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Data for Research & Development Programme Evaluation

This report has been prepared by Starlight Digital Services Ltd (‘Starlight’) solely for the purpose of providing an independent evaluation of the Data for Research & Development Programme (the “Programme”). The evaluation has been conducted in accordance with the agreed scope and timeframe.

The findings, conclusions, and recommendations set out in this report are based exclusively on information made available to the review team during the engagement. This information comprised documentation supplied by the Programme and interviews with stakeholders identified by the Programme’s Senior Responsible Owner (SRO). The review took place in December 2025 and January 2026. Starlight has not independently verified the accuracy, completeness, or reliability of the information provided and has relied upon it in good faith.

The analysis and judgements expressed in this report reflect the circumstances and evidence available at the time of the review. They should not be interpreted as providing assurance over future performance, outcomes, or value for money, nor as a comprehensive assessment of all risks, controls, or governance arrangements relating to the Programme.

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1 Executive summary

The NHS England Data for Research & Development Programme (Data for R&D) was established following the COVID-19 pandemic to make real-world healthcare data available to researchers on an unprecedented scale. There is widespread recognition that data systems must support both direct care and research to create learning health systems. This was and is seen as fundamental to the delivery of good health and care. It is not optional.

This independent evaluation was commissioned by NHS England's Data for Research and Development Programme and delivered by Starlight. The task was to interview a wide range of stakeholders to identify lessons learned, suggest recommendations for the future and assess the value for money of the Programme. The evaluation focused on interviewing key stakeholders from across researchers who use the services, policymakers, programme teams and service delivery teams. The evaluation also reviewed key documents.

The vision for the Programme is: *"By 2025, our vision is to have a world-leading NHS-wide health data research infrastructure that enhances patient care, sustains the NHS, and supports innovation, while benefiting the economy through attracting life sciences to work in the UK."*

There have been previous attempts to make healthcare data available for research, but nothing on the scale set out in 2022.

The Programme has achieved many foundational successes: the establishment of a network of eleven regional Secure Data Environments (SDEs), a National SDE and NHS DigiTrials. The Programme engaged with the public from the outset. New datasets which have not previously been easily accessible for research, such as pathology data have been onboarded. The NHS DigiTrials service has registered +1.6M consented participants[1]. A total of 545[2] research projects are supported. There are standard processes and commercial approaches shared across the

[1] https://digital.nhs.uk/services/nhs-digitrials

[2] Recorded in December 2025

network and commercial contracts in place to provide services to Life Sciences companies.

These achievements have been delivered during a period of significant political change with four UK governments and six changes to the Secretary of State for Health and Social Care. Funding delays necessitated the use of short-term staff, such as contractors, which poses a risk to institutional memory and capability development.

This document includes an evaluation of the programme achievements, value for money and lessons learned. The table below summarises the key lessons and provides a cross-reference to the complete recommendations.

Lesson Learned	Recommendation
Funding uncertainty delayed progress and undermined planning.	Move to multi-year funding cycles to support long-term planning and sustainability. (R1.1.1)
Information Governance is complex and subject to interpretation across many data controllers (recognising there is a data controller for each care provider in England). This risks delays in negotiating Data Sharing Agreements which could cause ongoing delays in the ability to scale the services.	Review Information Governance approval processes and/or introduce enabling legislation to accelerate data sharing. (R1.3.2)
Large recruitment is possible: Recruitment of 1.6m patients to participate in trials has been achieved	Consider incentivising research projects contingent on using the services established Define clear, consistent KPIs that drive use and adoption of the DigiTrials service Harmonise canonical data models to maximise screening, randomisation, feasibility, recruitment, follow-up and ROI (R2.1.1)
Benefits were originally far-reaching and linked to downstream activity such as research findings. Work has been done recently to review, revise and	Support the new benefits framework, with measurable, attributable statements, standard templates and a

Lesson Learned	Recommendation
update the benefits strategy and framework	dedicated benefits network to support SDEs and central teams. (R4.2.2)
Be mindful of the tension between public benefit and commercial interests.	Establish the strategy for managing the commercials & benefits - ensuring a truly balanced approach (R4.8.1)
Strong Engagement Success: Public engagement was a standout achievement with thousands of participants involved in deliberations and governance roles.	Maintain PPIE as a core principle in all future programmes and embed PPIE across governance levels. Include patient/public representatives in programme, regional, and project governance structures. (R5.1.1) Expand outreach and inclusion strategies to ensure underrepresented groups are represented (R5.3.1)

Despite the challenges faced by the Programme, individuals interviewed remain committed to the ongoing success and the potential for even greater impact in the future. They are inspired to play their part in identifying new discoveries, treatments, and practices to improve healthcare and health outcomes for people in the United Kingdom.

2 Programme vision and scope

2.1 Vision

"By 2025, our vision is to have a world-leading NHS-wide health data research infrastructure that enhances patient care, sustains the NHS, and supports innovation, while benefiting the economy through attracting life sciences to work in the UK. Our investments will support an efficient and resilient innovation ecosystem, ensuring rapid access to best-in-class data-enabled care improvements that will prevent, diagnose, and treat our biggest healthcare challenges, with benefits across multiple sectors."

2.2 Scope

1. Develop an England-wide ecosystem of NHS-owned and managed infrastructure to allow researchers access to secure, high-quality, linked datasets.
    a. Expanding the scope, capacity and capability of an England-wide national health data infrastructure platform
    b. Developing a network of sub-national/regional linked NHS health data infrastructure platforms and services
2. Increase clinical trials capacity and capability by driving trial set up efficiencies
3. Enable researchers to access a range of linkage-enriched genomics datasets from linked sources
4. Generate returns to the NHS by attracting life sciences investment and applying commercial principles
5. Enhance positive patient and public support

3 Evaluation methodology

3.1 Purpose

As is common with all Government Major Projects Portfolio initiatives, the Data for R&D Programme was subject to the Gateway review process. The final one of these, Gateway 5, took place in November 2025 and has reported its findings. This Programme Evaluation is intended to complement that review, with additional emphasis on identifying lessons learned and recommendations. This Programme Evaluation assesses why the Programme was initiated, what it intended to deliver, and whether it delivered value for money.

The Programme is in the process of closing down as a Government Major Project Portfolio (GMPP) initiative. A new GovCo, the Health Data Research Service[3] (HDRS) is being established. This is a UK-wide initiative designed to provide a single, secure, and coordinated gateway for researchers to access health and care data from across the country. It aims to simplify and speed up research into diseases and treatments by allowing approved users to access data from the NHS and other sources in a secure environment[4].

3.2 Scope

We sought feedback from a wide range of stakeholders to identify achievements, lessons learned and hear their recommendations for the future. We also assessed whether the programme delivered value for money.

We were asked to identify lessons learned and recommendations from this evaluation that may inform the mobilisation of the HDRS during its work to establish the UK's national institute for health data science which unites data across England, Wales, Scotland and Northern Ireland.

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[3] https://www.gov.uk/government/news/prime-minister-turbocharges-medical-research

[4] https://www.england.nhs.uk/blog/health-data-research-service-unlocking-the-potential-of-health-and-care-data-to-transform-lives/#:~:text=The%20Health%20Data%20Research%20Service%20(HDRS)%20is,researchers%20can%20access%20linked%20data%20more%20quickly.

