

digitalhealth

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BIRMINGHAM 12-13 MARCH 2024

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# Dr Danny Bosch

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Associate Director of BD and Commercial -  
Imperial College Health Partners/ Discover-NOW London  
SDE



AI,  
DATA AND  
ANALYTICS  
STAGE

Stage Sponsor:

**InterSystems**<sup>®</sup>  
Creative data technology

Discover-**NOW**



**London**  
SECURE DATA  
ENVIRONMENT

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

# Delivering secure data environments

Wednesday 13<sup>th</sup> March

15:30 – 16:15

# London Life Sciences Ecosystem

## Research & Academia:

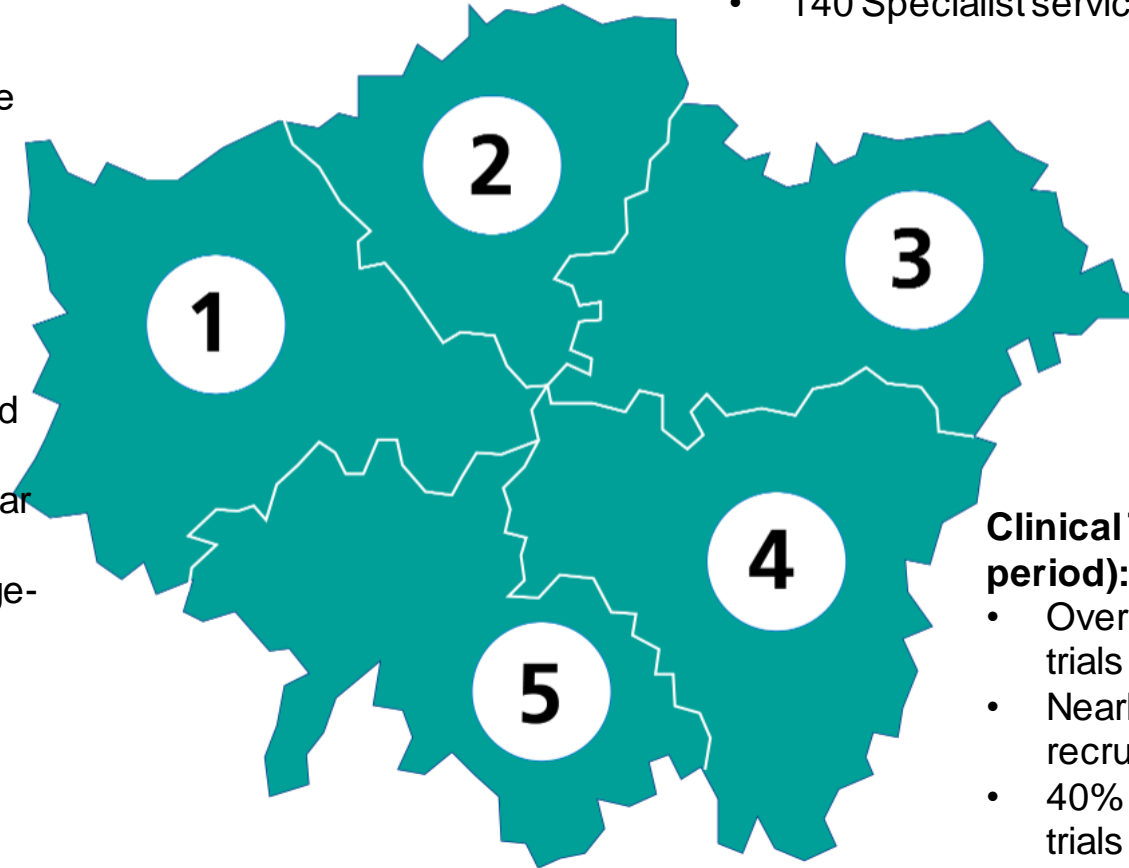
- 3 AHSCs (Kings' Health Partners, Imperial College Academic Health Science Centre, UCLPartners)
- 3 AHSNs (Health Innovation Network, Imperial College Health Partners, UCLPartners)
- 3 Clinical Research Networks
- 3 ARCs (Applied Research Collaboration)
- 8 Biomedical Research Centres
- 1 London Diagnostic Evidence Cooperative (based at Imperial)
- 2 Health Technology Cooperatives (Cardio-vascular disease – G&STT and Enteric Health- Barts)
- Health Informatics Cooperative (Oxford-Cambridge-London)

## Bioinformatics:

- 100k genomes (headquartered at QMUL)
- 3 Genomics Medicine Centres

## Healthcare system:

- 5 ICSs
- 39 Acute trusts (secondary, tertiary and quaternary care)
- 140 Specialist services



## Clinical Trials (in the 2015-2020 period):

- Over 5,000 commercial clinical trials took place,
- Nearly 43,000 people were recruited
- 40% of (NIHR portfolio) clinical trials in England took place in London and GSE (2016/20)

# This has to be about more than research and deliver value to the NHS

*The MVPs for the LDS and SNSDE support faster and better clinical and operational insights, which can be used through population health management and care planning to improve decision-making and treatment, delivering benefits to patients alongside system efficiency*

## Improved prevention and case finding capabilities...

...with improved **data quality**, standardising definitions and triangulating data sources to address variation and inconsistencies  
...through **access to tools and algorithms** that have been developed and validated on large scale data improving accuracy

