

# Linking health and social care data to improve services

NHS Arden & GEM CSU

[www.ardengemcsu.nhs.uk/asclld](http://www.ardengemcsu.nhs.uk/asclld)



# Session overview

- ✓ The data landscape
- ✓ North West pilot
- ✓ A national programme
- ✓ Benefits
- ✓ Lessons learned
- ✓ What next
- ✓ Questions



# About NHS Arden & GEM CSU

## OUR CUSTOMERS



# 90+

Working with a customer base of  
90+ organisations across  
health and care systems

- NHSE
- ICSs
- ICBs
- Trusts
- Primary Care
- Local Authorities

## OUR BUSINESS

 **£95m**  
Turnover 2021/22

**£34m**  
Generated in new  
business 2021/22 

## OUR PEOPLE



# 1,000+

Multidisciplinary staff

## 2021/22 HIGHLIGHTS

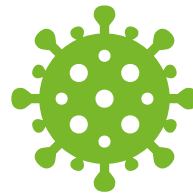
 **2** National award wins (and 4 shortlistings) in 2021/22

 Providing IT support to over 40,000 users

 National health inequality programme launched

Supporting COVID-19 recovery:

- Backlogs
- Capacity
- Front line



Helping systems to prepare:

- Transformation
- OD
- PMO



## OUR ACCREDITATIONS

**INVESTORS IN PEOPLE™**  
We invest in people Silver

**INVESTORS IN PEOPLE™**  
We invest in wellbeing Gold



# Background and data landscape



- **PCTs** (pre-2012) – linking data across health and social care took place but was inconsistent and uncontrolled
- **Health and Social Care Act 2012**
  - Set out NHS Digital’s (NHSD) responsibilities including the collection, analysis and presentation of national health and social care data
  - NHSD also had the powers to act as a safe haven and collect, hold and process personal confidential data (PCD) for purposes beyond direct patient care e.g. commissioning, planning, population health management
- **The DSfC programme** established a number of regional processing centres, known as **Data Services for Commissioners Regional Offices (DSCROs)** – these Regional Processing Centres (RPCs) support the information needs of commissioners with the provision of appropriate data controls
- DSCROs were part of, and responsible to NHSD – and now to NHS England (following the NHSD/E merger)
- DSCROs perform their services with staff from Commissioning Support Units (CSUs) and work with data in the regional processing centres (RPCs)



# Background and data landscape

## Practically, what does a DSCRO/RPC do?

- Manages data warehouses, databases and huge numbers of datasets from across the health system
- Keeps data secure, restricting access to authorised users only
- Works at scale across large geographical regions and with multiple organisations.

DSCROs typically receive **1000s of national and local data flows** each month through a variety of routes:

- Database to database transfers
- sFTP
- Secure email
- DLP (Data Landing Portal)



Data flows are both **manual and automated** with various levels of **standardisation**

Datasets can include a **few or 1000s of columns** of data and **10s to 100s of millions of rows**

### Manages patient identifiers

Date of birth → Age  
Postcode → LSOA  
NHS number → pseudonym  
Derive other data fields where appropriate

Only allow data to be released using **authorised means, to authorised users**, in an allowed format

Data is typically released **'pseudonymised'**

Anonymised in line with the ICO Anonymisation Code of Practice  
Personal non-confidential data

Data typically released via the DCSRO's **CSU Data Management or Business Intelligence Services**

### Benefits of using a DSCRO

- + **Expertise** in managing all aspects of datasets
- + Positioned to **operate at scale** and manage multiple datasets
- + **Subject matter experts** who can advise on national datasets, and understand local variations and nuances
- + Already hold health data, so social care data (with NHS number) can be **consistently pseudonymised** to allow linkage