3.3 Methodology

We followed HM Government's Magenta Book[5] guidelines, which assess the efficiency and effectiveness of programmes and projects. This provides a holistic assessment of the Programme, enabling us to examine why it was established, what it has achieved and how effectively and efficiently it was delivered. We assessed whether the programme delivered:

- The impact that was planned – by comparing the scope of the programme with the achievements delivered to date, identifying lessons learned and making recommendations for the future
- Value for Money – assessing whether the benefits outweigh the costs and whether the planned change remains an effective use of resources.

To carry out this review we:

- Agreed a list of 40+ stakeholders, identified in collaboration with the Data for R&D programme team, who were invited to participate by the Programme SRO. A copy of the invitation is included as Appendix B.
- Met with 37 stakeholders in small groups or one-to-one interviews. The stakeholders represented the breadth of the programme from SDE service providers and technical teams to patient representatives, national delivery teams and members of the programme team. Appendix A sets out the breakdown of contributors.
- Utilised a standard interview framework which is set out in Appendix C. Following each interview, we sent summary notes to attendees for their feedback and incorporated their feedback in the notes. The interviews are non-attributable, and all findings are summarised to represent the general themes
- Reviewed key programme documentation that had been previously collated for the Gateway 5 review. This included the Business Case and Addendums, the Gateway 5 Report, Case Studies and Audit reports.

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5 https://assets.publishing.service.gov.uk/media/5e96cab9d3bf7f412b2264b1/HMT_Magenta_Book.pdf

We have structured the report to bring together

- Feedback from interviewees - section 4 (supported by appendices A-C)
- Value for money assessment – section 5 (supported by appendix D-F)
- A consolidated list of lessons learned and recommendations – section 6 (supported by appendix H and separate excel spreadsheet).

4 Operational achievements

4.1 Context alongside Gateway 5 review

This Programme Evaluation was conducted following the development and publication of the Gateway 5 report. This evaluation is intended to be read in conjunction with the Data for R&D Gateway 5 review and does not seek to repeat in detail the findings from that review.

For context, the Data for R&D programme Gate 5 assessment was Amber:

"Successful delivery of the programme/project to time, cost and quality appears feasible but significant issues already exist requiring management attention. These appear resolvable at this stage and, if addressed promptly, should not present a cost/schedule overrun."

The Gateway 5 assessment noted that *"the significant progress made towards the overall objectives despite the challenging environment and highlights, in particular the solid foundation on which to build."*

The programme was established in 2022 with Gateway reviews in 2023 (Red) and 2024 (Amber). Over this period, there have been six changes to the Secretary of State for Health & Social Care across four distinct UK Governments. With each Government, there was a renewed commitment to the vision of making health and care data available at scale for research. Additional funding was secured in 2025/6 and, following the Sudlow review, a new GovCo called the Health Data Research Service will be formed in 2026.

Several interviewees described the three-year programme as 'three 1-year funded programmes', and this lack of financial stability created overhead costs, leading to the recruitment of short-term and/or temporary workers.

The successes of this programme should be attributed to the dedication and commitment of people across the network, through their collaboration in the Communities of Practice and their resilience in upholding the vision and scope whilst facing significant and ongoing disruption.

4.2 Programme Evaluation - Delivery of the scope and challenges

The Programme has partially met its objectives. Interviewees acknowledge the original scope was ambitious and broad. It encompassed the establishment of new infrastructure to support a wide range of healthcare research, clinical trials and genomics research, alongside conducting significant public and patient engagement.

Interviewees noted that each research project has unique requirements. There are a broad range of research activities taking place hosted by the SDEs. These range from discovery science through translational to clinical trials and regulatory approval. Each research project requires a unique combination of data sourced from within the NHS and is sometimes integrated with other data sources. The NHS data needs to be curated and transformed to make it ready for research. We mapped the original scope alongside feedback from stakeholder interviews. We reviewed key documents and have set out the key achievements and identified the challenges and opportunities raised. These are in the tables below.

4.2.1 England-wide ecosystem of NHS-owned and managed infrastructure

The key achievement of the Programme was the creation of an England-wide network of NHS-owned and managed infrastructure. A network of NHS-owned and managed SDEs is now in place. This includes eleven regional SDEs, complemented by England's national SDE and the NHS DigiTrials service. Collectively, they form the foundation of an England-wide network designed to provide secure access to high-quality, linked datasets for research.

- The scope, capacity and capability of an England-wide national health data infrastructure platform have been expanded because of this programme
- A network of sub-national/regional linked NHS health data infrastructure platforms and services has been developed

The Programme was necessarily ambitious but not set up to recognise the experimental nature of the work that would need to be done initially.

The Information Governance (IG) and basis for sharing data across NHS Trusts and other public bodies is currently negotiated on a case-by-case basis, because each organisation that collects this data for care is a data controller. This takes time to agree and to have the relevant risk assessments considered. There is emerging consensus that further work is needed to address this problem and find a single consistent approach that can support scaling the data available for research. Data quality varies, and preparing data for research requires an in-depth understanding of the data and its collection in the care setting. It is widely recognised that there is a role for regional SDEs as the processes of securing and interpreting data involve a network of human relationships and technical systems.

The regional autonomy has enabled innovation. This has delivered three service-delivery patterns and potentially reduced the risk of vendor lock-in, especially within the technical platforms. However, inconsistencies and variations have emerged across service operating models, capabilities, and processes, including IG and data onboarding.

How it's working	Opportunities & Challenges
The network is operational but uneven: Interviewees have reflected that different SDEs are at varying levels of maturity, with some more advanced in data linkage, service operations, and technical capabilities. "Federation" across the network is also taking place. Stakeholders recognise the progress but also acknowledge that the system is still developing towards consistent national coverage. Data completeness varies—some areas have established pipelines and negotiated data sharing agreements across their network; others remain in development. "Information Governance" is being used as an umbrella term covering legislative, policy, ethical and public-involvement requirements. The complexity of current data-controllership arrangements, where thousands of independent controllers hold decision-making authority, was raised repeatedly. Some SDEs negotiate approvals on a project-by-project basis, while others have established broader agreements covering multiple uses. Both approaches are resource-intensive and unsustainable at scale. Interviewees also noted that agreements may need to be revisited as operating models evolve, such as during moves toward greater federation.	Funding uncertainty has repeatedly disrupted delivery, diverting effort toward mitigation rather than strategic development. Stable, predictable funding remains a major opportunity to support long-term planning and build sustainable capability across the SDE Network. The term "federated" data is being used inconsistently—ranging from single sign-on to code sharing to multi-site linkage—creating ambiguity about expectations and slowing alignment on technical and governance models. "Information Governance" and data-sharing arrangements are highly complex and fragmented, requiring agreements with large numbers of independent data controllers. This complexity continues to make delivery at scale slow, repetitive, and difficult to sustain. A more coherent and consistent legal/IG framework would enable faster data flows while maintaining public trust. Accessing and preparing research-ready, multi-modal NHS data remains slow and resource-intensive due to the scale and diversity of underlying clinical systems. Common engineering approaches and shared extraction patterns could accelerate data curation and improve consistency across regions. Variation in SDE maturity leads to inconsistent onboarding timelines, interoperability challenges, and uneven researcher experience. Differences in technical platforms, workflows, and accreditation further compound this, limiting the ability to deliver a reliable and a coherent national service. Strengthening and standardising workflows, data pipelines, accreditation, and IG processes across the network represents a major opportunity to raise the maturity floor, improve consistency, and create the conditions for innovation at scale.

