Mandate for change

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In 2022, the Government announced it would invest up to £200 million to boost NHS healthcare data research.

This is set out in the Data Saves Lives strategy, which was written following the recommendations of the Goldacre review.

Goldacre Review (published April 2022)

Recommendations:

- ✓ adopt data access platforms across the NHS
- ✓ commit to open working practises to increase transparency
- ✓ earn public trust through concrete action.

Data Saves Lives strategy (published June 2022)

Outlines:

- → intention to move away from processes relying on data sharing to a model of data access
- → how a network of Secure Data Environments will facilitate this data access model.

Mandate for change

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73 years of NHS patient records contain all the noise from millions of lifetimes […] They represent deeply buried treasure that can help prevent suffering and death around the planet…

Goldacre Review (2022)

What is the Cheshire and Merseyside Secure Data Environment (SDE)?

The Cheshire and Merseyside SDE is the new name for the data store that has been in place since 2020 as part of the Combined Intelligence for Population Health Action (CIPHA) programme.

It securely stores data from GP practices and other providers to be used for insight-driven local service management.

It is being renamed because of how it will support the new North West SDE, part of the wider NHS SDE Network, which will improve NHS research, delivering faster, higher quality outcomes and findings.

We will need to establish a **new data-sharing agreement** with data controllers to support use of this data for research through the Cheshire and Merseyside SDE
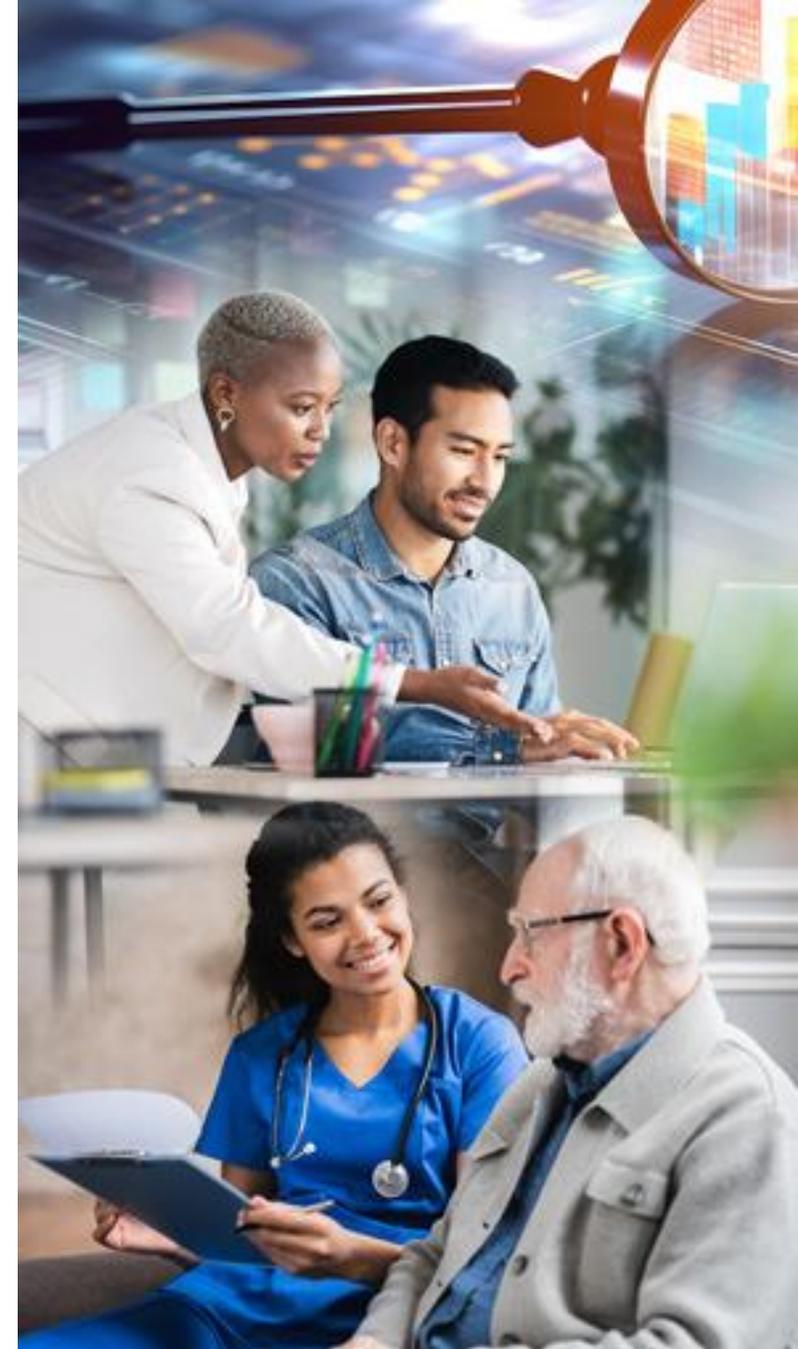
Building on past and ongoing successes