# The data development journey

**2018-2020**  
NATIONAL VOLUNTARY  
ASC CLD ESTABLISHED

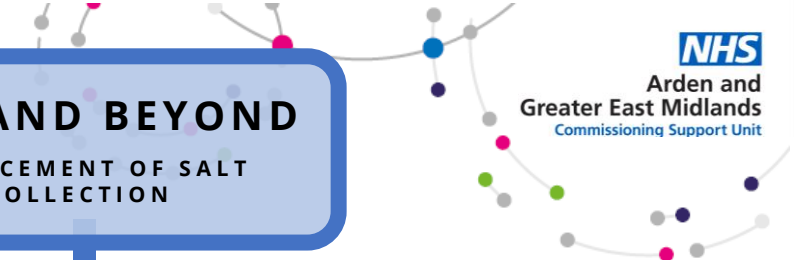
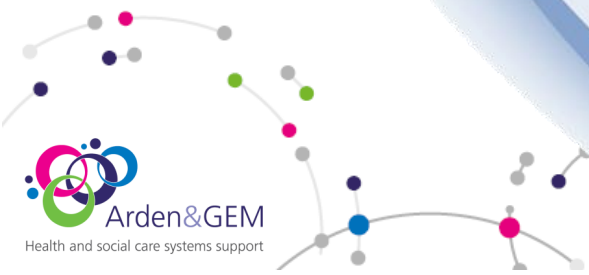
**2012**  
HEALTH AND SOCIAL  
CARE ACT

**2015**  
NORTH WEST PILOT

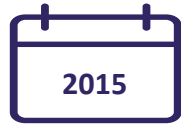
**2022**  
HEALTH AND CARE ACT  
ASC CLD VOLUNTARY  
COLLECTION ONGOING

**2023**  
ASC CLD MANDATED  
COLLECTION

**2024 AND BEYOND**  
REPLACEMENT OF SALT  
COLLECTION



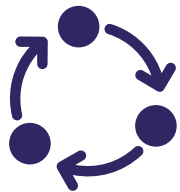
# North West pilot



Pilot work between the Department of Health and Social Care (DHSC) and NW DSCRO was first proposed in 2015



Main aim was to link health and social care data



Group established with 3 Clinical Commissioning Groups (CCGs) and Local Authorities (LAs)



Health/CCGs were the initial driving force

# North West pilot – challenges



## Governance



- Legal basis
- Purpose
- Organisations involved: LAs, CCGs, DHSC, NHSD/DSCRO, CSU
- Agreements needed:
  - ✓ Patient opt-outs?
  - ✓ Data Sharing Agreements?
  - ✓ Data Processing Agreements?
  - ✓ Privacy Notices?
  - ✓ Directions?
  - ✓ Data Provision notice (DPN)?

## Data quality



- Recognition of data quality (DQ) issues:
  - ✓ Incomplete
  - ✓ Inconsistent
  - ✓ Out of date
  - ✓ Inaccurate
- Data was for pilot purposes only, not for making decisions based on it
- Sharing the data gave us the opportunity to start to address DQ issues



# North West pilot

## OVERCOMING CHALLENGES

### Governance was slow to work through

- Directions were drafted
- Data Provision Notices (DPNs) were needed

### Some LAs had problems creating extract

- System and its local configuration has an influence on process

### Data submission to DSCRO via DLP (Data Landing Portal) was preferred route

- Enables validation as part of submission

### NHS number completion was variable

- Between 50 - 90%

## IDENTIFYING BENEFITS

### Benefits for CCGs

- ⊕ Linked health and social care data
- ⊕ More complete patient pathway

### Potential benefits for LAs

- ⊕ Replacement of SALT return
- ⊕ Identify missing NHS Numbers
- ⊕ Linked health and social care data



# A national programme



- The NW Pilot had proved the principle of an Adult Social Care Client Level Data collection
- Started work with DHSC on a national collection
- DHSC/NHSD – new Directions for a national but voluntary collection, Dec 2020
- Arden & GEM – Lead CSU/DSCRO
  - Working with the other DSCROs/CSUs to support all regions of England
  - Missing NHS number tracing
- ICBs and Local Authorities
  - Data submissions
  - Data disseminations and data sharing



# Benefits



## Single source of the truth

A dataset that LAs can use to answer day-to-day requests from service areas and commissioners



## National and local repositories



## Improved data quality, including completeness of the NHS number



## Improved communication and understanding

Improved consistency and transparency with central data transformations and standardised terminology

Providing more frequent and timely monitoring of social care activity, cost and outcomes