4.2.2 Increase clinical trials capacity and capability

This objective was set to increase clinical trials capacity and capability by driving trial setup efficiencies. The NHS DigiTrials service has developed a national-scale capability that has already registered +1.6 million consenting participants[6] willing to participate in clinical trials. This capability has supported the delivery of major priority trials, including high-profile studies such as RECOVERY and NHS-Galleri, demonstrating that large-scale, digitally enabled recruitment is possible.

Trials take many years to be set up and to deliver. Anecdotal evidence was presented to illustrate this point: clinical trial recruitment commenced in 2007, and publication concluded in 2024. With long lead-times such as these, it is essential that capacity and capability is embedded within a programme to ensure progress can be made.

However, interviewees noted that the Programme did not sufficiently appreciate the complexity of clinical trials, including regulatory burdens, recruitment, feasibility workflows, and timelines. Some interviewees view the introduction of expertise as far too late, citing June 2024, when two-thirds of the programme had already passed. Additionally, a trial strategy was produced by February 2025, but the governance structures were not configured to prioritise trials and some view that focus on meeting this objective has stalled. Engagement with key stakeholders should continue; in particular, researchers running clinical trials should be included as domain representatives in relevant programme boards.

[6] Ref https://digital.nhs.uk/services/nhs-digitrials accessed January 2026

How it's working	Opportunities & Challenges
The programme is showing strong momentum, with digital recruitment proving to be faster and more efficient than traditional trial recruitment methods. Integration of the service into broader NHS platforms (such as the NHS App) is expected to further accelerate reach and participation. Early experience indicates that digitally supported trials can scale rapidly, reduce set-up barriers, and widen access to research opportunities across England.	There is significant potential to improve efficiency across the full clinical trial lifecycle by making better use of linked datasets and automated workflows, although these capabilities are not yet fully realised. Digital recruitment creates opportunities to increase diversity in trial participation, particularly among groups historically under-represented in research. The +1.6M-strong volunteer base represents a substantial opportunity to attract additional commercial and academic trials, strengthening the UK's research offer and long-term return on investment. Not all datasets required for efficient feasibility assessments and follow-up are fully linked or consistently available, limiting the full benefits of data-enabled trials. Embedding digital recruitment pathways more deeply into NHS services and patient touchpoints could further accelerate progress but requires operational alignment and sustained investment. As recruitment activity scales, maintaining public trust remains essential; continued transparency, communication and robust oversight are necessary to sustain confidence in data-enabled trial methods.

4.2.3 A range of linkage-enriched genomics datasets from linked sources

This objective was to enable researchers to access a range of genomics datasets from linked sources, including globally significant assets held at UK Biobank and Genomics England. Three SDEs: Thames Valley and Surrey, West Midlands and Wessex are part of the Central & South Genomics Medicine Service Alliance service footprint. This has enabled the development of a linked genomic and other clinical phenotype dataset, which is a build-out on the data held by Genomics England as an extension to the 100,000 Whole Genome Sequence programme. The work achieved to date has acted as a catalyst for federated genomic research environments but there is a lack of clarity on data coverage and roadmap.

How it's working	Opportunities & Challenges
The work has created a strong foundation for federated genomic research, showing that joint efforts between SDEs and national genomic programmes can meaningfully expand research-ready datasets. Early integrations demonstrate feasibility and momentum, with SDEs beginning to incorporate phenotype data from multiple care settings and link them securely to genomic records. The collaboration is viewed as a catalyst for future large-scale genomic research environments, even though national-level genomic integration is still emerging.	A clear strategic roadmap is needed to set out what genomic and phenotype data exist today, how coverage will expand, and how researchers can access these datasets consistently. Technical harmonisation remains incomplete. Further alignment to standards such as OMOP and GA4GH is required to enable seamless linkage between genomic and clinical data. Early successes present an opportunity to accelerate adoption, but clearer communication, consistent commercial frameworks, and targeted funding incentives will be required to drive uptake. Larger, more representative sample sizes are still a challenge; achieving them would significantly improve statistical power for precision medicine, rare disease research, and population-level studies. Genomic integration across regions is uneven, with substantial variation in maturity and data availability. Although OMOP conversions have progressed regionally, harmonisation across the wider network is still at an early stage.

4.2.4 Generate returns to the NHS by attracting life sciences investment and applying commercial principles

This objective focused on generating returns to the NHS by attracting life sciences investment and applying commercial principles. Returns to the NHS are being generated by attracting transactional income from commercial researchers, such as the life sciences industry, and applying commercial principles. Commercial frameworks have been developed and shared amongst the network of SDEs. However, interviewees recognised there is a capability gap, and they are at the early stages of maturity. Interviewees identified that contracting will still need to be done through local host organisations as the data controller and the holders of the governance approval to provide access to data (usually under a Section 251 exemption).

One consistent recommendation for HDRS is to establish a single “front door” for contracting and commercial approaches. This would be a route to offer customers streamlined access to the network of SDE services and to manage the pipeline of requests and the coordination of pricing and proposals. This should ensure users are directed to the most appropriate services. If centralised commercial support is considered, it is important to retain connectivity with commercial leads. These teams are embedded in each SDE, have access to that local network along with access to clinical and research expertise that ensures the clinical context for the data provided is not lost. Each SDE needs autonomy to set project prices as the underlying costs vary. This ability would be lost if all the commercial work is done centrally

The Programme is in the process of updating its approach to tracking benefits, as the Gateway 5 review noted; it is not complete, and there is still significant work to do to implement a full tracking approach.

How it's working	Opportunities & Challenges
The commercial activity is emerging, with SDEs beginning to secure income through paid-for research collaborations. The existence of shared frameworks has helped move the system towards greater consistency, though implementation varies across regions. Commercial engagement is becoming more structured, but the ecosystem remains distributed, which can make it harder for external partners to navigate.	Balancing public benefit with commercial return continues to present a structural tension, requiring clear principles, transparent governance, and consistent decision-making across the network. Creating a single, coherent "front door" for commercial engagement remains a significant opportunity. It would simplify navigation for external partners, improve coordination of proposals, pricing and contracting, and help direct commercial enquiries to the most appropriate SDE capabilities—strengthening the UK's overall offer to industry. A unified commercial approach could also support better forecasting, more consistent revenue tracking, and a fairer distribution of commercial opportunities across regions. Commercial capability and capacity vary widely across the Network, with key-person dependency identified as a risk in several regions. Financial returns differ substantially by research area and SDE maturity. This variability makes it difficult to build a stable, long-term sustainability model for SDE services. A more holistic commercial model, combining shared processes, a single front door, common data catalogues, and coordinated commercial functions, could mitigate these disparities, support cross-subsidy where appropriate, strengthen capability, and create a clearer pathway toward long-term sustainability.

4.2.5 Enhance positive patient and public support

There has been significant engagement of the patient and public over the course of the Programme and those interviewed highlight the positive impact that has had on the programme. The investment in securing support through patient and public involvement and engagement was seen by many as essential to the Programme's success. The Programme needed broad public support for the concept of sharing real-world health data safely, securely, proportionately, whilst maintaining privacy with researchers. The concept of sharing data is accepted (among those consulted, such as PPIE panel attendees) if it does not leave the NHS. The public's participation in governance committees, such as Data Access Committees, has ensured transparency and accountability in research projects.