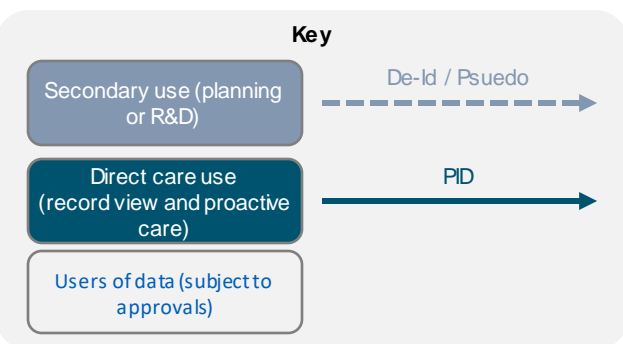
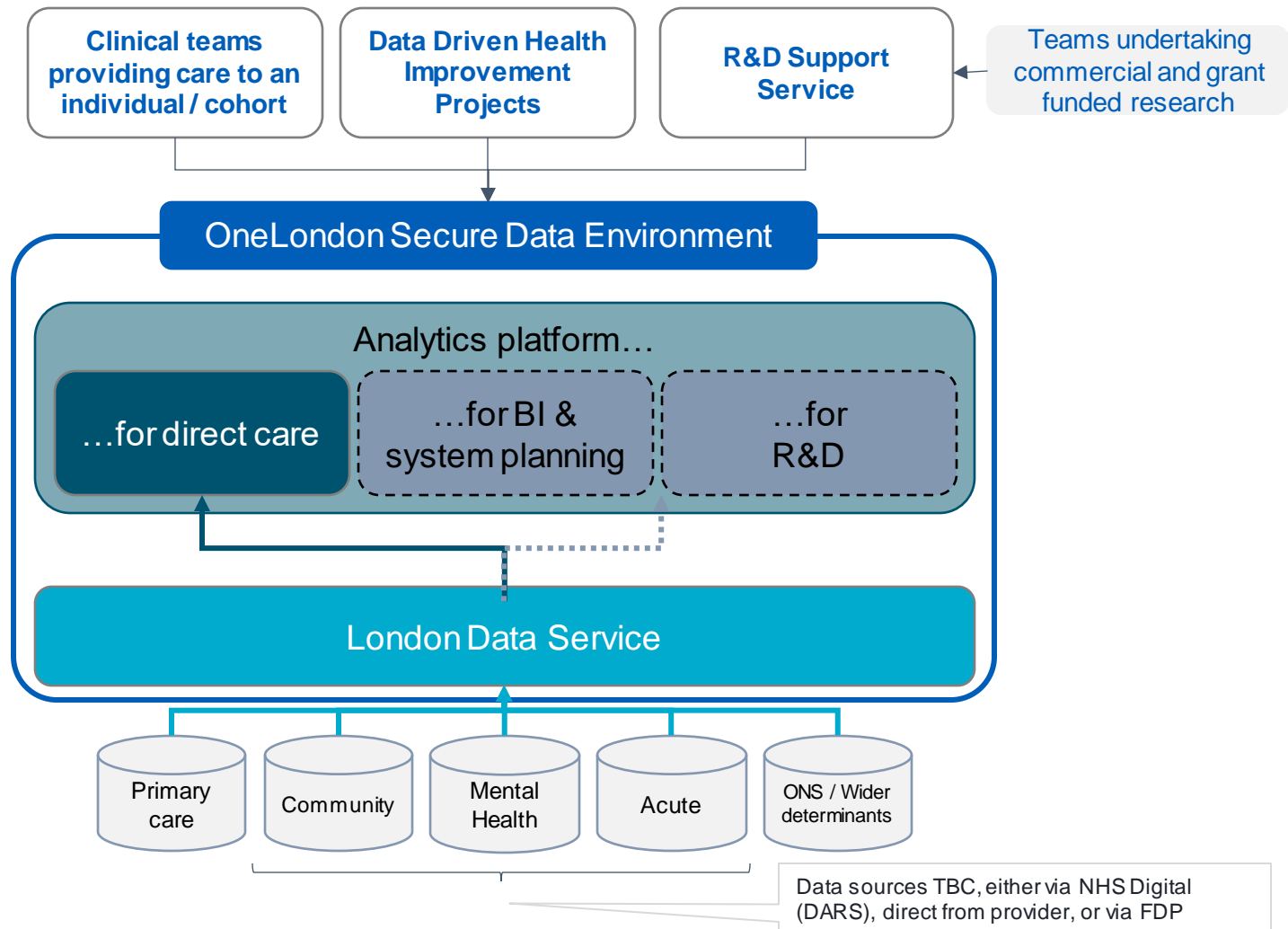
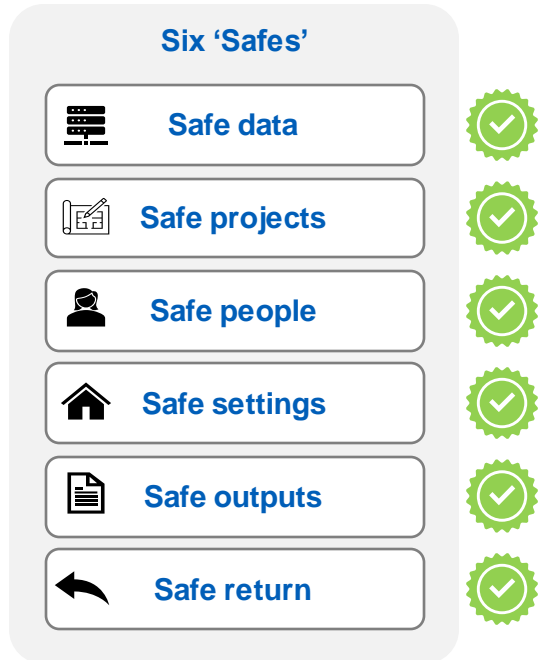
## Reduced inequality within and across London's population...

