linked to GP records	Outcomes after the visit
Caafi Health record	De-identified, in the SDE	Follow-up, diagnoses, treatment

Status: data-sharing agreement signed; GP linkage approval, DPIA and governance sign-off

What the community gets back

Visible in the data

Communities often missing from routine health data

Better follow-up

Evidence on where people fall out of care

Informed commissioning

Needs that are less visible elsewhere

Community voice throughout

1. Choose the questions
2. Interpret the findings
3. Share results back in plain language

Community clinic data can help explain who services reach and what happens next



A community clinic view of health inequalities



Reliable data and a safe route to GP linkage



Community involvement that gives findings meaning

CaafiHealth

Thank you

We look forward to your questions in the Q&A session

caafihealth.com



South West SECURE DATA ENVIRONMENT

Part of the NHS Research Secure Data Environment Network

NHS

Lightning sessions:

Royal Cornwall Hospitals Trust imaging data





Sandy Anderson

NHS
Royal Cornwall Hospitals
NHS Trust

Skin Lesion Dataset
Royal Cornwall Hospitals Trust

Dr Sandy Anderson
MBCHB, MRCS, MD, MRCGP, SCE
Consultant Dermatologist & Clinical Lead
Honorary Research Fellow
University of Exeter



Outstanding
Care for One+All

Is Cornwall the Perfect Skin Cancer Research Microcosm?

Isolated peninsula in South-West England
Stable population (89% in same house after 1 yea
10,000 referrals/yr suspected skin cancer
Melanoma incidence twice UK average
51 GP practices refer to single NHS hospital
One MDT
One histopath laboratory
Very little private practice skin cancer work



Research Asset – Community Lesion Imaging Clinics

Community setting

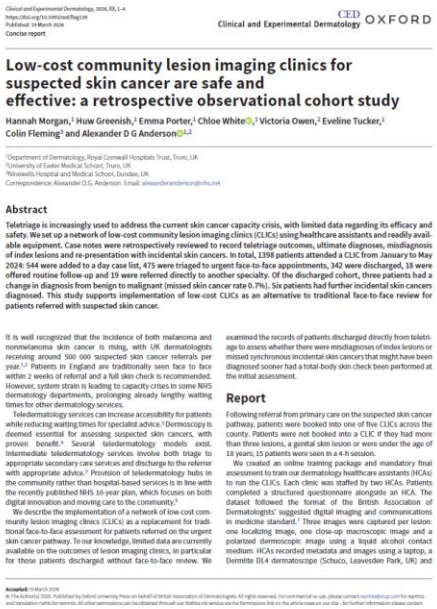
High quality dermoscopic and macroscopic images

Coded metadata

Retrievable

Admin support for ground truth diagnosis

AI ready



Clinical and Experimental Dermatology, 2026, XX, 1–4
https://doi.org/10.1093/ced/llag039
Published: 19 March 2026
Concise report

CED OXFORD
Clinical and Experimental Dermatology

Low-cost community lesion imaging clinics for suspected skin cancer are safe and effective: a retrospective observational cohort study

Hannah Morgan,[1] Huw Greenish,[1] Emma Porter,[1] Chloe White,[1] Victoria Owen,[2] Eveline Tucker,[1] Colin Fleming[3] and Alexander D G Anderson[1,2]

[1]Department of Dermatology, Royal Cornwall Hospitals Trust, Truro, UK
[2]University of Exeter Medical School, Truro, UK
[3]Ninewells Hospital and Medical School, Dundee, UK
Correspondence: Alexander D.G. Anderson. Email: alexanderanderson@nhs.net

Abstract

Teletriage is increasingly used to address the current skin cancer capacity crisis, with limited data regarding its efficacy and safety. We set up a network of low-cost community lesion imaging clinics (CLICs) using healthcare assistants and readily available equipment. Case notes were retrospectively reviewed to record teletriage outcomes, ultimate diagnoses, misdiagnosis of index lesions and re-presentation with incidental skin cancers. In total, 1398 patients attended a CLIC from January to May 2024; 544 were added to a day case list, 475 were triaged to urgent face-to-face appointments, 342 were discharged, 18 were offered routine follow-up and 19 were referred directly to another specialty. Of the discharged cohort, three patients had a change in diagnosis from benign to malignant (missed skin cancer rate 0.7%). Six patients had further incidental skin cancers diagnosed. This study supports implementation of low-cost CLICs as an alternative to traditional face-to-face review for patients referred with suspected skin cancer.

It is well recognized that the incidence of both melanoma and nonmelanoma skin cancer is rising, with UK dermatologists receiving around 500 000 suspected skin cancer referrals per year.[1,2] Patients in England are traditionally seen face to face within 2 weeks of referral and a full skin check is recommended. However, system strain is leading to capacity crises in some NHS dermatology departments, prolonging already lengthy waiting times for other dermatology services.

Teledermatology services can increase accessibility for patients while reducing waiting times for specialist advice.[3] Dermoscopy is deemed essential for assessing suspected skin cancers, with proven benefit.[4–6] Several teledermatology models exist. Intermediate teledermatology services involve both triage to appropriate secondary care services and discharge to the referrer with appropriate advice.[7] Provision of teledermatology hubs in the community rather than hospital-based services is in line with the recently published NHS 10-year plan, which focuses on both digital innovation and moving care to the community.[8]