The Gateway 5 report commends the programme's engagement with patients and the public as one of its standout achievements. As noted by the Gateway 5 report, the Lessons Learned, the programme's approach to PPIE should be fully captured and communicated to the HDRS Set up Team and more widely. It is recognised that this work needs to continue, and patient / public representatives need to be across the governance levels.

How it is working	Opportunities & Challenges
Engagement has become an embedded and valued part of how the Programme operates, with public representatives already contributing to governance committees and advisory groups. The Programme has built strong foundations for continued involvement, but the maturity and consistency of engagement still vary across regions.	Ensuring patient and public representatives participate across all levels of governance remains essential for maintaining trust, legitimacy and transparency, but doing so consistently across regions is challenging. Sustaining meaningful involvement is resource-intensive, and short-term funding cycles and operational pressures risk reducing continuity and depth of engagement. Expectations and practices for PPIE vary across the Network; creating a clearer, more consistent framework, while still allowing for local flexibility, would support a more coherent experience for contributors and users. Engagement must be continuous rather than episodic; maintaining long-term involvement is crucial to sustaining public confidence in the responsible use of health and care data. Achieving diverse and inclusive representation remains a persistent challenge, as reaching under-represented or seldom-heard groups requires targeted effort, tailored approaches and sustained investment. Ensuring diverse representation, reaching groups who are under-represented or seldom heard, requires ongoing effort and investment.

5 Value for money assessment

In reviewing the Data for R&D Programme for the value it has delivered against expectations the following has been assessed:

- The amount of funding received, how this compared to the original intent and how it has been spent.
- The delivery against expected achievements set out in the Programme Business Case.
- The progress against the original benefits set out.

When looking at the Value for Money of a project or programme it is considered best practice to focus on the “4 Es" (Economy, Efficiency, Effectiveness and Equity):

- Economy: Is the programme buying inputs (resources, staff) at the best price
- Efficiency: Is the programme converting inputs into outputs (services delivered) with minimal waste
- Effectiveness: Are the outputs delivering the intended outcomes (impacts)
- Equity: Is the allocation of benefits fair across the ecosystem (or will it be)

We have therefore set the highlights of our findings out against these areas. A more detailed review is included in Appendix D.

The Programme has delivered substantial enabling infrastructure and momentum despite funding and structural constraints, but achieving long term value for money will depend on strengthening cost control, performance management, benefits capture and fair distribution across the ecosystem.

The key value for money lessons learned and recommendations are covered in section 6 below.

5.1 Economy – how well the programme buys inputs

The Programme has broadly lived within its funding envelope but has not optimised inputs due to structural constraints. Over 2022/23–2024/25, it secured £206M against an original £175M approval (reduced from the original ask of £200M in the business case), with an additional £81M for 2025/26 taking total funding to around £290M (this includes c£19M of non-core pass through funding). An average underspend of approximately £5M a year reflects delayed approvals, annual stop–

start releases of funding and capital and revenue budgets not aligning to actual programme needs rather than cost reduction.

Central programme spend follows NHS commercial guidance, but despite an agreed three-year programme of funding, repeated one-year settlements and programme “end dates” have made it hard to recruit permanent staff, driving reliance on short-term resource, which is inherently more expensive than a substantive workforce. Going forward creating a stable environment where suitably capable permanent resources can be onboarded swiftly and retained effectively will be critical to long term economically effective delivery.

At the regional level, SDEs are embedded in host NHS Trusts, ICBs or Health Innovation Networks and Programme funding is a contribution to wider costs; this means there is no clean, standalone view of the total cost of SDEs available to the Programme. This is exacerbated by the fact that the SDEs are all independent of the Programme, their governance chains run through their host bodies, and there is no central power to mandate activities or require access to information.

Across the SDE Network, there are high costs which have to be met for access to data from third-party systems providers despite the underpinning work being undertaken under central frameworks contracts, which should include this access in the requirements.

5.2 Efficiency – turning inputs into services with minimal waste

Despite funding instability, the programme has built out the core research infrastructure and supporting functions, but efficiency is weakened by fragmented structures and immature performance management. Central funding has created:

- A research ecosystem, comprising of the NHSE SDE, regional SDEs, and NHS DigiTrials,
- Public trust and engagement in the governance through e.g. data access committees and a programme of national public deliberations,
- Defined operating models,

However, loosely federated delivery, variable maturity, and limited central leverage over SDEs, due to their independent structuring and governance, means the Data for

R&D Programme team cannot easily standardise processes or mandate consistent reporting, leading to inefficiencies. Additionally, the lack of linked or centralised systems, particularly a customer relationship management system (CRM), means that providing data for reporting is resource intensive, even with some SDEs having suitable stand-alone tools. The ongoing discovery of the complexities of providing the services and the differing levels of SDE maturity have made these activities difficult until now but the overall programme is now at a point where the benefits outweigh the effort of implementation.

The Programme has recognised these weaknesses and is acting by:

- Introducing “Baseline” run and maintain vs “Transform” investment and change funding categories so transformation projects can be actively managed
- Building account management for SDEs
- Starting work on agreements that strengthen reporting obligations
- Exploring standardised business systems; and
- Commissioning a comprehensive performance management framework

These steps are necessary to reduce waste, improve visibility and support targeted interventions.

5.3 Effectiveness – are outputs delivering intended outcomes

The Programme has made tangible progress on strategic objectives but is more effective as a foundational enabler than as a direct deliverer of end outcomes. The original PBC forecast around £1.7Bn of quantified benefits over ten years, revised to £1.4Bn after funding changes and then to £1.6Bn as delivery expectations evolved. However, these benefits were largely framed as long run, system level impacts (e.g. changes to disease areas such as cancer outcomes, cardio-vascular disease or operational improvements such as imaging efficiency or growth outcomes such as the life sciences use of real-world data). While it is the programme’s direct role to provide infrastructure and services that enable others to deliver those benefits. This review has found:

Benefits were included for which the data and services provided are only early "enablers", preventing control over delivery and making attribution and measurement difficult.

The only clearly attributable direct benefit to date is SDE income, which is being measured but needs validation and richer data from SDEs.

Other real benefits – productivity gains, process improvements, reduced duplication, regional standardisation – exist but are not fully documented, although remedial work is underway following an internal review.

Governance, standardisation and support for benefits management are incomplete.

At the same time, substantive outputs have been achieved:

- The SDE Network now exists, covering the whole population of England
- Over 5,700 people have been engaged through PPIE
- There is a coherent commercial framework and pricing structure that is conceptually agreed but not consistently applied across all SDEs
- Standardised templates for key documents and processes are in development, but this is still a work in progress.
- There is aggregated Profit & Loss monitoring for the programme (but not at local level on an individual SDE basis.)

There is breakeven modelling showing a credible but challenging pathway to covering operating costs by 2027/28, with risk-adjusted revenues for the current pipeline forecast at around £10m (not all delivered in 25/26).

These outputs match the programme's role as a foundational platform, which will support many downstream improvements in health outcomes or operational efficiencies even if these are not yet visible or attributable.