...through **consistent application of solutions**, ensuring patients benefit from research outputs and innovations irrespective of location  
...**widening the reach** of research and development, building solutions for the diverse population and implementing them at scale across London

## Organisational efficiency...

...with a **common approach** to information governance, data management and public leadership through the Citizens Advisory Group  
...accessing wider **analytical capabilities** and developing solutions on standardised data that can be applied locally  
...utilising a **cloud first framework** to rapidly onboard more data as required

# The platforms are 'six safes' compliant – i.e. a Secure Data Environment



# Discover-NOW London SDE Overview

Community & Mental Health



GP Practice



Hospitals



Covering  
**>10 m**  
people

Over  
**10yrs**  
historic  
data

With  
**>1000**  
Partner  
ISAs

## London Data Service (Patient Identifiable Data)

### Core Data

- Activity
- Prescriptions
- Demographics



### Reference Data

- Organisation
- BNF
- Postcode 'out codes'



### Derived Measures

- Long Term Conditions
- Electronic Frailty Index (eFI)
- Spend



## London snSDE (De-identified data)

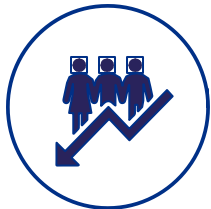
### Today, in progress:

- *Over 300 research data access applications*
- Including over **15** major industry clients
- *Over 39* published manuscripts and abstracts

## Our services



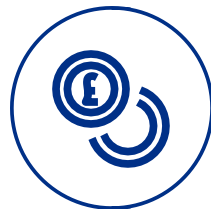
Feasibility



Retrospective studies



Patient identification and recruitment



Health economic evaluations



Artificial Intelligence (AI) and machine learning



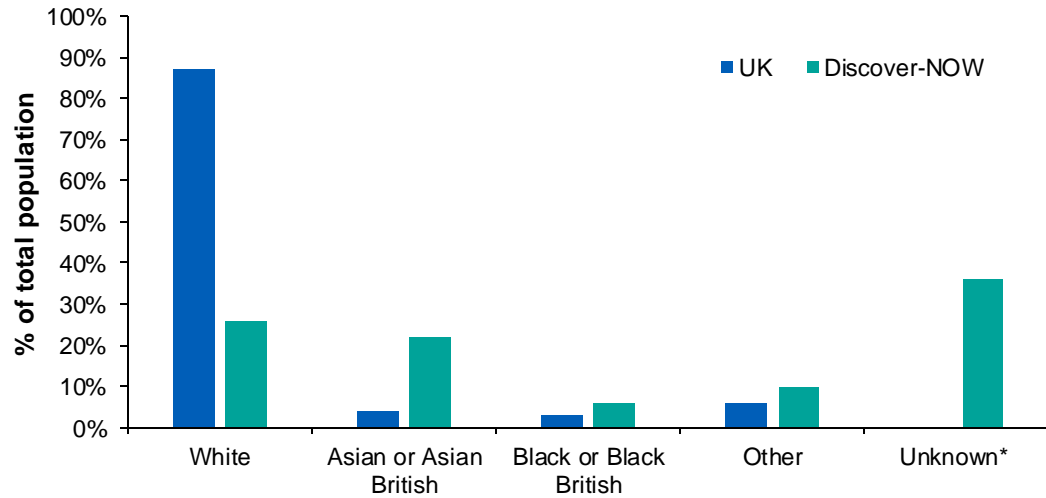
Health implementation



Direct access  
*In planning*

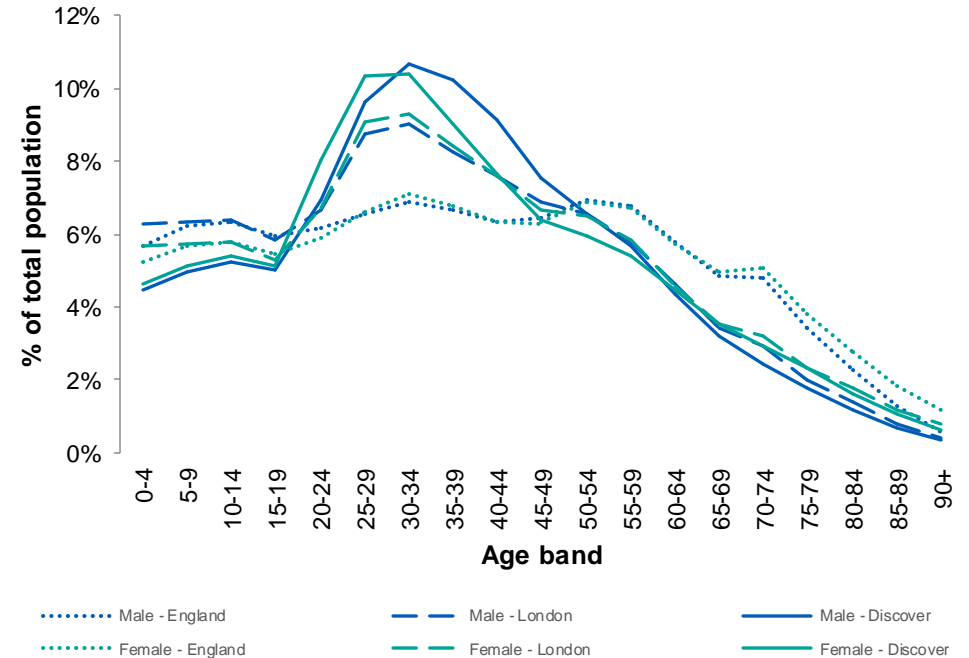
# Data in the Discover-NOW dataset is extremely diverse in ethnicity, sex and age