Secure Data Environment Roadmap

The Combined Intelligence for Population Health Action (CIPHA) programme was established in 2020 and was integral to the region's pandemic response being adaptable and data driven. The Cheshire and Merseyside SDE is the next step for improving the use of data for research and planning. Here is an overview of progress made so far and what comes next:

2. June 2020 – Tier One DSA
Overarching standards agreed for sharing confidential information. 99% sign up achieved across Cheshire and Merseyside

4. September 2021 – Tier Two DSA: Population Health
This DSA was issued to broaden the use of the data for Population Health (supporting epidemiology reporting, research into novel interventions, planning service provision and predicting outcomes for vulnerable populations) and to replace the Control of Patient Information notice (COPI) used during COVID-19.

6. Tier Two DSA: research in academia
Partner organisations will be asked to sign a new data sharing agreement for secured and appropriate data to be shared with researchers in Academia.

8. SDE public engagement
Public engagement will be undertaken to explain SDEs, covering what they are, how they will work and the various ways the public can opt out of their data being used.

Looking back...
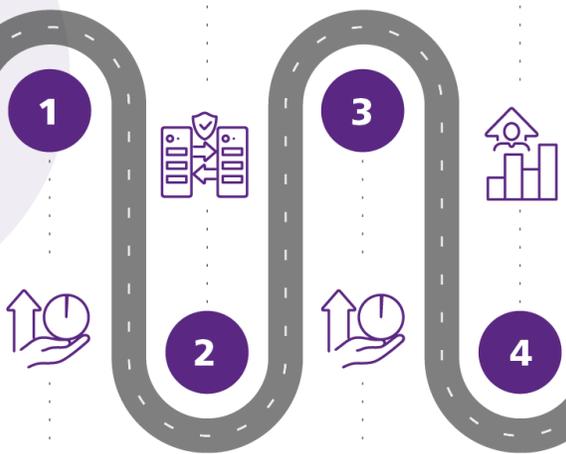
Next steps...

1. June 2020 – Tier Zero DSA
This overarching agreement set out partner organisations' agreement to share information responsibly as CIPHA is created. 99% sign up achieved across Cheshire and Merseyside.

3. June 2020 – Tier Two DSA: COVID-19
In response to the COVID-19 pandemic this DSA was issued for data sharing to manage COVID-19 and assist recovery. 99% sign up achieved across Cheshire and Merseyside.

5. Secure Data Environment (SDE) partner engagement
Information about Cheshire and Merseyside SDE and its place in the wider SDE network will be shared with partner organisations.

7. Tier Two DSA: research for commercial organisations
A data sharing agreement to share data for research for commercial organisations will be developed.

9. SDE launch
Approved researchers access appropriate data through SDEs, which will be more efficient and secure than before.

Population Health Reporting

Waiting List Insights

- Demographic breakdown of waiting list by Provider, Place, PCN & Practice, stratified for risk of an adverse outcome.
- Create bespoke cohort using waiting time, specialty, condition, demographics, protected characteristics and many other variables.