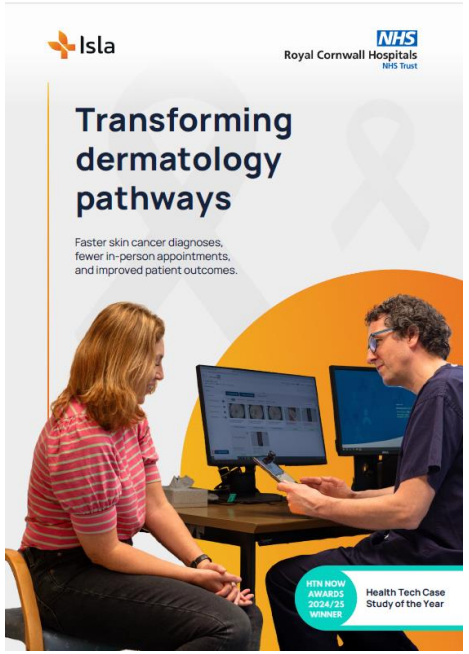
We describe the implementation of a network of low-cost community lesion imaging clinics (CLICs) as a replacement for traditional face-to-face assessment for patients referred on the urgent skin cancer pathway. To our knowledge, limited data are currently available on the outcomes of lesion imaging clinics, in particular for those patients discharged without face-to-face review. We examined the records of patients discharged directly from teleteriage to assess whether there were misdiagnoses of index lesions or missed synchronous incidental skin cancers that might have been diagnosed sooner had a total-body skin check been performed at the initial assessment.

Report

Following referral from primary care on the suspected skin cancer pathway, patients were booked into one of five CLICs across the county. Patients were not booked into a CLIC if they had more than three lesions, a genital skin lesion or were under the age of 18 years; 15 patients were seen in a 4-h session.

We created an online training package and mandatory final assessment to train our dermatology healthcare assistants (HCAs) to run the CLICs. Each clinic was staffed by two HCAs. Patients completed a structured questionnaire alongside an HCA. The dataset followed the format of the British Association of Dermatologists' suggested digital imaging and communications in medicine standard.[9] Three images were captured per lesion: one localizing image, one close-up macroscopic image and a polarized dermoscopic image using a liquid alcohol contact medium. HCAs recorded metadata and images using a laptop, a DermLite DL4 dermatoscope (Schuco, Leavesden Park, UK) and

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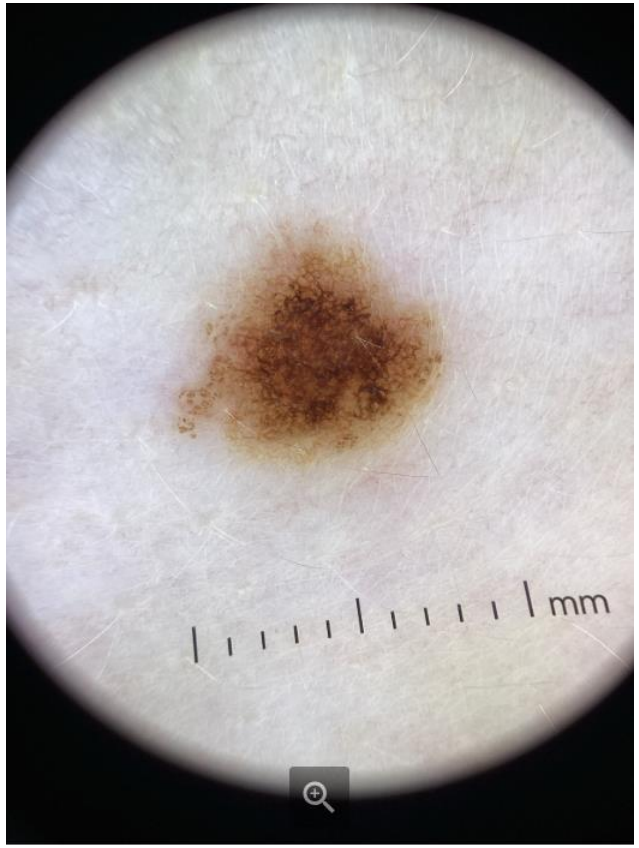
Macroscopic Image