**Ethnicity population distribution:  
UK and Discover<sup>1</sup>**



\* Unknown n within Discover-NOW dataset, most are likely to be white

**Age and gender population distribution:  
England, London and Discover**  
England & London data:  
ONS Census 2021 rounded to the nearest 100



<sup>1</sup>Bottle, A., et al. (2020) How an electronic health record became a real-world research resource: comparison between London's Whole Systems Integrated Care database and the Clinical Practice Research Datalink. BMC medical informatics and decision making, 20(1), 1-11.

## We utilise a streamlined data access governance process in NWL

- The NWL Data Access Committee (DAC) is a nominated body that provides a governance mechanism for evaluating project applications requesting data from Discover. Membership is made up of lay members, academic reps, CCIO, DN rep, Trust R&D directors, WSIC rep, NIHR/CRN rep and IG reps. Access to the dataset is decided by the NWL Research Access Committee except for access to feasibility and anonymised reports.
- The NWL DAC has responsibility to ensure that access is consistent with the Discover Principles Charter, provide clear patient benefit, and requests do not pose undue risk to the individuals, communities or organisations to which they relate.
- HRA approval has been received to use the de-identified Discover dataset for retrospective studies.
- To date over **300 data access applications** have been approved and **over 39 manuscripts and abstracts published** as a result of use of the data.



**Complete and  
submit the application  
form**



**Your application  
will be reviewed  
by the DAC**



**If access is approved,  
you will have a log in  
automatically  
generated**



**Your access will  
be granted within  
4-6 weeks**

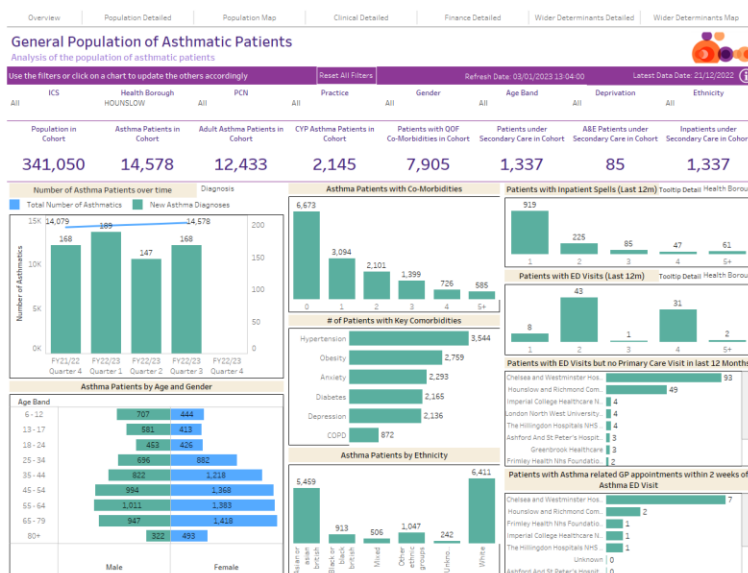


**Further support is  
always on hand  
through the Discover-  
NOW team**



# Reducing Health Inequalities – London Asthma Decision Support Tool

- LADS (The London Asthma Decision Support Tool) brings together **air pollution, demographic and social deprivation data** with routinely collected NHS data for the first time ever.
- This was a collaborative approach between NWL and SEL Integrated Care Boards (ICBs), allowing 80 PCNs to be able to access data. This use of data has been guided by the recommendations gained from the London Health Data Strategy deliberations



Between  
January 2023 –  
April 2023

**400** fewer prescriptions of short-acting beta-antagonists (SABAs)

**2,422** more patients prescribed inhaled corticosteroids

**71** people on six or more SABA medications risk-stratified

*Dr Sarah Elkin, Consultant in Respiratory Medicine at Imperial & Co- Clinical Director of the London Respiratory Clinical network said “The true power of this data is that it will allow an understanding of outcomes across a population enabling increased support & intervention to be delivered to areas of need and in a way that supports local delivery approaches. We hope to be able to extend the use of this tool across the whole of London.”*

# Reducing Health Inequalities – Chronic Kidney Disease Management

- AstraZeneca, ICHP, North West London Applied Research Collaboration (ARC), Imperial College Healthcare Nephrology Department, and the London Kidney Network (LKN) collaborated on a data-led approach to improve the diagnosis and early management of CKD in North West London (NWL).
- The project used qualitative insights gathered from interviews with patients at risk of CKD, patients diagnosed with CKD, primary and secondary care clinicians, along with population data analysis and an academic literature review, to understand the largest challenges and opportunities in existing NWL pathways.
- The resulting pathway recommendations include, but are not limited to, early-stage CKD education options for primary care and patients to access, CKD screening support for patients, training, and an implementation package and CKD search package, for Primary Care.