Enhanced Case Finding

- Ability to search GP-registered patients in Cheshire & Mersey ICS (~2.5m)
- Stratify patients by demographics, conditions, service utilisation, risk and other variables.
- Shows a population level view but also has the ability to drill to patient level.

ICS Population Health

- Central hub for CIPHA population health dashboards.
- Provides demographic and geographic breakdown of key population health indicators inc.
- Includes NHS Health checks and All Fairer Together (Marmot), NHS Health checks, CORE20PLUS5, starting/ living/ aging well and more.

Fuel Poverty

- Informs planning for winter re patients potentially affected and interventions required.
- Shows 'cold homes' and enables segmentation by geography, conditions and risk scores.
- Includes LSOA fuel poverty data and household energy performance certificates.

Mental Health Explorer

- Provides levels of prevalence, demographic insights and epidemiological make up of mental health cohorts, including general MH, SMI, suicide, self-harm.
- Visualises demographic breakdown and comorbidity profile of these cohorts.

CVD, Stroke and Respiratory

- Large suite of metrics to support CVD, Stroke & Respiratory prevention.
- View geographic and demographic breakdown of any metric.
- All metrics filterable by standard demographic, geographic and diagnosis data points.

Vaccine Epidemiology

- Covid vaccine epidemiology - JCVI, demographic & geographic breakdown of covid vaccine and boosters including priority groups and pregnancy register vaccination rates.
- Snapshot and trend of flu vaccination rates by demographic influencers, geography & site.

Covid Analytics Hubs

- Covid early warning tool JCVI group breakdown of case rates, deaths, hospitalisations and vaccinations.
- Covid capacity & demand inc case rates, hospital. admissions& staff absences
- Long covid disease profile and referrals.

Data into Action - Research

System P

- Improving Direct-oral acting anticoagulants (DOACs) medicine reviews
- ✓ ACMI - Anticholinergic Medicines Index – looking at how the application of a multi-facted risk score can help reduce complications and adverse events.
- ✓ District Nursing case management modelling.
- ✓ End of life pathway evaluation

RESTORE

- Complex households segmentation model informing service redesign in Liverpool, Knowsley and Cheshire West
- Predictive modelling of adverse mental health events in adolescents.
- Identifying early risks to prevent children being taken into care

Ways 2 Wellbeing

- Ways to Wellbeing
- Evaluating health impacts of Citizen Advice on prescription in Liverpool
- Assessing the impact of Liverpool city councils welfare scheme on patients outcomes

Networked Data Lab

- Network Data Lab
- Identifying the unmet needs of carers
- Evaluating the impact of Liverpool's COVID-19 shielding programme

Liverpool Combined Authority Transport – the 10A bus route (GroundsWell)

- Introduction of 'green' hydrogen buses in Liverpool with associated greening at bus stops
- We will survey baseline behaviour and wellbeing and link these (consented) data to the population living close to and further away to assess relative health benefits in short and long term, evidencing need for more

Dock Branch Park (GroundsWell)

- Regenerating railway line into green infrastructure (walking & cycling) in Birkenhead, one of the most deprived areas in C&M.
- Survey behaviour, wellbeing and link (consented) data to health use. Assess relative health benefits for people living close Vs not, evidencing need for more investment to prevent illness.

C-GULL (Birth cohort)

- A major new birth cohort that will improve research and health of a new generation in Liverpool
- Multiple opportunities to learn from in depth surveys linked to wider population health utilisation data
- Consented survey linked to health utilisation data and wider environment data.

Groundswell

- Informs planning for green infrastructure (parks and transport) to keep people active, preventing ill health and hospital admissions.
- Reduces NCDs, especially for those who need it the most.
- Removes siloes of data so people and systems all work together for maximum benefit

COVID-19 Testing

Initiative

- NHS Cheshire and Merseyside data was used in a national pilot of community testing, with rapid lateral flow tests being extended to people without COVID-19 symptoms.

- It was hoped this would reduce or contain transmission and provide a way to reduce COVID-19 restrictions.

Results

- Between 3 December 2020 and 31 July 2021, 668,243 residents in the Liverpool City Region (LCR), from five years old and older, had registered results from testing centres or home testing kits.