5.4 Equity – fairness of benefits across the ecosystem

Equity is emerging positively but remains incomplete. The Programme's design and delivery explicitly sought to level up the research data landscape by funding 11 regional SDEs, and the national SDE (England), creating England-wide coverage and reducing historic concentration of data infrastructure in a few centres. Funding

flows have supported a broad mix of regions, and SDEs typically sit within NHS Trusts that serve varied populations, including more deprived areas.

Public and patient benefit has been a central emphasis: significant investment in PPIE, including examples like West Midlands allocating about 10% of its budget to engagement; national public deliberations; local PPIE in SDE design; and development of communities of practice around PPIE, IG and communications. Data use registers across all SDEs are intended to improve transparency about who benefits from access.

However, some risks remain:

- Variation in SDE maturity and local capacity means that some regions are currently better able to exploit the Network's opportunities than others.
- Genomics, imaging and complex multimodal datasets have not yet been integrated at the scale originally envisaged, limiting equitable access to cutting-edge capabilities. There are examples of the use of integrated datasets that include genomic, imaging and hospital data, for example, the GEL Driver Project, which onboarded radiology and pathology image data that was then linked to clinical data and genomics profiles to support the training of deep learning models for cancer diagnoses and therapy.
- Commercial arrangements and revenue opportunities may cluster around more advanced SDEs unless pipeline management and governance deliberately support equal distribution.

5.5 Summary

Overall, the Programme shows reasonable levels of economy under difficult conditions, improving levels of efficiency, strong effectiveness as an enabler (rather than an outcomes engine), and promising but incomplete equity potential.

Strengthening financial transparency, performance and benefits management, along with developing a collaborative and equitable operating model design under HDRS will be crucial to locking in value for money.

6 Lessons learned and recommendations

Through the interviews and value for money assessment a series of lessons learned and recommendations have been identified. These are brought together below and are available in the supporting Excel document. They are categorised as follows:

- Grouped by the relevant area of scope originally defined in 2022
- Contain at least one recommendation
- Mapped to the Gateway 5 themes
- Recommendations are numbered and themed
- An impact and deliverability assessment has been undertaken

This should mean that the lessons learned and recommendations from both reviews can be consolidated.

6.1 Objective 1: Provide a network of NHS-Owned and Managed Infrastructure

The interviewees identified that it is essential to maintain momentum, address the stop/start funding and ensure that all SDEs arrive at comparable service standards, functionality and features to offer researchers a consistent capability and user experience. The challenge of Information Governance was mentioned frequently as it is seen as a significant barrier to scaling the services.

Lesson Learned	Recommendation
Funding uncertainty delayed progress and undermined planning.	Move to multi-year funding cycles to support long-term planning and sustainability.
Federation & Fragmentation: Regional autonomy enabled innovation but created inconsistencies in operating models, processes, governance, data linkage and technical standards.	Review Information Governance approval processes and consider introducing enabling legislation to accelerate data sharing.
	Develop workforce capability: hiring to substantive posts (assuming there is a move to multi-year funding)
	Define the requirement for a single "Front Door" for governing the service Continue to work towards process standards by defining the operating frameworks (to allow appropriate variation and handoffs) Take a User Experience-design-led approach to define the consistent service user experience across providers
	Define data coverage goals and onboarding timelines and track progress to deliver consistent and comprehensive data sets for all regions
	Establish benefits tracking and reporting from the outset
	Continue the work on identifying successful operating models and blueprint(s) to establish technical and service standards These blueprints become the method to assess progress and work towards the reduction of unnecessary diversification for the future

Lesson Learned	Recommendation
	Retain the ability to innovate around a core service in response to researcher demand and the introduction of datasets
	Define clear, consistent service KPIs and review no less than annually
	Define roles and accountabilities for every stakeholder to reduce risks of overlap or gaps (include in scope the national bodies such as to HDR UK, HDRS, NIHR avoid confusion)
	Define federation and its principles (while resisting an over-centralised “command and control” approach). Establish clear governance with accountabilities, service standards, risk appetite, and reporting enforced. Continue the work to define "Lead SDEs" or "Specialised" SDEs that could be aligned to key functions and/or data. Incentivise alignment to common standards. Linked to accountabilities - ensure the roles of the National SDE (NHS England) and Regional SDEs are clearly defined to reduce the risk of overlap or gaps developing
Communities of Practice resulted in improved collaboration, governance alignment, and stakeholder confidence, helping to share knowledge and expertise	Maintain Communities of Practice for knowledge sharing, capability building & collaboration
Working with Researchers has ensured services are fit for purpose.	Continue to engage with the research community to identify the priority datasets that are required. Continue to offer research funding to target research to particular areas of benefit (e.g. aligned to research agenda/health outcomes) or functionality (NHS DigiTrials to improve capacity
Integration of Primary Care Data, Mental Health Data, Community Health data: There is limited availability of GP, community and	Prioritise integration of additional data sets including primary care, community and mental health datasets. Recognising there are dependencies on securing data sharing agreements with a large number of data controllers and/or changes to legislation

Lesson Learned	Recommendation
mental health data, which risks diminishing the opportunity for research	
Frequently changing reporting requirements consumed significant effort and restricted ability to streamline (automate)	Implement the performance framework and MI tooling so that central and regional teams share a single view of activity, cost and performance, reducing duplication and manual reporting. Consult on the requirements (what is feasible and achievable with the data, systems and capability in place today). Ensure a balanced load to deliver insight at a reasonable cost and resource commitment Consider developing a roadmap to review and update reporting requirements incorporating lessons learned on a regular e.g. 6 monthly basis
Technical Standardisation: Data models and standards were developed (using OMOP for example) to enable interoperability across SDEs. 'Federation' and/or 'interoperability' is only partial.	Standardise logical architecture, data models and data access processes across Secure Data Environments (SDEs) where the foundations are now in operation. Document the patterns (blueprints) that work and share across the network of SDEs
	Continue to implement the requirements for federation and interoperability (working with researchers to ensure fitness for research leveraging genomic data and image data where required).

6.2 Objective 2: Clinical Trials Capacity and Capability

Clinical Trials have significantly lengthy timelines. Ensuring the right representation in the governance groups. The requirements of the necessary clinical trials infrastructure should be considered early on in any significant programmes.

Lesson Learned	Recommendation
Large recruitment is possible: Recruitment of 1.6M people to participate in prospective research projects (including trials) has been achieved	Offer research funding contingent on using the NHS DigiTrials service Define clear, consistent KPIs that drive use and adoption of the NHS DigiTrials service Harmonise canonical data models to maximise screening, randomisation, feasibility, recruitment, follow-up and ROI Support recruitment via clinical teams as well as direct to potential participants
Clinical trials expertise is essential to embed as early as possible	Maintain Clinical trials expertise at national level
There is no unified search tool across SDEs to identify eligible patient cohorts for feasibility or recruitment	Develop a national cohort discovery layer - essential for trials but also beneficial to all research.
Governance complexity and IG delays hindered trial onboarding.	Review the IG and governance pathways to ensure they can support large scale clinical trials with 3rd parties without undue delays incurred in approvals processes
Lack of user involvement in trial service design.	Embed academic and commercial user representatives in trial service governance and design.
Multi-region trials need consistent governance, data flows, and recruitment processes	Standardise trial-related workflows across SDEs

6.3 Objective 3: Genomic Datasets

Interviewees offered limited feedback on the achievements delivered in this area of the scope. For completeness, the lessons learned and recommendations received are set out in the table below.