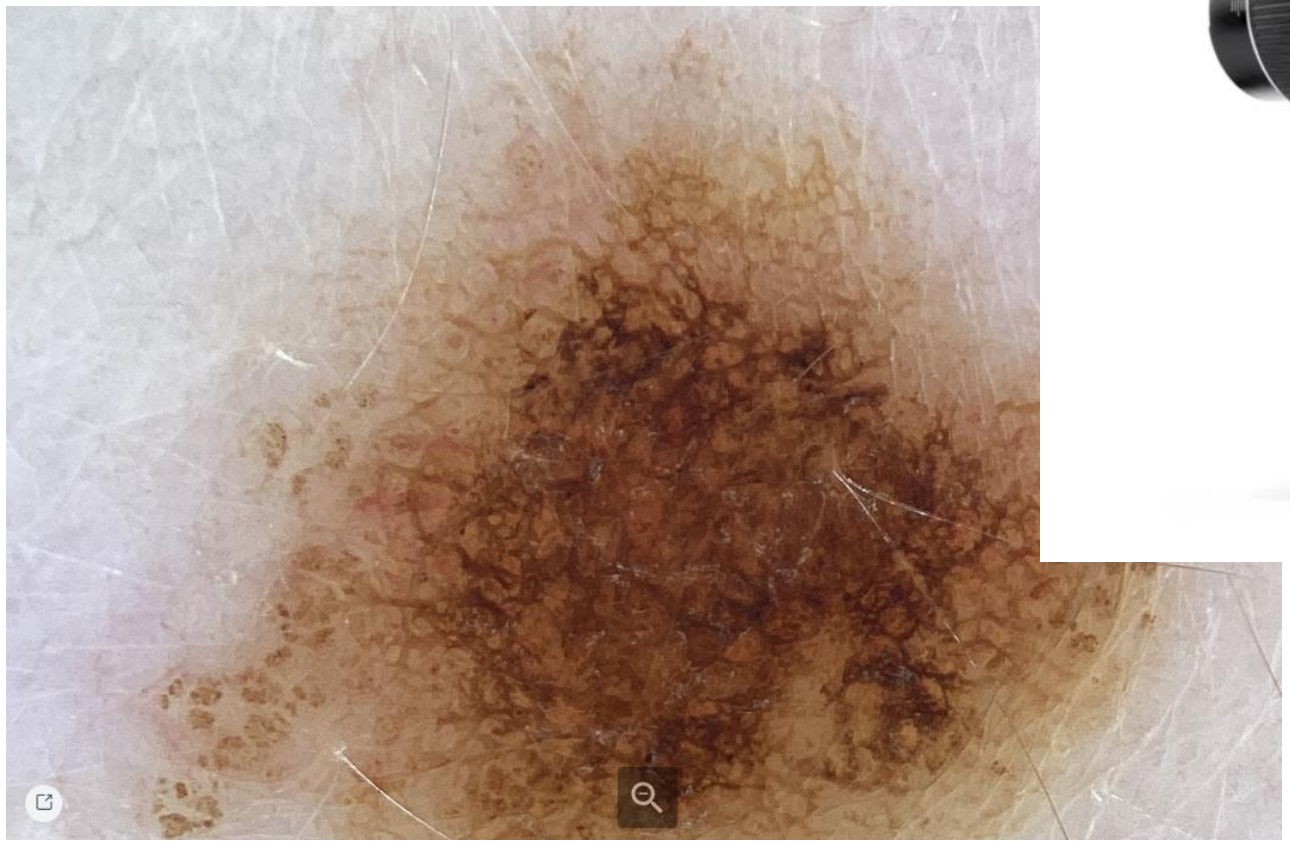






Dermoscopic Image

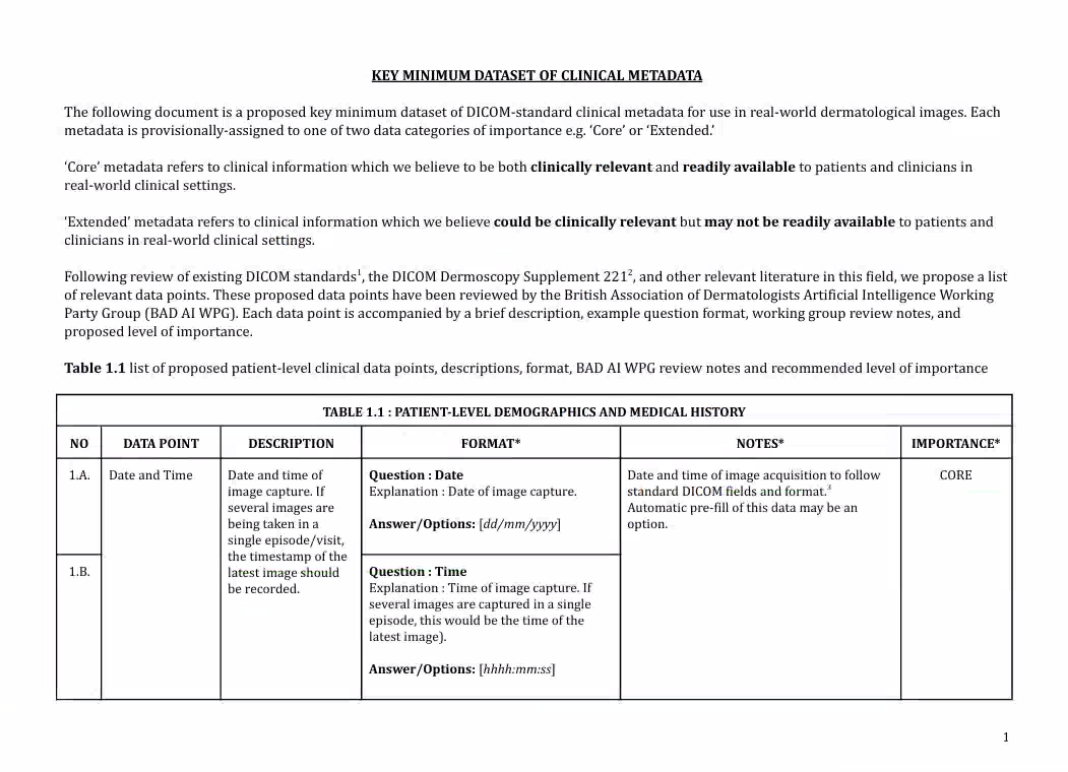






Metadata

Collected in line with BAD DICOM standard & Dundee team



KEY MINIMUM DATASET OF CLINICAL METADATA

The following document is a proposed key minimum dataset of DICOM-standard clinical metadata for use in real-world dermatological images. Each metadata is provisionally-assigned to one of two data categories of importance e.g. 'Core' or 'Extended.'

'Core' metadata refers to clinical information which we believe to be both **clinically relevant** and **readily available** to patients and clinicians in real-world clinical settings.

'Extended' metadata refers to clinical information which we believe **could be clinically relevant** but **may not be readily available** to patients and clinicians in real-world clinical settings.

Following review of existing DICOM standards[1], the DICOM Dermoscopy Supplement 221[2], and other relevant literature in this field, we propose a list of relevant data points. These proposed data points have been reviewed by the British Association of Dermatologists Artificial Intelligence Working Party Group (BAD AI WPG). Each data point is accompanied by a brief description, example question format, working group review notes, and proposed level of importance.