- The pilot led to an estimated **21% reduction in cases up to mid-December 2020**.

- More than half (57%) of LCR residents completed rapid lateral flow tests between 6 November 2020 and 30 April 2021.

- More information is on the Government website.

Events Research Programme (ERP)

Initiative

- NHS Cheshire and Merseyside data was used for research into restarting large-scale events during COVID-19 restrictions.

- The ERP was looking to determine what risk mitigations would allow for larger events to return.

Action

- Between 17 April and 15 May 2021, nine pilots were conducted in the region under the ERP, including a concert in Sefton Park, nightclub events and a business event.

- Across the pilots, there was a variety of indoor and outdoor settings, with various audience sizes and styles, including seated and standing arrangements.

Results

- In Liverpool, 13,000 people attended dance and music festivals over a bank holiday weekend, safely at a scale that was not seen anywhere since the pandemic

- Timely access to linked testing and ticketing data was effective in enabling rapid contact tracing around Liverpool events

- More information is on the Government's website.

Fuel poverty dashboard

Initiative

- NHS Cheshire and Merseyside developed a fuel poverty dashboard to identify people at risk of poor health outcomes due to cold homes and fuel poverty.

- The dashboard draws on health and care information on 2.6 million Cheshire and Merseyside residents.

- It was used to identify people who had a 50% or higher risk of emergency admission in the next 12 months, were not in a care home, and were living in the most deprived and fuel poor areas. That identified 1,317 individuals who would be targeted to improve outcomes.

- Primary care and community care teams could use this information to optimise treatment and deploy warm home initiatives.

Results

- 85 patients were contacted through the St Helens WarmHomes for Lungs project, resulting in 85 referrals to the wellbeing team, 14 referrals to the pulmonary rehabilitation team, and 18 patients being onboarded to the COPD telehealth service.

- 65 patients received £500 payments from household support funds – a total of £32,500 in payments – and all patients received a Winter Warmer Pack, providing vital, life-improving support to the most vulnerable residents.

How will SDEs make a difference?

Why health and care data matters

Information collected by health and care organisations helps to improve individual care, speed up diagnosis, plan local services and research new treatments.

We know from the Covid-19 pandemic that data saves lives. It also saves everybody time and NHS and care services money that can be put back into patient care.

Secure Data Environments (SDE)

The Department of Health and Social Care and the NHS in England are investing to move from processes that rely on data being shared to a system where data is accessed.

This will be done using online platforms known as Secure Data Environments, which are designed to give NHS data more protection.

What is a Secure Data Environment (SDE) for research?

SDEs are **data and research analysis platforms.**

They store **de-identified health and care data.** Personal information, such as names, addresses or NHS numbers, are replaced with artificial, or 'pseudo', information.

Approved researchers will be able to use technical tools to analyse de-identified data on the platform without receiving a copy.

SDEs control:

- who can be a user
- what users can do
- what findings can be removed.

Why is the NHS making this change?

SDEs will address existing drawbacks of data sharing. They will also standardise research practices.

They have been designed to realise the untapped potential of NHS data by improving:

Patient privacy – SDEs must ensure information remains confidential at all time.

Security – NHS data will only be hosted on systems with high levels of protection.

Efficiency – SDEs enable different sources of data to be linked, giving researchers access to bigger sets of data faster.

Keeping data secure

What controls apply to the Cheshire and Merseyside SDE?

The SDE follows the Five Safes Framework to ensure data is accessed and used in a secure and responsible way. All researchers must complete Five Safes training.

Safe data: data is treated to protect any confidentiality concerns.

Safe projects: research projects are approved by data owners for the public good.

Safe people: researchers are trained and authorised to use data safely.

Safe settings: a SecureLab environment prevents unauthorised use.

Safe outputs: screened and approved outputs that are non-disclosive.

What controls apply to the Cheshire and Merseyside SDE?

- **All data is de-identified and pseudonymised.** Researchers cannot access identifiable data.

- **Organisational sharing agreements** will be established between the research organisation and the data controllers.