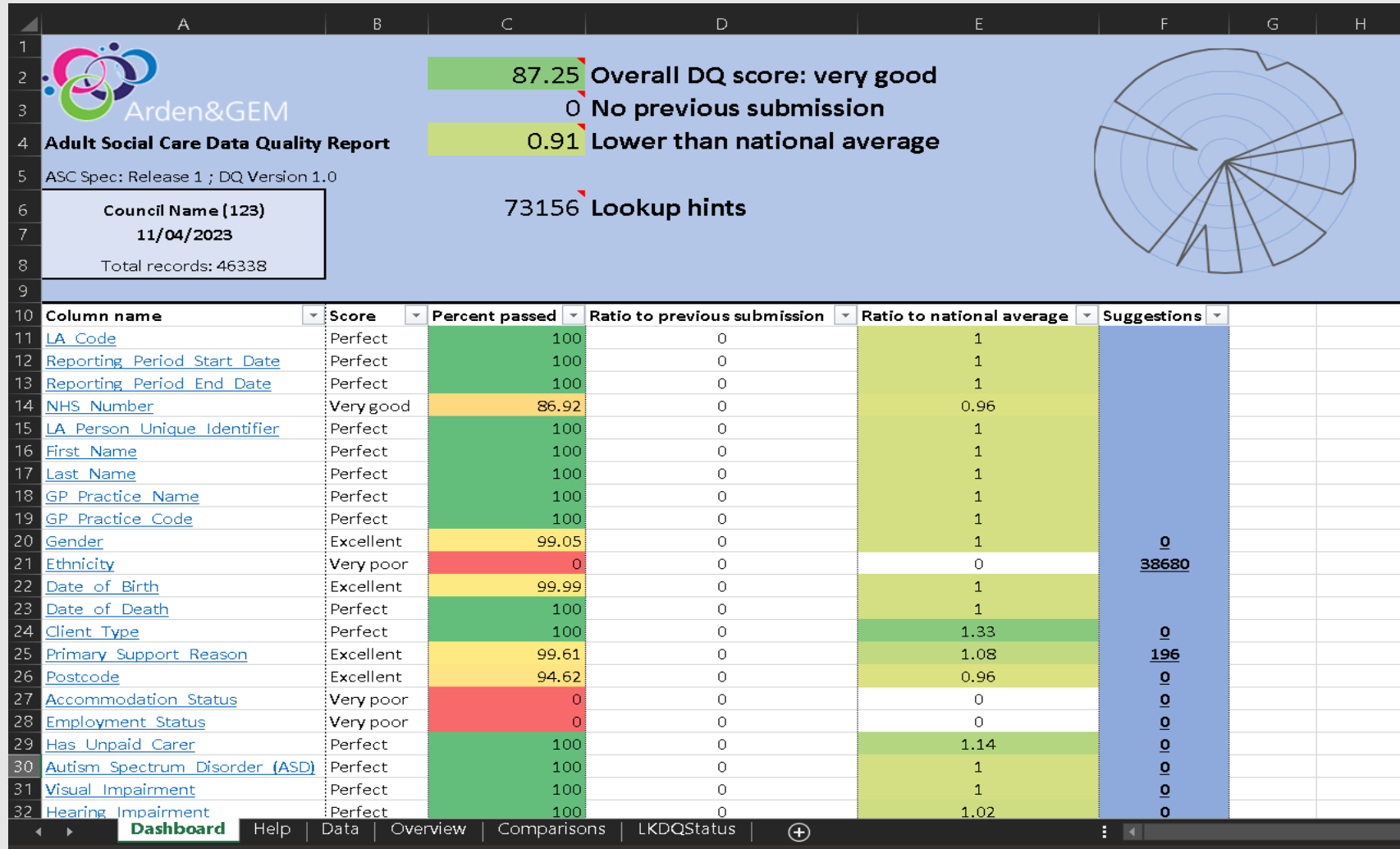
## Linked health and social care data

Whole patient pathway and journey  
Seeing impact of health on social care and vice versa

Identifying where there are blockers in care pathway



# Benefits – Data quality



# Benefits – Data quality

## Validity and Completeness Checks

### Validity Check - data items with a defined list of values

#### Overall scores

Valid %	Invalid %	Blank %
78%	8%	14%

#### Data Item Name

Accommodation Status	61%	14%	25%
Assessment Type	75%	0%	25%
Autism Spectrum Disorder (ASD)	90%	0%	10%
Cost Frequency (Unit Type)	74%	6%	20%
Delivery Mechanism (Long Term Community or Prison Only)	67%	28%	5%

Valid %	Invalid %	Blank %
61%	14%	25%
75%	0%	25%
90%	0%	10%
74%	6%	20%
67%	28%	5%

### Completeness Check - data items without a defined list of values

#### Overall Completeness score

74%
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#### Data Item Name

GP Practice Code	35%
GP Practice Name	75%
LA Code	100%
Planned units per week	100%
Provider CQC ID	25%

Complete %
35%
75%
100%
100%
25%

Select Local Authority or All for all Local Authorities submitting:

LA ⌵ ✕

- 706: Islington
- 707: Royal Borough of...
- 710: Southwark
- 713: Westminster
- 717: Barnet
- 724: Haringey
- 727: Hillingdon
- 813: Portsmouth
- 815: East Sussex
- 904: Gloucestershire
- 909: Bristol
- 912: Devon
- All

# Case study – Liverpool



Liverpool  
City Council



*Liverpool was the first LA to formally signed up to CLD and began submitting data into the DLP in May 2021, with subsequent monthly uploads scheduled. The development was front-loaded to set up and configure, but now CLD supports business as usual reporting and requires 30 minutes per month to run*

*The CLD data set is very adaptable and fits well with the rapidly developing nature of social care without disrupting local process. Its modular nature lends itself to being able to explore innovative approaches to data collection and analysis. Liverpool is currently using Power BI, but we did also experiment with SSRS, Tableau and Business Objects (WEBI).*

*The long term benefits of this data resource cannot be understated. We have positioned the CLD to be the building blocks of all data and intelligence requirements for the LA.*

*We can never forget that all data collected and shared must be for the benefit of the service user. It should be core to the principles of any data sharing project that the service users are the central and loudest voices, after all who is better placed in the whole system.*



# Benefits from linked data



## Client Pathway

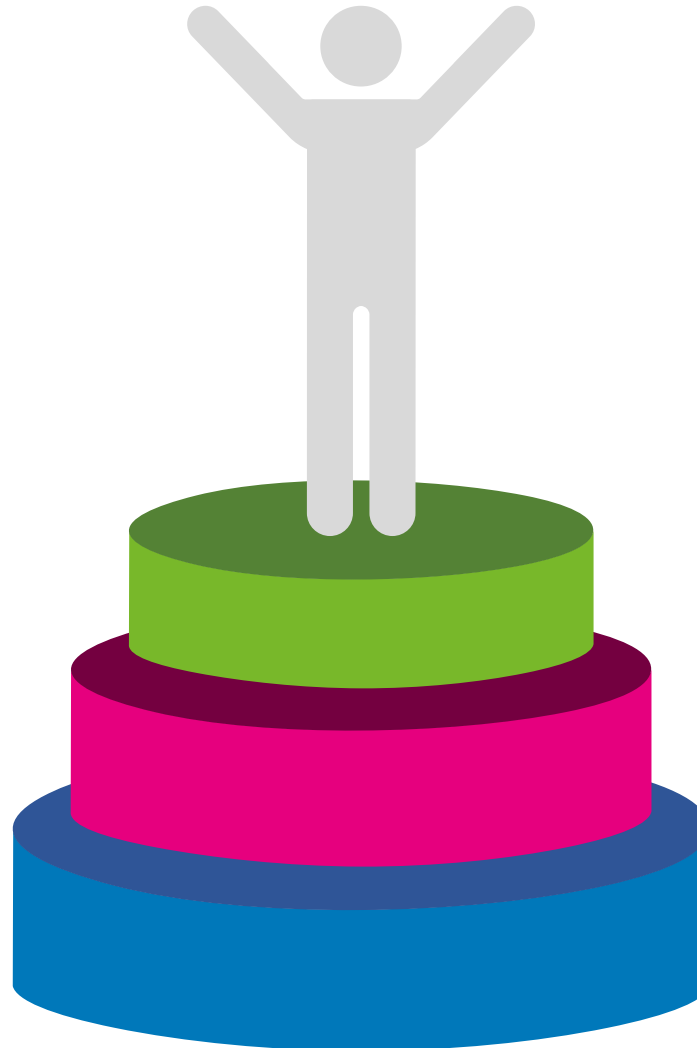
See client journey through health settings & ASC services: Person level data allows us to model our dynamic and complex systems allowing for flexibility and responsiveness to changing demand

## COVID vaccinations

The identification of a much greater number of carers known to health and care to invite them for their COVID-19 vaccine

## Insight: Unpaid Carers

Anonymised version of CLD data was utilised as the social care foundational data spanning a 3 year period, additional data sets from primary health, community health and to some extent secondary health have been utilised to provide a chronological picture of unpaid carers.