**£1.45 billion** is billed annually to the NHS for CKD costs

**Two in 10** people with the disease are currently diagnosed



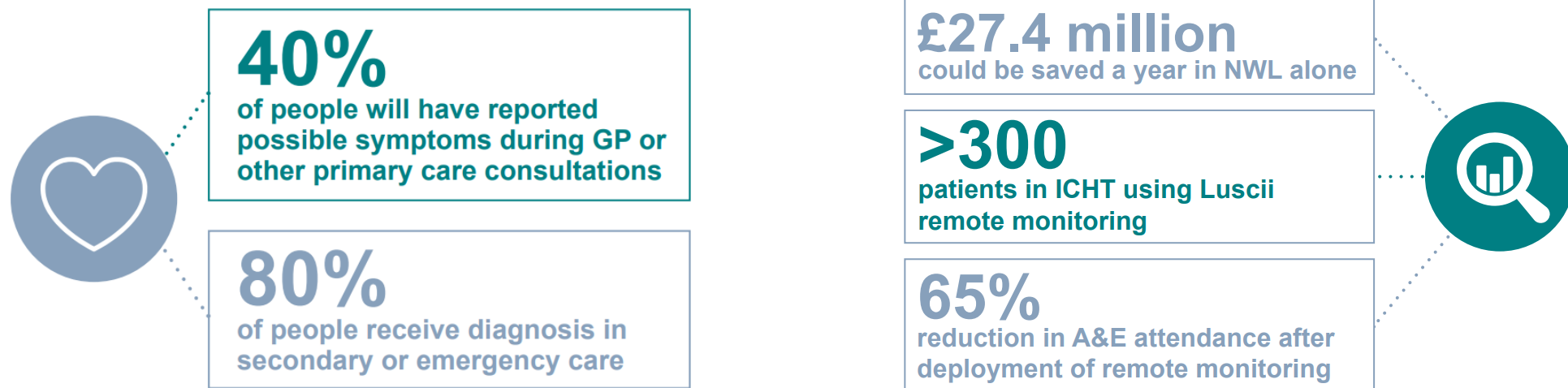
**42** In one pilot, GP practice searches identified review appointments for 42 previously off-guidance high-risk patients

*Dr Neville Pursell, NWL CVD Executive Co-Chair said*

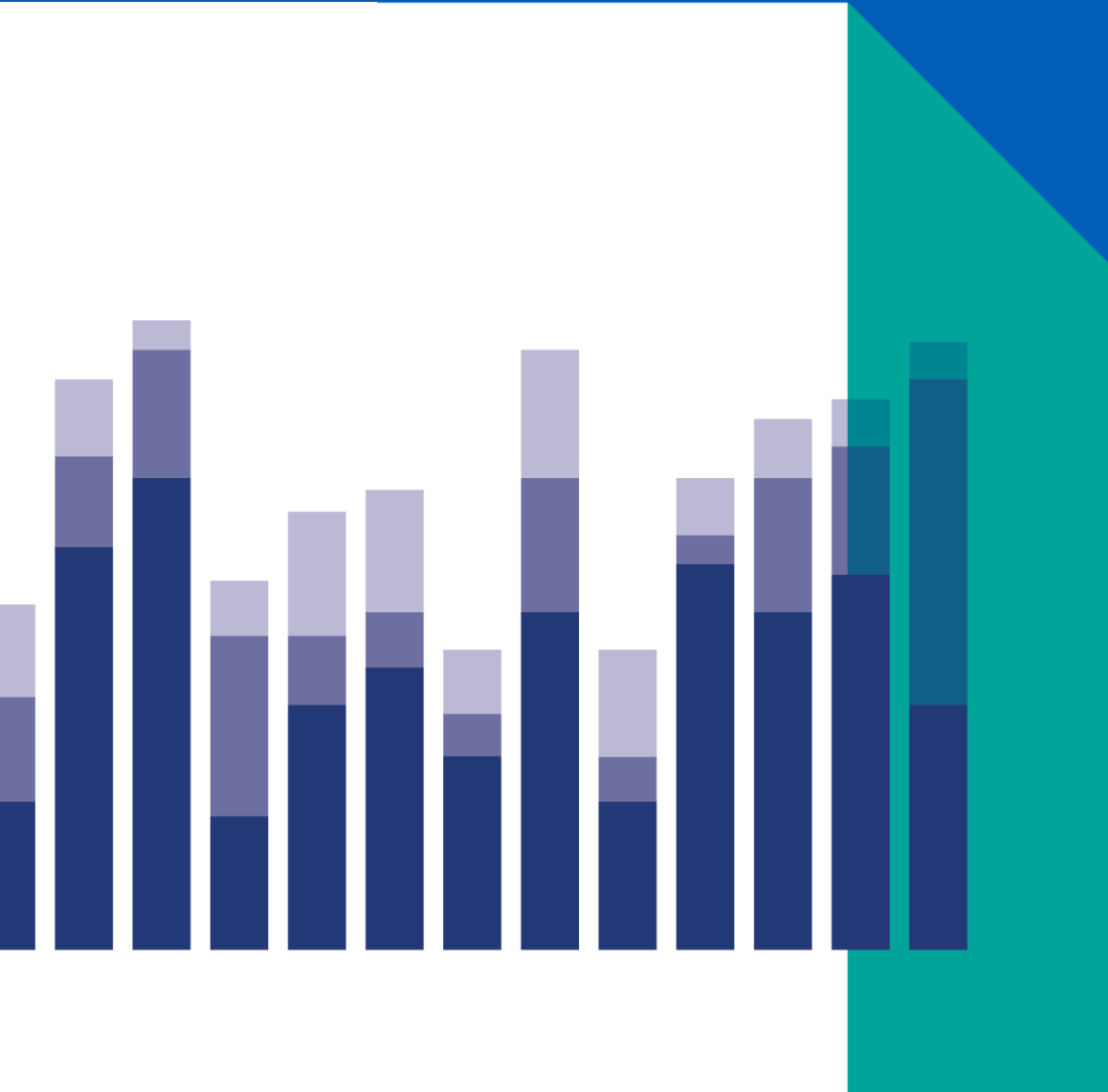
*“It’s not often we see a project like this that connects primary and secondary care with true innovation and teamwork.”*