- **Individual data sharing contracts** with researchers will be established, with set parameters.

- Approved researchers can **only access the specific data** they have requested – data is minimised.

- An **'airlock' system** will be in place, meaning information can't be removed without approval.

- All organisations accessing data must be **certified** under the Data Security and Protection Toolkit.

- The Data Asset and Access Group (DAAG) must **approve access** against set criteria.

Data access approval

A Data Access and Asset Group (DAAG) for Cheshire and Merseyside will:

- include members from the NHS, local authorities, universities and the public

- provide oversight and approval on all data access requests – including making sure organisations meet required conditions for access

- ensure information governance requirements are met – including adequate patient and public involvement and engagement

- check that this process is developed in line with any changes to national policy and escalate the Information Governance sub-committee when changes need to happen.

Data access approval process

1. Interest
Researcher has a project idea and registers this interest.

2. Planning
Researcher reviews data catalogue and prepares a funding application.
Work begins to map data flows / sources.

3. Approval
Researcher ensures governance requirements are met, applies for ethics and completes DAAG application.

4. Access granted
Once checks are completed access is granted.

5. Live
Researcher works on the data in the Secure Data Environment with airlock in place to prevent data extraction.

6. Closed
SDE access is closed once study finishes.

Start

Finish

Technical information: what data goes to and from the Cheshire and Merseyside SDE?

Where the data comes from

PATIENT LEVEL LINKED DATASETS THAT FEED SECURE DATA ENVIRONMENT

NATIONAL DATA SOURCES

- Patient / citizen
- GP practices
- Mental health
- Cancer care
- Acute and maternity care
- Social care
- Community Services