Lesson Learned	Recommendation
While there is growing demand from researchers to link SDE data with UK Biobank and Genomics England, it's difficult to understand what data is available	Considering developing a strategic roadmap to provide clarity on genomic and phenotype data coverage and availability. Drive adoption of the service through combination of blueprints, incentives / research grant funding and commercial agreements Monitor the use and adoption of the service through defined KPI
Technical Harmonisation: OMOP harmonisation was achieved regionally, but genomic integration lagged.	Agree scope and requirements for technical and data requirements e.g. link phenotype-genotype data using harmonised standards (OMOP + GA4GH). Work with relevant researchers to develop appropriate datasets/technical services Monitor adoption and use of the services with relevant KPIs

6.4 Objective 4: Fair financial returns to the NHS

Commercial Frameworks have been designed but it's recognised that more work needs to be done to establish consistent approaches and a mature service offering to the market of Academic and Commercial researchers and their organisations.

Lesson Learned	Recommendation
Value for Money - Economy	Support greater consideration of the needs of the SDE Network being integrated into centrally supported contracts (Frameworks and large IT services) with Third Party suppliers.
	Define the purpose and use of all management information (MI) so SDEs understand why spend and activity data are needed and how they will support improvement. Continue to automate the reporting of MI, increasing transparency and reducing the reporting load.
	Continue and deepen work to increase transparency of regional spend, including more precise requirements in future funding agreements and better systems (e.g. common Customer Relationship Management system /finance Management Information to track expenditure.
Value for Money - Effectiveness	Increase the levels of commercial capacity across the network and develop shared capability. Continue work on standardisation of templates and processes, including pricing, to support equality of opportunity and returns for SDEs and speed and consistency in pricing across use cases for customers.
	Support the new benefits framework, with measurable, attributable statements, standard templates and a dedicated benefits network to support SDEs and central teams.
	Continue to reframe programme benefits around what the programme directly controls (rather than long-run clinical outcomes: - data volumes, accessibility, quality and timeliness; - network maturity; - user uptake; - income; - process improvements; and - support to priority use cases and enabling new areas of research

Lesson Learned	Recommendation
	Recognise that outcomes such as improved cancer or dementia care will be realised primarily through research and service partners acting on the findings of research and judge the Programme's effectiveness on the quality and uptake of the infrastructure and data assets it provides to support this work.
	Work with the Network to develop more detailed financial reporting geared towards demonstrating long sustainability.
Value for Money - Efficiency	Continue to formalise "Baseline" run and maintain vs "Transform" funding and manage the latter as discrete, outcome- based projects with clearer milestones and accountabilities.
	Design operating and funding models around a "central coordination plus commissioned local delivery" reality, using performance, support and peer pressure rather than only top-down directives to improve efficiency.
Value for Money - Equity	Design commercial and investment approaches that avoid reinforcing existing advantages, for example by earmarking some funding and support to bring lower maturity regions and data types (e.g. imaging and genomics) up to a common baseline.
	Keep equity and balance – regional, demographic and by disease area – explicit in future benefits and performance frameworks, including metrics for project distribution, dataset coverage and inclusion of underserved populations.
Commercial Frameworks: Revenue generation is emerging, but coordination is weak (lack of standardised commercial approach & capability) and dispersed across the network.	Introduce shared visibility of commercial opportunities (pipeline) and balance public benefit with commercial interests. Continue to adopt a single commercial framework, pricing models and associated processes, ensuring these are used in all service providers across the network of SDEs
Benefits realisation was premature given significant levels of theoretical potential benefits were assumed to be delivered within the first three years when the reality is they will take 10 years to realise.	Build on the new benefits strategy, linking to actual activities being supported, reviewed and updated on a 6-monthly basis Consider using categories when tracking benefits (Created, Enabled, Influenced) to reduce the risk of double-counting benefits and reflect the Programmes role. If needed, update the Theory of Change approach to reflect multistage approach to delivery for enabled and influenced benefits.
Benefits Realisation: Original benefits were overstated and remain backloaded.	Define and communicate clear principles for balancing public benefit with commercial returns.

Lesson Learned	Recommendation
Be mindful of the tension between public benefit and commercial interests.	Establish the strategy for managing the commercials & benefits - ensuring a truly balanced approach

6.5 Objective 5: Patient and Public Support

Interviewees noted the significant effort was invested in patient and public engagement. This has been successful in improving the public's understanding of why access to healthcare data is necessary for the future. As with other aspects of the Programme, the recommendations below highlight the ongoing need to engage with the public. It is suggested that public representatives should be included at all layers of the governance structures. There are also recommendations to standardise PPIE practices and expand outreach and inclusion, so England's diverse population is represented fairly across this programme.

Lesson Learned	Recommendation
Strong Engagement Success: Public engagement was a standout achievement with thousands of participants involved in deliberations and governance roles.	Maintain PPIE as a core principle in all future programmes and embed PPIE across governance levels. Include patient/public representatives in programme, regional, and project governance structures.
Trust and transparency are critical for public confidence in data sharing. High public trust achieved through transparency and inclusion.	Ensure clear communication about data use and governance safeguards; keep NHS involvement visible.
Diverse Representation: Need to scale engagement among diverse communities.	Expand outreach and inclusion strategies to ensure underrepresented groups are represented
Short-term funding cycles undermined continuity of engagement efforts.	Secure stable funding and long-term planning for PPIE activities to sustain momentum.
The commitment to PPIE is a core continuing element of the programme. Representation in governance structures is essential for legitimacy and accountability.	Ensure the lessons learned from the Programme's approach to PPIE are fully captured in the evaluation of the programme and communicated to the DHSC-led HDRS Set Up Team, and more widely.
Consistency in Practices: Engagement varied across regions.	Clarify roles and responsibilities of all PPIE groups across the network. Foster collaboration between national and regional teams, sharing best practice to ensure a consistent approach, messaging so as to amplify the work
	Develop a national framework to standardise PPIE practices while allowing local flexibility, so all SDEs can engage their communities effectively and consistently. Communicate clearly about data use and governance safeguards; keep NHS involvement visible.
There is inconsistent documentation and sharing of insights from PPIE activity across the Network, resulting in valuable learning being lost, uneven transparency, and limited ability for SDEs and national teams to build on one another's engagement work.	Ensure that insights and learning from PPIE activity is written up and, wherever possible, published for transparency

6.6 Programme Delivery and Gateway 5 Review

The Data for R&D Programme is anticipated to move from programme management controls to be delivered as an ongoing service led through a newly formed GovCo, the Health Data Research Service. It is appropriate to review the current governance and controls to ensure they are fit for purpose. Many interviewees commented that the roles and accountabilities for all stakeholder groups need to be reviewed to ensure there is no overlap or confusion. Future governance should clarify accountability between central and regional teams to avoid ambiguity.

The Gateway 5 review has identified that programme governance and reporting has improved over the course of the Programme. It is difficult with a national programme enabled by regional teams to strike the right balance. But there needs to be accountability for programme delivery between the central team and their delivery partners: for both delivery and benefits realisation.