## Improving care – The iHeart project

- A collaboration brokered by ICHP through the Discover-NOW hub, involving NHS (Imperial College Healthcare Trust, NWL ICS) and industry (AstraZeneca, Eko DUO, Luscii), created a safe space for partners to come together to redesign a complete end-to-end pathway for Heart Failure care.
- The Discover dataset was used to assess the extent of the challenge, mapping the pathway for patients with HF and establishing how often they were presenting to healthcare service, and the associated costs, as well as patient outcomes.
- The data analysis emphasised that patients diagnosed in the community setting had significantly improved outcomes compared to those diagnosed in hospital prior to the project.



# Thank you for your attention



# Appendix

## Linked longitudinal patient level data including...

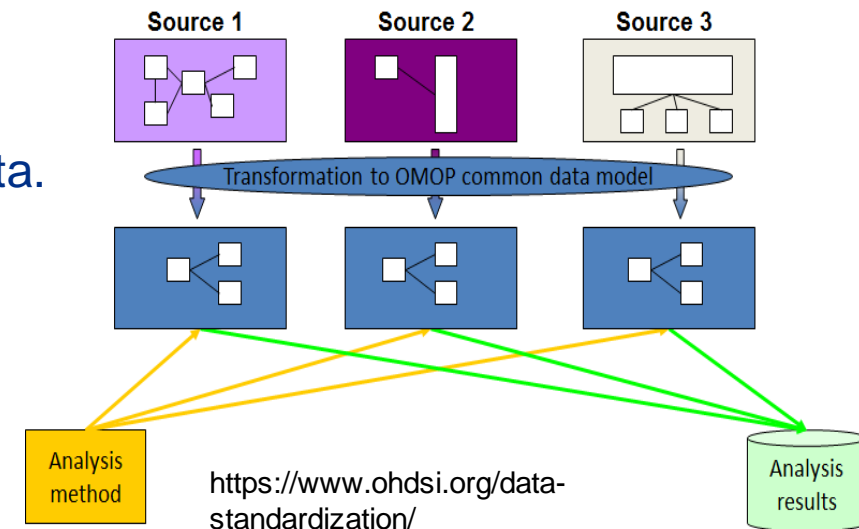
Data	Detail
Patient index	All NWL registered patients, including those who have died or left NWL.
Secondary care (SUS)	Emergency department (ED) attendances, admitted patient care (APC) episodes & spells, outpatient appointments. From 2015 onwards.
Secondary care (SLAM)	Financial data from hospital trusts, including non-activity payment items. From 2015 onwards.
Primary care	GP events and prescriptions.
Mental Health	Activity at NWL mental health trusts.
Community	Activity associated with NWL community trusts.
High-cost drugs	Secondary care prescriptions classified as 'high cost' for payment purposes.
Social care	Care package details.
Waiting list	Referral to treatment (RTT) patient tracking list (PTL), open pathways, clock starts and clock stops.
Patient history	Dates of collated primary care events and prescriptions, community, mental health, social care.
Patient segmentation	Long term conditions, frailty, pollution estimates, deprivation, demographics.

With the majority being updated on a fortnightly-monthly basis (some daily).

Data from outside the London SDE can be securely **imported** into the environment (providing there is a patient identifier). This patient identifier allows **linkage** to patient data already available within the dataset. Data is then de-identified ready for data analysis.

## Interoperability and federation

- **Data interoperability** is the ability to merge and aggregate different datasets through data formatting and standardisation.
- This unlocks potential for **data federation** across multiple data sources / providers, providing:
  - **Larger cohorts, greater diversity, and generalisability**
  - **Improved data quality and power**
  - **Increased flexibility and efficiency**
- To federate, a common data model (CDM) should be applied to data.
- **Discover-NOW London SDE** plans to transform data into the **Observational Medical Outcomes Partnership (OMOP) CDM**.
- OMOP transformation will permit federation across different subnational SDEs for impactful research.