SDE

- NHS England
- Adult social care
- Births and deaths
- Wider determinants
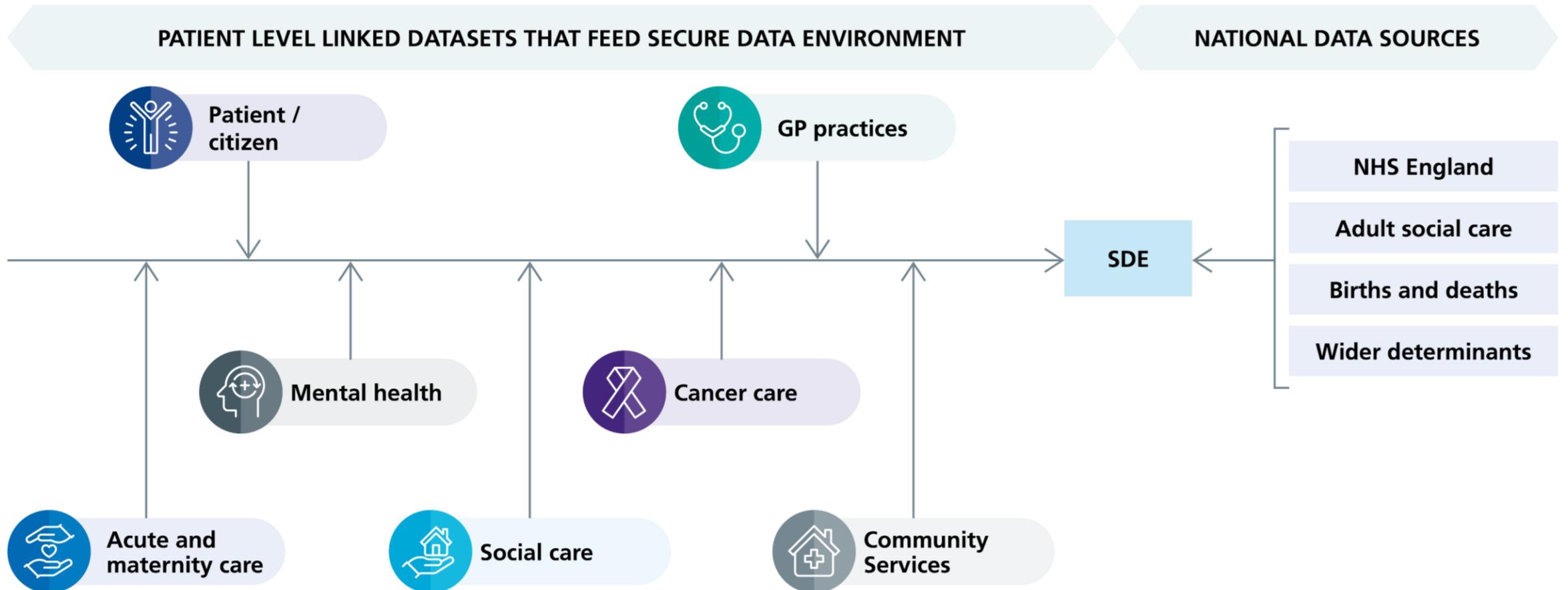
Cheshire and Mersey Secure Data Environment: Data Flow Diagram
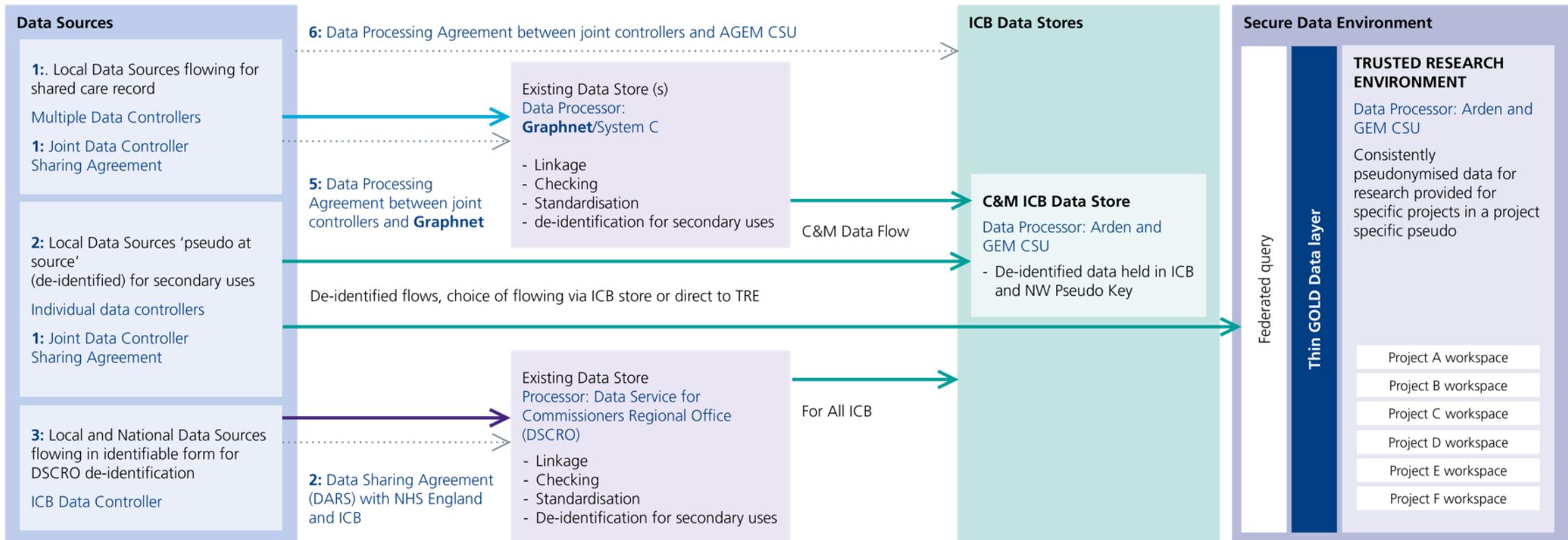
Local data sharing arrangements for 'Secondary Uses'