## Complex case

Complex cases analysis to see what interventions have been put in place across health and care, resulting in a more coordinated care package, provided more efficiently with better outcomes for individuals

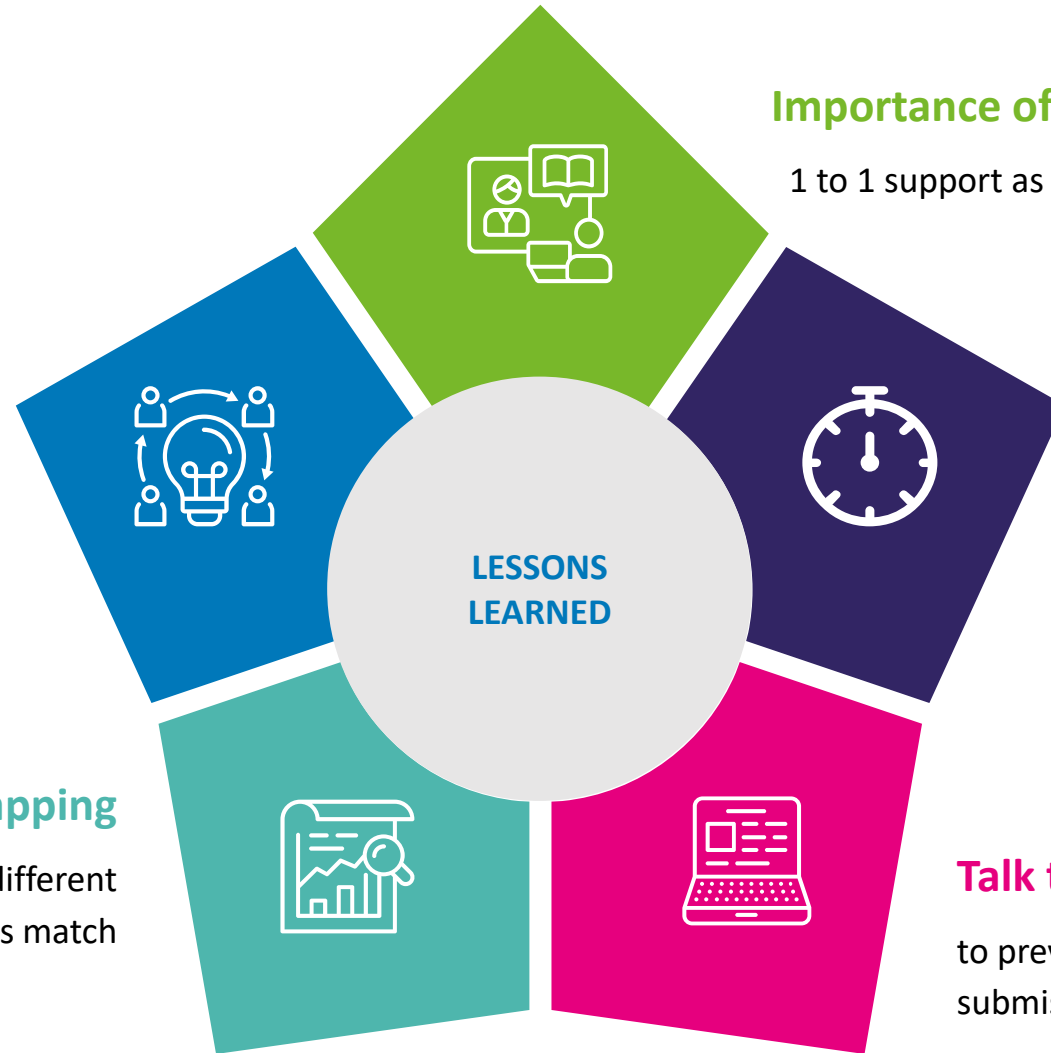
## End to end referral pathway

Opportunity for advice and guidance for lower level need to access VCSE support

## Hospital discharge & capacity management

Councils, ICBs and Acute Trust Partners are working together developing single view capacity and demand models to help manage patient flow through acute settings and into community / residential support.

# Lessons learned



## Importance of engagement with LAs

1 to 1 support as required to address issues and concerns

## Flexibility in submissions and submission deadlines

- be mindful of the local pressures LAs are operating under
- focus on fixing DQ at source, not after submission

## Talk to IT departments

to prevent common issues e.g. firewall blocking submission, validation tool macros disabled

## Reference group supported establishment of collection

representatives across regions and systems

## Importance of data mapping

data descriptors within different organisations don't always match





# A national programme – next steps



## DHSC/NHSE – new Directions for a national *mandated* collection

- April 2023
- Updated specification and guidance in response to feedback
- Dataset to be a new data standard

## Mandated submissions for all councils

- Minimum quarterly
- More frequent submissions
- Support with automation of submissions to reduce burden