7 Conclusion

The Data for Research & Development Programme has overseen the development of the foundations for a network of English Secure Data Environments and DigiTrials service that will form a foundation for England's node of the United Kingdom's Health Data Research Service.

The scope of the Programme was ambitious, and substantial progress has been made despite funding uncertainty and delays. The five objectives of the Programme have been partially met. The original benefits were defined for a 10-year programme, so it is too early to assess these in detail. The technical platforms are delivered, and these are hosting (as of December 2025) 559 research projects.

The Network of SDEs with a regional and national footprint is essential for good support of research projects – the regional footprint means the network of human relationships is in place and the SDEs are close to the point of data collection, they understand the local use of data and the local configuration of the data systems such as Electronic Patient records.

The key lessons and recommendations identified by this review should be considered as part of the close-down of this Programme and used to inform the planning for HDRS and future development of the UK's health data infrastructure.

8 Appendices

Appendix A: Stakeholder contributors

The Data for R&D Programme Evaluation Team would like to thank the individuals who have contributed to the Programme Evaluation.

43 Individuals were identified & invited of which 37 accepted and were interviewed (in 33 interview sessions) representing National Leadership & Policy, SDEs & DigiTrials as well as Researchers.

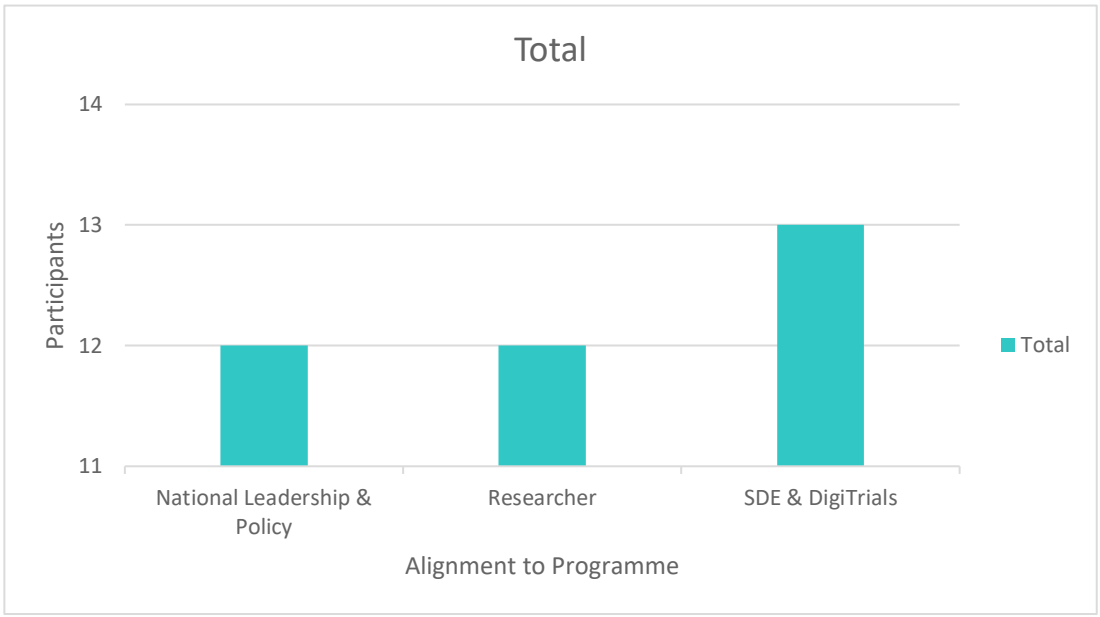


Figure 1 Evaluation Participants

8.1 Observations

While the main body of the evaluation contains weighted insights, extracted lessons learned as well as recommendations, it is still of interest to consider the very subjective nature of what interviewees spent the majority of time discussing. Interviews were deliberately open (while ensuring there was sufficient coverage across questions for the appropriate interviewees) meaning the interview flow was largely down to the interviewee to control.

The conversations tended to focus on the achievements linked to:

- Delivery of infrastructure

- Development of capacity and capability of the SDEs,
- The foundations to support future clinical trials
- Engagement with patients and the public

The discussions focused less on the objectives linked to the development of genomic datasets and the delivery of fair financial return to the NHS.