Type of Agreement	Between...	Purpose	Data Assets covered
Tier 0: Memorandum of Understanding	Joint Data Controllers in Cheshire and Merseyside ICB	The document sets out an organisation's agreement in principle to share information with the partner organisations in a responsible way	Local data assets flowing from C&M ICB Data Controllers
Tier 1: Data Sharing Standards	Joint Data Controllers in Cheshire and Merseyside ICB	Tier One Data Sharing Agreement Standard These are the overarching standards which outline the agreed procedures for sharing confidential information.	Local data assets flowing from C&M ICB Data Controllers
Tier 2: Data Sharing Agreement	Joint Data Controllers in Cheshire and Merseyside ICB	Population Health inc. Risk Stratification	Local data assets flowing from C&M ICB Data Controllers
Tier 2: Data Sharing Agreement	Joint Data Controllers in Cheshire and Merseyside ICB	Research in Academia	Local data assets flowing from C&M ICB Data Controllers

Local Data Processing Agreements

Type of Agreement	Between...	Purpose	Data Assets covered
Data Processing Agreement	Joint Data Controllers in C&M ICB and Graphnet	Allows Graphnet to process data on behalf of joint data controllers	Local data assets flowing from C&M ICB Data Controllers
Data Processing Agreement	C&M ICB and AGEM CSU	Allows Arden and GEM to process data on behalf of the ICB	Local and National data assets flowing from C&M ICB Data Controllers

National Data Sharing Agreements

Type of Agreement	Between...	Purpose	Data Assets covered
Data Sharing Agreement	C&M ICB and NHSs England	Commissioning Planning Risk stratification Invoice validation Research	National data assets flowing from NHSE to C&M ICB
Sub-licencing Agreement	Sub-licences providers and other organisations to access the ICB controlled data	Commissioning Planning Risk stratification Invoice validation Research	National data assets flowing from NHSE to C&M ICB

Opting out

People can opt out of their de-identified data being used for research in several ways:

GDPR – right to object: prevents data sharing for any reason, including between different services.

Type 1 opt-out: prevents your GP practice sharing your data for anything except your care, except when it is required by law.

National data opt-out: prevents your personal and healthcare information being used for research and planning. This can be changed any time.

Cheshire and Merseyside local data opt-out: allows people to opt out of individual studies.

A leaflet with more information on this is available on the NHS Cheshire and Merseyside website.
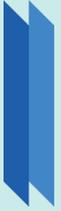
Next steps

What are we asking for?

We will soon ask you to sign a data sharing agreement (DSA) for this work.

Once the new agreement is in place, your organisation will need to update its privacy notice. A template for this, along with other materials, is available at www.cheshireandmerseyside.nhs.uk/sde

Organisations already sharing data with NHS Cheshire and Merseyside for population health management (PHM) and planning will use existing processes.

Patient and public involvement

- Public and patient involvement activity will take place from late 2023. It will gather people's views on how their data is used.

- Focus groups will take place across Cheshire and Merseyside and will seek views on the use of de-identified personal data for research and population health support in the context of a secure data environment.

- Feedback from the groups will be used to inform future engagement events and the materials created to inform people of the use of data for research.

	Nov 23	Dec 23	Jan 24	Feb 24	Mar 24
Phase 1: Equality impact assessment and targeted public engagement.					
Phase 2: Co-production of public facing materials					

Patient and public involvement

- A general public awareness campaign will look to inform the wider public about the Cheshire and Merseyside SDE and using data for research. This will be done through the existing communication and engagement channels of partner organisations, including social media. During this phase we intend to develop a public advisory group that would be central to the programme development.

- The deliberative engagement phase would involve more in-depth engagement across Cheshire and Merseyside. Larger venues will be secured to hold open public events. The deliberative engagement events will give the public an opportunity to deliberate key aspects of using data for research. The content for these events would be designed by subject matter experts and the public advisory group. Feedback from these events will be used in the development of the SDE going forward.

	Apr 24	May 24	June 24	July 24	Aug 24	Sept 24
Phase 3: General public awareness campaign and the development of a public advisory group						
Phase 4: Deliberative engagement						

Questions

If you have any questions not covered in this presentation, we have FAQs on the NHS Cheshire and Merseyside website.

If you still have questions that haven't been covered already and aren't in the FAQs, you can contact us by emailing:

dataintoaction@cheshireandmerseyside.nhs.uk