Table 1.1 list of proposed patient-level clinical data points, descriptions, format, BAD AI WPG review notes and recommended level of importance

TABLE 1.1 : PATIENT-LEVEL DEMOGRAPHICS AND MEDICAL HISTORY

NO	DATA POINT	DESCRIPTION	FORMAT*	NOTES*	IMPORTANCE*
1.A.	Date and Time	Date and time of image capture. If several images are being taken in a single episode/visit, the timestamp of the latest image should be recorded.	**Question : Date** Explanation : Date of image capture. **Answer/Options:** [*dd/mm/yyyy*]	Date and time of image acquisition to follow standard DICOM fields and format.[3] Automatic pre-fill of this data may be an option.	CORE
1.B.			**Question : Time** Explanation : Time of image capture. If several images are captured in a single episode, this would be the time of the latest image). **Answer/Options:** [*hhhh:mm:ss*]		

1

Final diagnosis

- 13 subclasses

Source of final diagnosis

- Teletriage
- Consultation
- Biopsy
- Excision

Lesion history metadata

Patient risk factor metadata

Processing Prior to SDE Upload

12 Month records review to identify misdiagnoses/re-presentation

Ultimate diagnosis and source of diagnosis added in Isla

Patients without research consent excluded (approx. 7%)

Cases with missing dermoscopic or macroscopic image excluded

Cases with identifiable features on macroscopic image excluded (manual screen)

All cases fully anonymised (can't be linked back to original NHS records)

Draft export from Isla reviewed, amended and agreed with Dr Anderson

Current Dataset & Format

2440 lesions

JPEG dermoscopic image

JPEG macroscopic image

CSV file with metadata

- 1 row per lesion
- Metadata from questionnaires plus diagnosis and source of diagnosis
- Column for filename of dermoscopic JPEG
- Column for filename of macroscopic JPEG

Coming Soon!

Further approx. 1400 lesions to be uploaded

Future similar sized sets every 6/12 or so

DICOM conversion work

Parallel datasets

Questions?

Our values

Respect

Compassion

Honesty

Teamwork



Outstanding
Care for **One+All**

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NHS

Lightning sessions:

Avon Longitudinal Study of Parents and Children

Mark Mummé





CHILDREN OF THE 90s







In partnership with NHS

University of BRISTOL

HTTPS://WWW.BRISTOL.AC.UK/ALSPAC/

Avon Longitudinal Study of Parents And Children

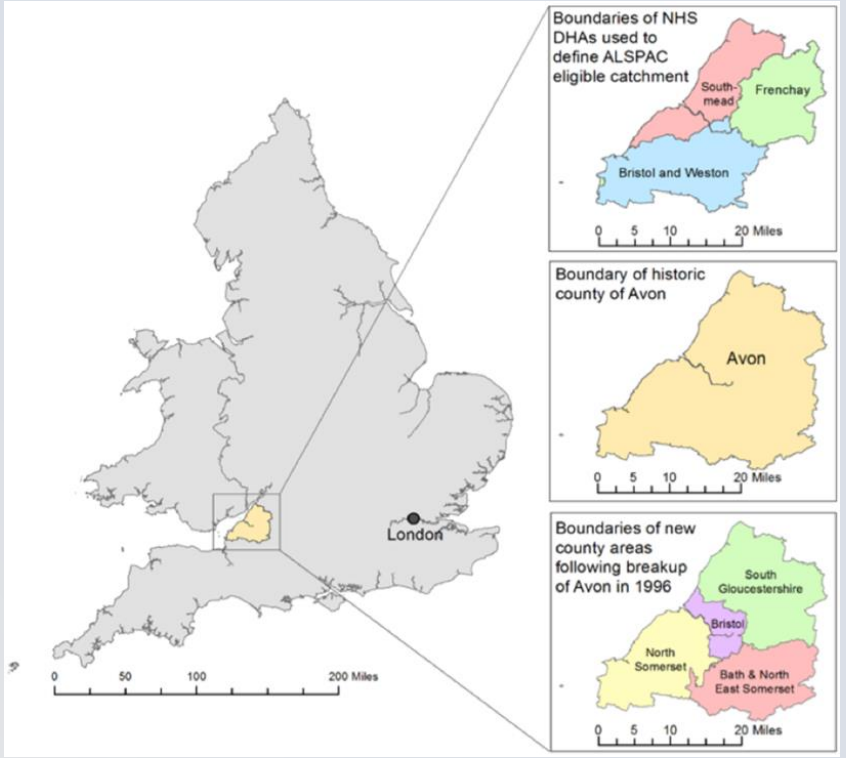
PRESENTED BY

MARK MUMMÉ

OCTOBER 2026

The Birth of ALSPAC

Recruited 14,541 pregnant women resident in the AVON area, with expected dates of delivery 1st April 1991 to 31st December 1992.



Three Generations of Participants

- GENERATION ZERO (G0) – ORIGINAL MOTHERS AND PARTNERS/CARERS.
- GENERATION ONE (G1) – ORIGINAL CHILDREN OF THE 90S.
- GENERATION TWO (G2) – CHILDREN OF THE CHILDREN OF THE 90S (COCOS)

Longitudinal Data

- QUESTIONNAIRES
- FACE-TO-FACE CLINICS
- BIOLOGICAL SAMPLES
- OMICS
- LINKAGE

Data Linkage

Blended Consent Model:

Direct, or Explicit, Consents: ~1/3rd

Indirect, or s251(*), Consents: ~2/3rd

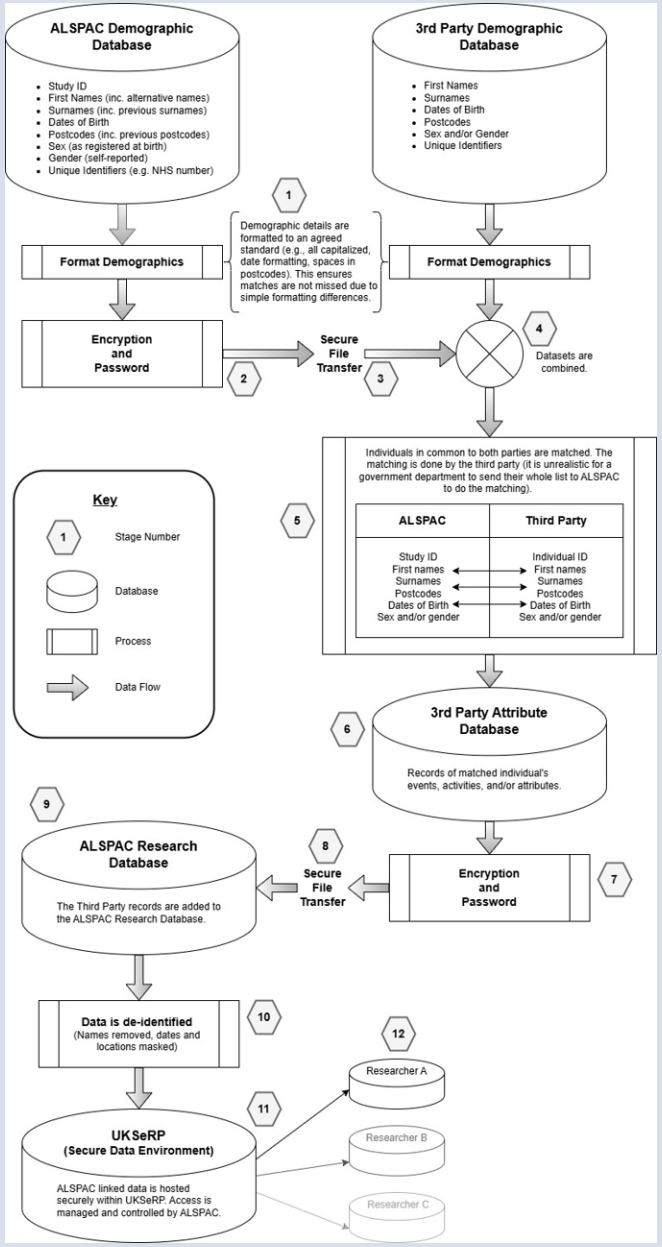
Dissent: ~1 in 16

(*) Section 251 of the NHS Act (2006) allows the Health Research Authority to support the provision of identifiable health data in specific circumstances.

Linking Datasets

General method of linking to a third-party dataset:

- Many steps
- Several transfers
- Snapshot in time



Five Safes – Safe Data

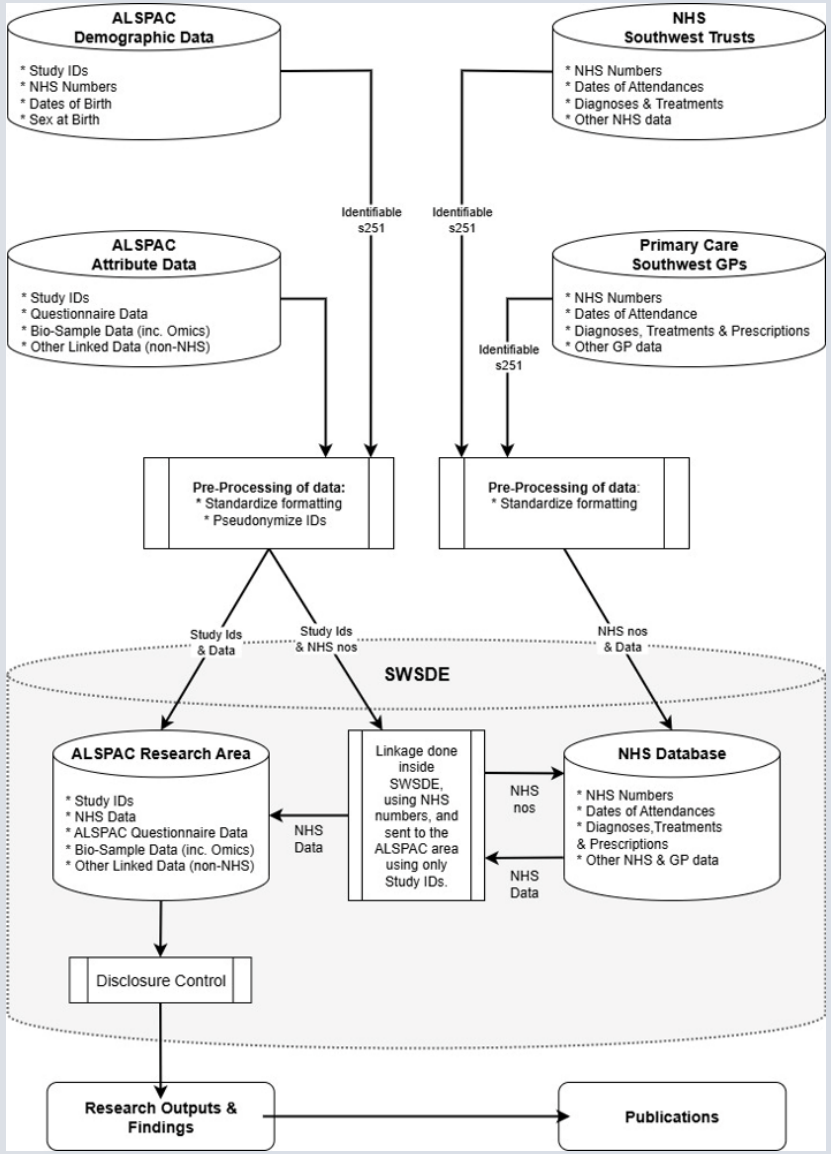
What's in a name?

- Secure Data Environment
- Trusted Research Environment
- Secure Research Environment
- Data Safe Haven

Linking in the SWSDE

Simpler method of linking to local health data:

- Less steps
- Single transfer of IDs
- SWSDE continuously updated



Exemplar Project

The link between questionnaire-reported disordered eating and eating disorder medical diagnosis.