## 200

GP practices onboarded  
by February 2024



Analysis completed for patients  
diagnosed with heart disease, atrial  
fibrillation and valvular heart disease



Potential **savings and health impact**  
assessment to be  
completed by August 2025

## Challenge

Heart failure is a progressive condition affecting over 2% of the population and consuming 4% of the NHS budget. It carries a higher risk of death than most cancers and is increasingly common. TRICORDER aims to use an AI-powered tool to proactively identify patients at risk in GP records.

## Summary

This groundbreaking project marks the first sector-wide deployment of an AI tool in primary care, involving 200 GP practices by February 2024.

It aims to assess the cost-effectiveness of Eko-DUO, an AI-powered stethoscope, in early detection of heart failure and related cardiovascular diseases.

Integrating data from over 2.5 million patients in North West London, sourced from the Discover-NOW London Secure Data Environment (SDE), with clinical trial data, the project seeks to determine the efficacy of an AI-powered tool to proactively identify at-risk patients.

Launched in January 2023 and running until ~August 2025, it has received £1.18 million funding from the National Institute for Healthcare Research (NIHR).

## Outcomes

- **Demonstrating the efficacy of an AI-enabled stethoscope in primary care** for swift diagnosis of cardiovascular diseases.
- Enhancing clinical decision-making, patient outcomes, and minimising A&E visits.
- Projecting **£100m savings for the NHS** through nationwide implementation of Eko-DUO in primary care.
- Guiding policy, prevention strategies, and public health initiatives for optimal impact.

## Partners

Imperial College  
London

Discover-NOW

London  
SECURE DATA  
ENVIRONMENT



GIG  
CYMRU  
NHS  
WALES

Bwrdd Iechyd Prifysgol  
Betsi Cadwaladr  
University Health Board



NIHR | National Institute  
for Health Research





>17k

Patient records reviewed in the studies



**2 papers** submitted to academic journals and **evidence used by NICE** for clinical decision making

50%

**Associated reduction** in risk of hospitalisation or death as a result of Sotrivimab vs no treatment

## Challenge

This study was performed due to the sparsity of clinical trial data and the need for the assessment of the real-world effectiveness of Sotrovimab. In our first descriptive study - from 1 December 2021 and 31 May 2022 6.2% of untreated patients were hospitalised and 1.9% of untreated patients died within one month of COVID-19 diagnosis.

## Summary

Data from the London SDE was used to complete two studies. The first described characteristics and outcomes of patients receiving Sotrovimab, Nirmatrelvir / Ritonavir, Molnupiravir, or no treatment. The second study assessed the effectiveness of Sotrovimab in high-risk patients with similar patients receiving no treatment.

The studies analysed the following real-world data: patient characteristics; prescription data; high-risk conditions; and acute patient outcomes, all available within the SDE environment.

Using this data researchers were able to assess the effectiveness of Sotrovimab versus no treatment in high-risk patients to generate real world evidence to be considered as part of health care recommendations from NICE and to help inform national clinical decision making.

## Outcomes

Compared with no treatment:

- Sotrovimab treatment was associated with a reduced risk of hospitalisation or death by 50%
- In patients >65 and patients with renal disease sotrovimab treatment was associated with a reduced risk of hospitalisation by 89 and 82%, respectively

The outcomes of the studies have been written up as two manuscripts submitted to academic journals.

The real world evidence has been cited by NICE as part of their 'Therapeutics for people with COVID-19' guidance.

## Partners



Discover-NOW



# Feasibility studies

Discover-NOW supports researchers to assess the feasibility of potential future studies using our large scale deidentified linked data set. With a population of over 2.5 million we can help locate eligible patients to be screened and invited to participate in studies. We have a team of experts with skills in data access and analysis, information governance and project management to support you to get the answers you need in a safe, secure and timely way, providing justification for further investigation.

## How we work with you

We create a tailored feasibility study utilising one or more of our following services:

- **Interrogation of the Discover dataset** to identify where your drug, device or intervention is likely to provide the most benefit to patients and the wider NHS
- **Support you in designing and testing your protocol** using FARSITE
- **Provide you with access** to a real-world health care system in North West London and clinical and patient collaborators

*As a researcher I gained valuable insights into the application of the data to answer clinically important research questions. My collaboration with the Discover-NOW team on real-world studies using the dataset has been an intellectually stimulating and fruitful experience led by a very professional team with expertise in navigating the complexity of high-volume data studies.*

*Dr Naila Arebi, Consultant Gastroenterologist St Mark's National Bowel Hospital, Honorary Senior Lecturer Imperial College*

# Retrospective studies

Discover-NOW supports researchers to assess the feasibility of potential future studies using our large scale deidentified linked data set. With a population of over 2.5 million we can help locate eligible patients to be screened and invited to participate in studies. We have a team of experts with skills in data access and analysis, information governance and project management to support you to get the answers you need in a safe, secure and timely way, providing justification for further investigation.

## How we work with you

We generate high-quality evidence and reports which are suitable for academic publication. Examples of how we can support you include:

- **Map patient outcomes** as a result of specific interventions.
- **Evaluate prescribing patterns**, patterns of referrals, patient and clinician behaviours
- **Examine evidence** of adherence/lack of adherence to clinical guidelines.
- **Identify treatment gaps** and the subsequent impacts.