## Arden & GEM – Lead working with all other DSCROs/CSUs

- Improved DQ reporting
- More frequent submissions e.g. monthly, in line with health and requirements following Covid

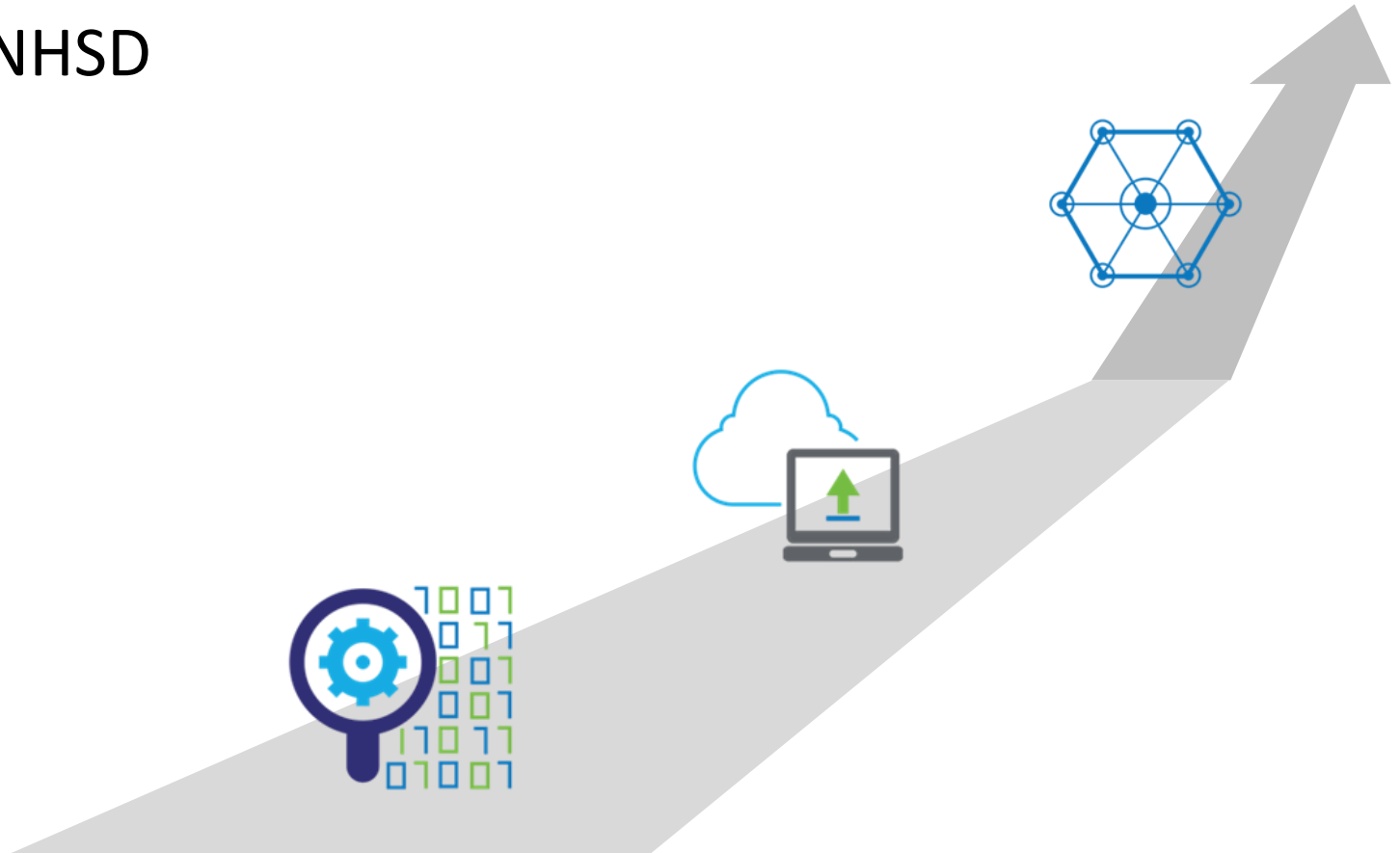
## Integrated Care Boards (ICBs) and Local Authorities

- Closer working across health and social care as part of ICB formation
- Linked data to be shared with ICBs and LAs and other ICS partners



# What next – longer term?

- Enhanced data derivations returned to local authorities
- Extraction direct from systems
- Central collection by NHSD



# Any questions?



Get in touch with us at:

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