To investigate the relationship between questionnaire-reported disordered eating and medical diagnoses, factors influencing diagnosis, and socio-economic position (SEP) associations using data from ALSPAC and the NHS.

It will also compare outcomes between those with self-reported symptoms and those with formal diagnoses.

Data Sources:

- Questionnaires
- Geo-data (addresses)
- NHS
- Primary Care

Thank you

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NHS

Lightning sessions:

Perinatal and maternal care outcomes dataset

Isobel Ward







Perinatal & Maternal Care & Outcomes Dataset: *A DAFNEA project*

University of BRISTOL

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What?

DAFENA funding enabling…

- Development of a novel linked data asset for mothers and babies born in Bristol NHS Foundation Trust, with the vision of scaling this across the South West
- Perinatal & Maternal Care & Outcomes Dataset (PeMCOD) will support research and service improvements to support equitable care and improved health outcomes for all mothers and babies

DAFENA funding enabling…

- Development of a novel linked data asset for mothers and babies born in Bristol with the vision of scaling this across the South West
- Perinatal & Maternal Care & Outcomes Dataset (PeMCOD) will support research and service improvements to support equitable care and improved health outcomes for all mothers and babies

Objective

PeMCOD will harmonise and link several routinely collected NHS service datasets to create a detailed collection of the demographics, health exposures, maternal and neonatal health care pathways and outcomes of each baby, from conception to early childhood.

Why?

NATIONAL MATERNITY REVIEW

BETTER BIRTHS

Improving outcomes of maternity services in England

Better births, 2016

National Maternity and Neonatal Investigation

Independent Investigation into Maternity and Neonatal Services in England

Amos review, 2026

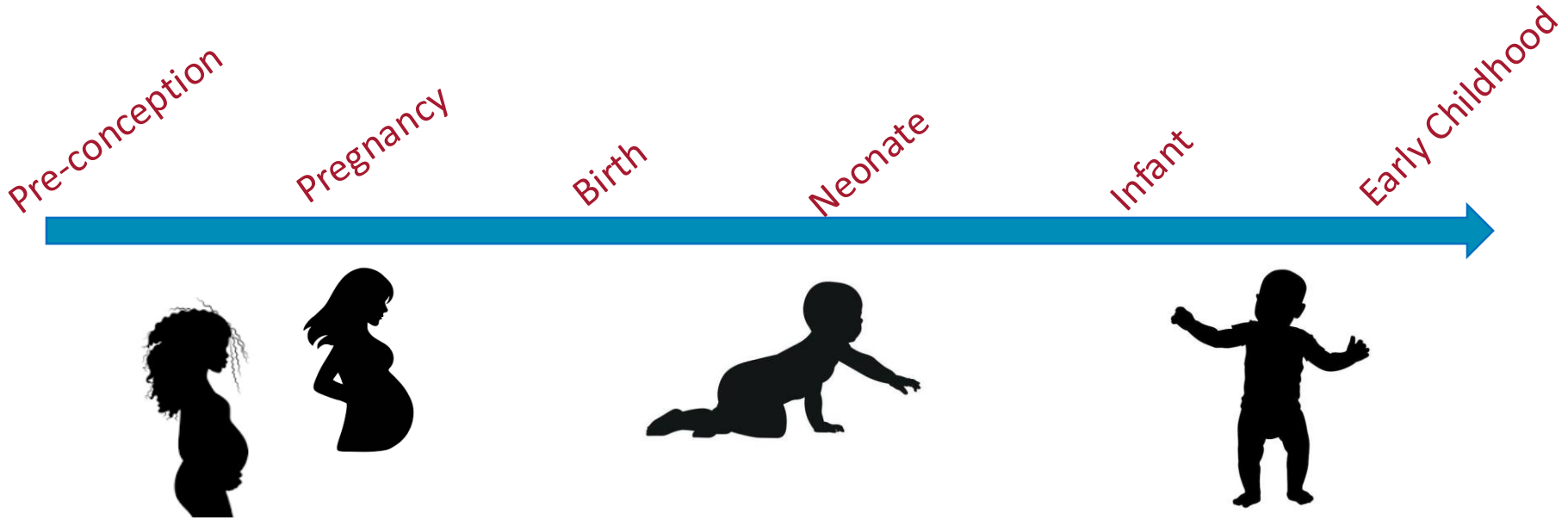
Maternity Services Data Set (MSDS)

Information about the Maternity Services Data Set (MSDS) including information for maternity service providers and their system suppliers to implement the MSDS and submit maternity services data.