*"Since the initial scoping meeting, the Discover-NOW team have been consummate professionals throughout our collaboration and a delight to work with. They have excellent capabilities, access to an enormous dataset and have contributed to what will end up being a very significant real-world evidence publication that will change practice."*

*Richard Jones, Global Medical Manager - Men's Health, Besins Healthcare*

# Patient identification and recruitment

Discover-NOW can support you to identify and recruit to studies. Our Health Research Register comprises thousands of patients who have consented to be contacted about taking part in research studies relevant to them.

Further, using our specialised, GDPR-compliant FARSITE tool, we can identify and invite people to participate in research through their GP. Our highly skilled team can assist you in rapidly defining the protocols for your study to ensure only those patients eligible for your study are invited to take part.

## How we work with you

- **Enable early testing and refining of protocol designs** to ensure eligibility of patients prior to recruitment.
- **Identify eligible patients** who can be screened and invited to participate in your study.
- **Improve study success rates** by testing and refining early protocol designs using real world data and clinical expertise.

*The register being linked to the Discover dataset enabled us to identify accurately and rapidly cohorts of patients that fit the exclusion and inclusion criteria of the protocol, and who were also located within close proximity to the hospital, saving considerable time and effort for the recruitment process.*

National Heart and Lung Institute team, Royal Brompton Hospital London

# Health economic evaluations

Discover-NOW can support the evaluation of a new product or intervention through analysis of real world clinical, population and economic data. Our expert team can generate insights and evidence in relation to patient benefit and / or value for money by linking health outcome and cost data, supporting you to make informed decisions about treatments and interventions. We also provide innovators/ new products with the real-world evidence as required by regulators to support agile market access. We are exploring providing real world evidence to support value-based pricing.

## How we work with you

- **Generate answers** to your questions.
- **Provide evidence** to support the development of business / investment case.
- **Provide insights** to communicate to stakeholders, payers and regulators.

*The unique richness of the real-world Discover-NOW dataset was expertly navigated by the team who delivered precise answers to our questions, all presented in a clear format accessible for interpretation by our diverse range of clinical, academic, policy and industry stakeholders. The overarching mission and values that motivate the Discover-NOW team make them a pleasure to work with, and we look forward to future work together.*

Dr Patrik Bachtiger, Cardiologist and Clinical Research Fellow in Digital Health, Imperial College

# Health Implementation

Discover-NOW is deeply rooted in a health and care system. Working together, our analysts, innovation specialists and engagement leads can support you to help shape services and products and evaluate their effectiveness. Fundamentally we understand the challenge of health implementation and we can help close the gap between what we know and what we do (the know-do gap) by identifying and addressing the barriers that slow the uptake of proven health interventions and evidence-based practices. We use a combination of data and service design skills to quantify the problem, design interventions and assess the impact of these interventions in an agile way in a real world health data ecosystem.

## How we work with you

- **Use service design** to digitise and enhance existing care pathways to enable personalised care.
- **Problem quantification** across the existing pathway using our longitudinal data set and data analytics capabilities.
- **Measure the impact** of the intervention in the data using our analytical and modelling capabilities.
- **Develop methods** to co-design solutions with patients and clinical involvement.
- **Form Innovation Partnerships** to help define shared problems and work with the health and data ecosystem to design solutions.
- **Create the evidence** to inform business case development and potential scaling across the NHS.

*Discover-NOW offers clinical scientists exciting possibilities to investigate cardiovascular diseases and their outcome in a real-world setting – an invaluable addition to the evidence provided by clinical trials.*

Thomas Lüscher, Professor of Cardiology. Royal Brompton & Harefield Hospitals

*[Discover-NOW's] role as a facilitator between the NHS, academia and industry partners to provide a level playing field and a safe environment to experiment is critical to the success of innovative and transformational work.*

Ross Stone, Global Programme Director, Healthcare, AstraZeneca



# AI and machine learning

Using our large-scale linked dataset, our team of expert analysts can test algorithms and new software technologies in real-life scenarios to determine if the technologies are effective and scalable. We have skills in data science, advanced statistical analysis and utilise Data Robot, an automated platform that speeds up the build and deployment of models.

## How we work with you

Our highly skilled team of data scientists and analysts will work with you to assess your objectives, and can provide expertise in:

- **Validation of an existing algorithm** to test scalability and effectiveness.
- **Health economic analysis** and performance of algorithms.
- **Predicting the behaviour of new technologies** in real life scenarios.



*We're hoping that we can move forward with rolling out the clinical interface to a wider group of clinicians and patients across NW London, with continued collaboration – what we've got is a really great data set for this type of work.*

Tony Willis, Clinical Director, NWL CCGS



# Direct Access (in planning)

Discover-NOW can support with direct access to the longitudinal primary and secondary care linked dataset available in the Discover-NOW, London Secure Data Environment.

Following appropriate approvals, you will be provided access to a sandbox area within the SDE server to access and analyse the specific data of interest for your research project. There will be opportunity to bring in your own statistical packages to support the analysis.

## How we work with you

- **Identify data of interest and environment requirements** to provide the appropriate space to carry out research
- **Support data access applications and onboarding** to ensure timely access and guidance when analysing data
- **Bringing in the appropriate statistical packages** to ensure best practice and rigorous study design is achievable

## *On the potential of direct access*

*A supported service providing direct access to data, and the relevant supporting statistical tools and packages would be very valuable*

Large Pharma