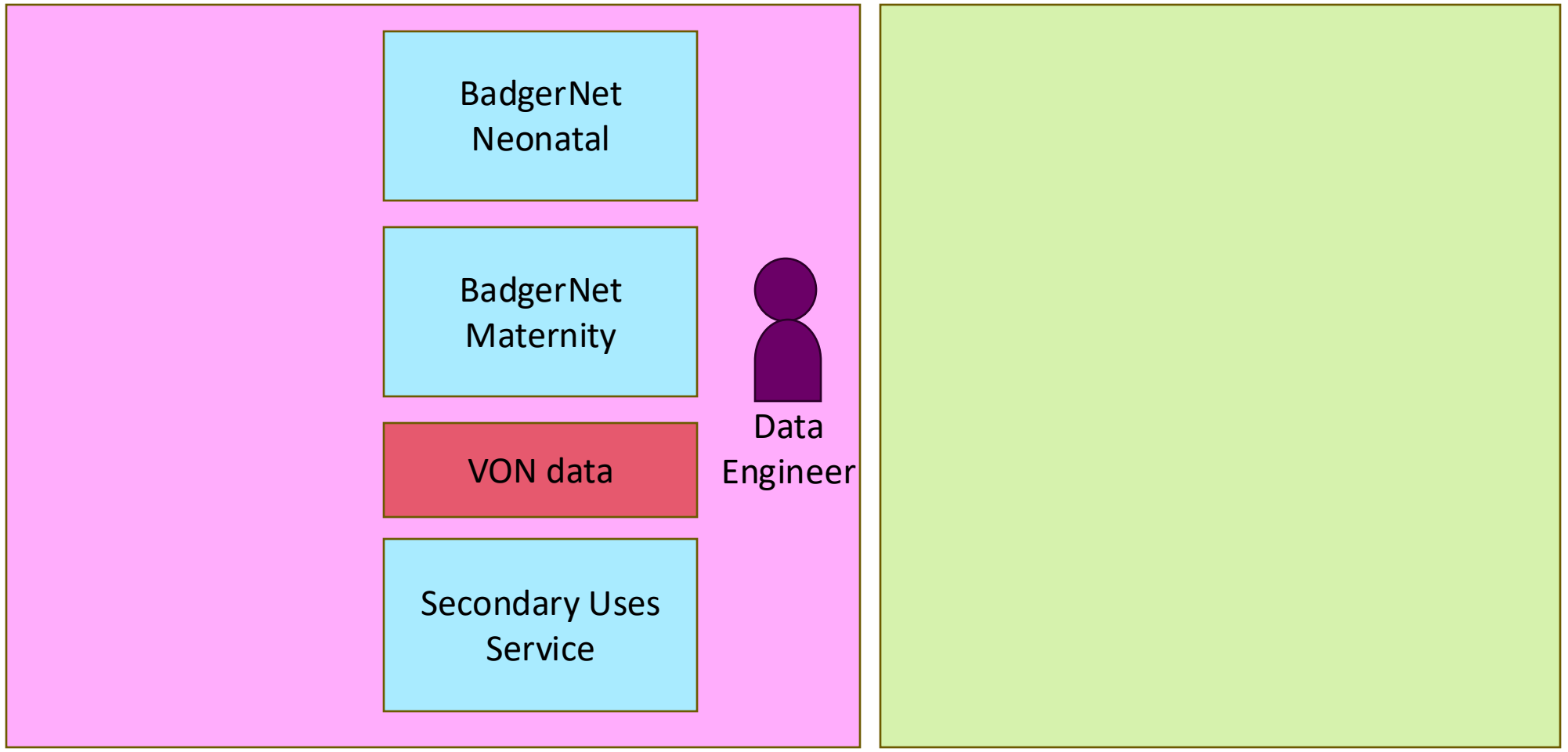
How?

Proof-of-concept: Cohort of deliveries in Bristol

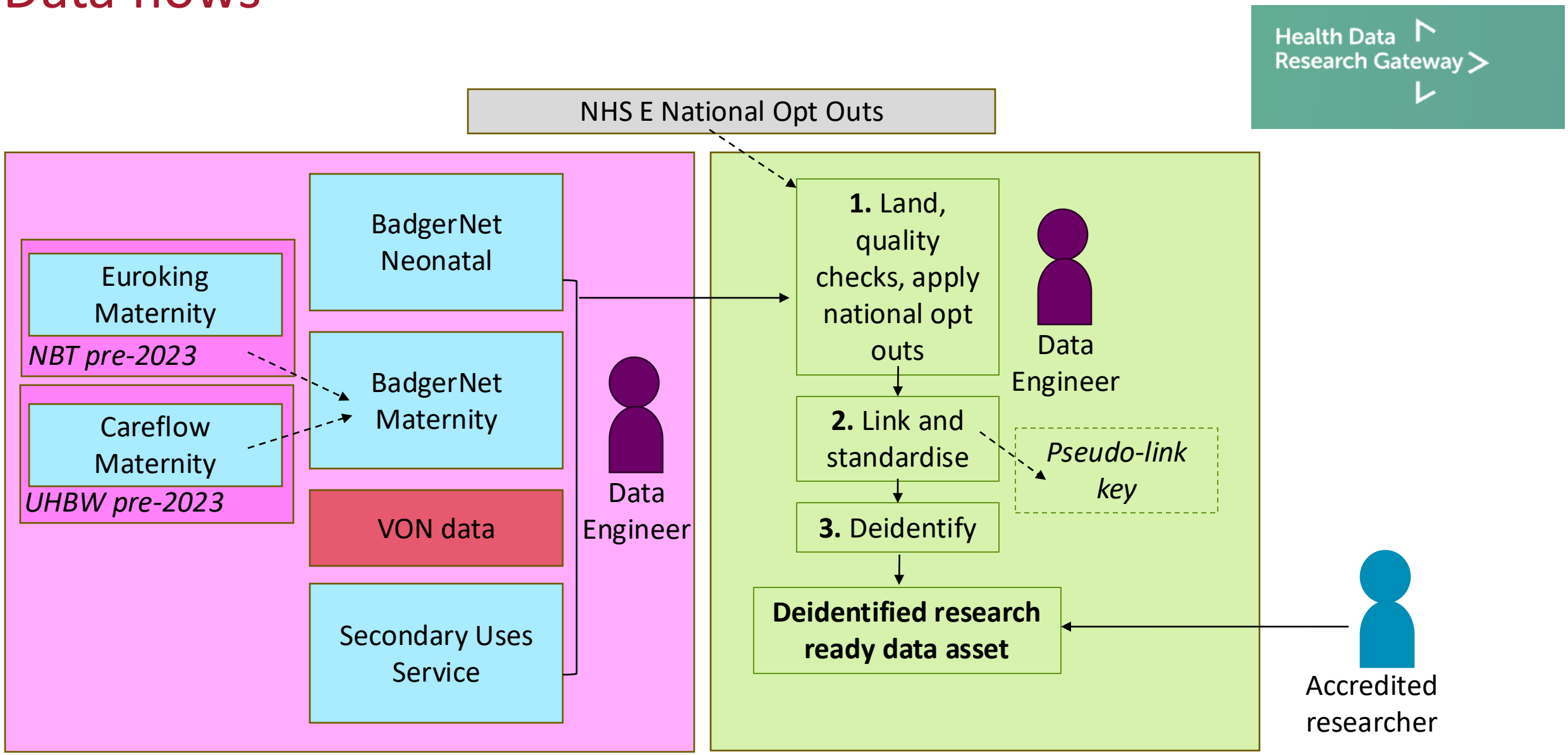
- The cohort will be approximately 450,000 births, of which 15% (67,500) will have been admitted to neonatal/transitional care units for specialised inpatient neonatal care.
  - An estimated 8% (3,600) of the cohort will be in the high-risk preterm group, with high expected mortality and multi-morbidity rates.
- This linkage will generate the first comprehensive life-course dataset of its kind in the region, enabling analyses that are currently impossible because data is held in separate systems.



Data flows


BadgerNet Neonatal
BadgerNet Maternity
VON data
Secondary Uses Service
Data Engineer
Bristol NHS Foundation Trust
South West SDE

Data flows


Health Data Research Gateway
NHS E National Opt Outs
Euroking Maternity
NBT pre-2023
Careflow Maternity
UHBW pre-2023
BadgerNet Neonatal
BadgerNet Maternity
VON data
Secondary Uses Service
Data Engineer
1. Land, quality checks, apply national opt outs
2. Link and standardise
3. Deidentify
Pseudo-link key
Data Engineer
Deidentified research ready data asset
Accredited researcher
Bristol NHS Foundation Trust
South West SDE

Public engagement

- Engagement with parent partners is central to the work we design and deliver to optimise maternity and perinatal outcomes.
  - *Our approach across all perinatal programmes is to ensure that parent partners are equal contributors to design, development and implementation. Prior decade long collaborations resulting in the implementation of PReCePT, PERIPrem and latterly Black Maternity Matters mean that our parent and VCSE partners are equally in favour of the development of a linked data set and have identified the lack of access to this as a rate limiting factor in the progression of improving outcomes and evaluating implementations.*
- We will work closely with our system partners, such as Black Mothers Matter and wider VCSE partners to ensure that communication regarding PeMCOD address any concerns that specific communities may have around data utilisation.

Impact

Research and operational innovation

What are the differences in maternity outcomes by ethnic group and deprivation locally?

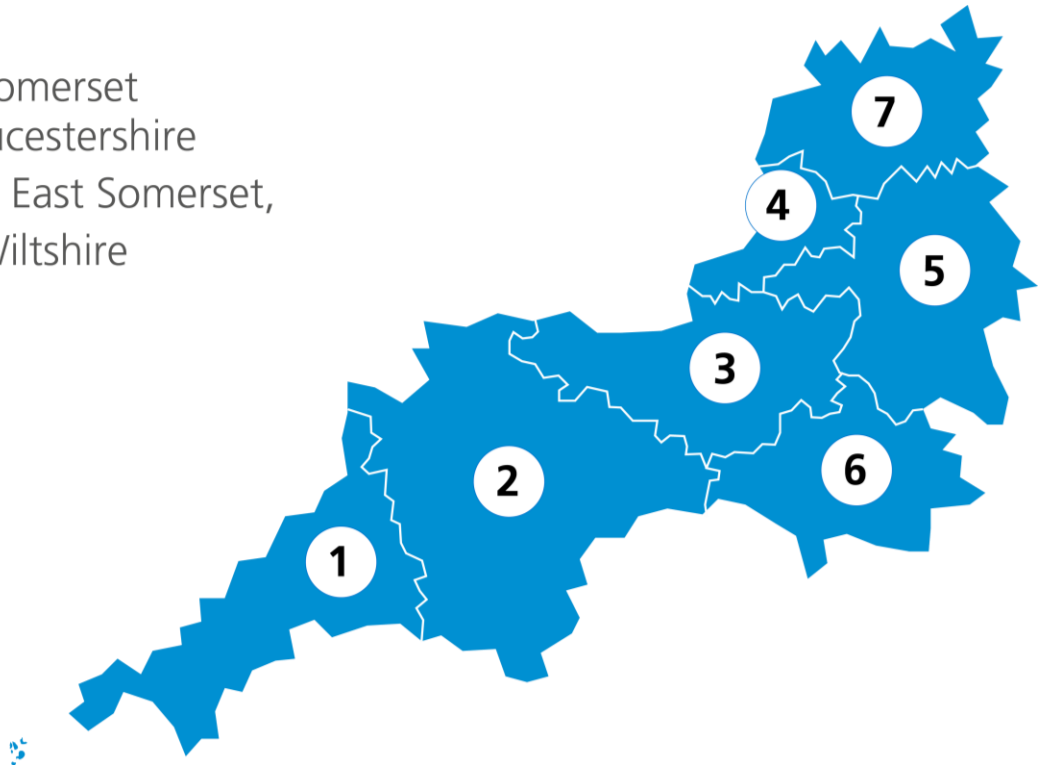


Has the implementation of Prevention of Cerebral Palsy in PreTerm Labour (PReCePT) resulted in a reduction in Cerebral Palsy?

Has the implementation of Perinatal Excellence to Reduce Injury in Premature Birth (PERIPrem) bundle been equitable, and secondly, has this resulted in an improvement in outcomes for preterm babies?

.....The South West

1. Cornwall and the Isles of Scilly
2. Devon
3. Somerset
4. Bristol, North Somerset and South Gloucestershire
5. Bath and North East Somerset, Swindon and Wiltshire
6. Dorset
7. Gloucestershire





....and beyond

Thank you

Isobel Ward,
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