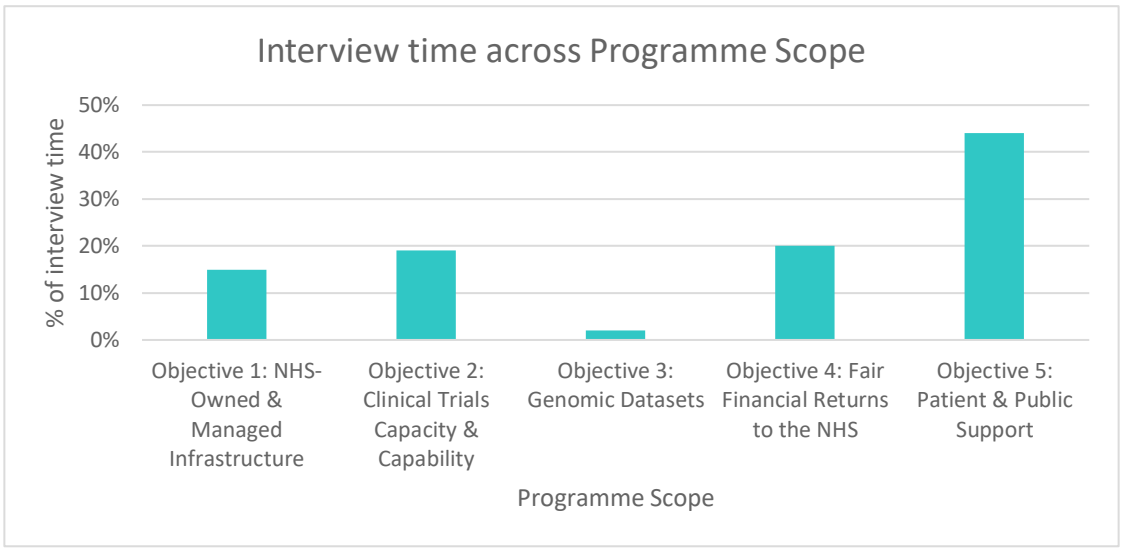


Figure 2: Analysis of transcripts aligned to scope of the programme

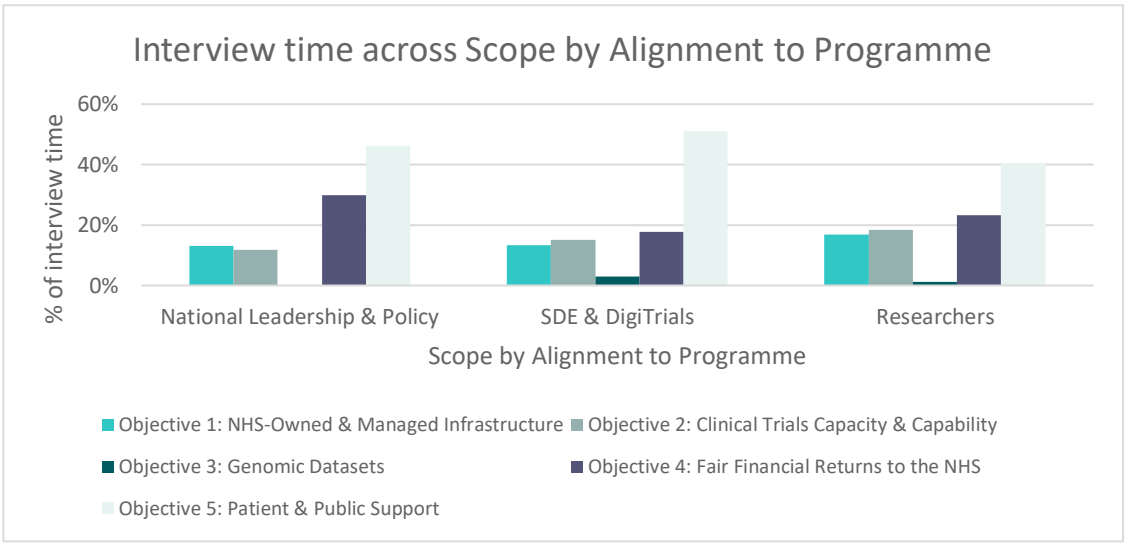


Figure 3: Time spent during interview per Objective by role in the programme

Appendix B: Invitation to participate from SRO

The following text was sent via from the Data for R&D Programme SRO to potential participants in this Programme Evaluation:

We have commissioned an independent review of the Data for R&D programme, and I am writing to invite you to participate in that review. Starlight Consulting has been commissioned to do this work. This will accompany our recent Gateway 5 review, which was a requirement to close down our status as a Government Major Project Portfolio (GMPP). We believe it's important for this independent assessment to focus on lessons learned and benefits to help the transition to Health Data Research Service (HDRS) and to inform the scale-up of services.

The review is a key opportunity to test whether the programme delivered on its strategic objectives, realised the intended benefits and is set up for a sustainable future, including its role as the foundation for the Health Data Research Service. Your insight and experience as a stakeholder in the programme are critical to providing a balanced, evidence-based view of what is working well and where further focus is needed.

Over the coming weeks, the review team will be arranging a series of structured interviews and small group sessions with partners across the SDE Network. We are also seeking to capture the perspectives of those you have used SDE Network services. These conversations will focus on areas such as:

- *The value and impact you are seeing from the SDE Network and data-enabled clinical trials*
- *How well the programme has delivered the planned benefits*
- *Lessons learned including what will be required to sustain and grow the service*

All insights that you share with Starlight Consulting will be held in confidence, only shared as part of an aggregated description and not directly attributable to you as an individual or to the organisation that you represent. You will be provided with the opportunity to consent or not, to being named as a contributor in the final report.

I'd be very grateful if you could confirm your willingness to participate. Please reply to this email, copying (redacted), (redacted) and (redacted), and we will coordinate dates and materials.

Thank you in advance for your continued support and for contributing candid feedback to this important review.

Appendix C: Interview questions

The following questions were used as a foundation for each stakeholder interview. The questions have been informed by HM Gov's Magenta Book

1. Was there a clear vision and were there any red flags? *(provides clarity on the social outcomes of the programme and key themes)*
2. How was the programme developed and agreed, with hindsight should anything have been done differently *(design outlines how the collaborating orgs and their teams worked together to deliver the vision)*
3. Was the plan delivered and was there sufficient flexibility to deal with problems arising? Implementation and ability to enact requirements within this environment – how to frame for Data for R&D *(plans could be adapted as the programme progressed while still providing confidence of delivery)*
4. Was/is there good leadership within the programme, governance and delivery teams and what have you learned and changed through the programme? *(motivating an extensive network of people reference to the wide network, working groups, communities of practice)*
5. Is there evidence of good collaboration within the stakeholder groups and what have you adapted during the programme? *(collaboration is key to transformation in a multi-dimensional environment that cuts across organisational boundaries)*
6. Is there clear accountability for decision making and is there anything you improved, or would like to change? *(clear accountability for transformation within the programme enables productivity and improved decision-making, leading to better outcomes)*
7. Are the delivery teams and end-users (recipients) of the service engaged and what would you do differently, if anything? *(transformation requires people to be engaged and change their ways or working, communicating effectively with all stakeholder groups including end users is crucial at every stage of delivery. As this change affects wider society is there evidence that thought has been given to the end users and how effectively they're being engaged in the complete process from design to implementation)*

8.2 Appendix D: Value for Money

Highlights have been set out against the 4Es (Economy, Efficiency, Effectiveness and Equity) in the main body of the document. This appendix has been included to provide greater depth for those who wish to understand the basis of the findings.

In reviewing the Data for R&D programme for the value it has delivered against expectations, we will look at the following:

- The amount of funding received, how this compared to the original intent and how it has been spent.
- The delivery against expected achievements set out in the Programme Business Case.
- The progress against the original benefits set out.

We have commented on the changes in context and challenges faced and made suggested recommendations throughout, both for the Programme as it progresses and to be taken into consideration in the future.

8.3 Funding and Budget

The submitted PBC for the three years to 2024/25 sought investment of £200m for the Programme. The original approval from the then Secretary of State (SoS) outlined a £25m required reduction in funding from the NHS England allocation, granting £175m. Through the initial duration of the Programme, further investments were secured from other sources, bringing the total investment for the 3 years to £206m. As a result of the PBC Addendum submitted in 2025 and additional £81m was granted for 2025/26 which brings the total to £290m.

The table below shows the breakdown of the funding for the 3 completed years and the forecast for the current year. It should be noted that, as shown, c£20m of the funding was on a pass-through basis for tangentially connected projects.

Funding Source	22/23	23/24	24/25	25/26	Grand Total
NHSE	£ 23,500,000	£ 47,100,000	£ 50,900,000	£ 47,200,000	£168,700,000
DHSC	£ 9,230,000	£ -	£ 1,900,000	£ 22,000,000	£33,130,000
BEIS/DSIT	£ 12,400,000	£ 10,000,000	£ 10,000,000	£ 12,000,000	£44,400,000
Ministerial Discretionary	£ -	£ 5,000,000	£ 5,000,000	£ -	£10,000,000
SoS Sign Off Total	**£ 45,130,000**	**£ 62,100,000**	**£ 67,800,000**	**£ 81,200,000**	**£ 256,230,000**
NHSE revised budget adjustments	£0	£0	-£24,000,000	£0	-£24,000,000
Further adjustments	£0	£0	-£9,470,392	£0	-£9,470,392
NHSE budget adjustments	**£ -**	**£ -**	**£ (33,470,392)**	**£ -**	**£ (33,470,392)**
Additional Funding - DHSC	**£ -**	**£ 10,000,000**	**£ 38,100,000**	**£ -**	**£ 48,100,000**
North West Data Action Accelerator 1	£ -	£ 1,300,000	£ 3,600,000	£ -	£4,900,000
SDE Network	£ -	£ 2,400,000	£ -	£ -	£2,400,000
GeL driver project	£ -	£ 2,500,000	£ -	£ -	£2,500,000
Clinical Digital Pathology Infrastructure	£ -	£ -	£ 6,400,000	£ -	£6,400,000
North West Data Action Accelerator 2	£ -	£ -	£ 180,000	£ -	£180,000
RWE	£ -	£ -	£ 250,000	£ -	£250,000
NPIC	£ -	£ -	£ -	£ 1,500,000	£1,500,000
HInM	£ -	£ -	£ -	£ 1,500,000	£1,500,000
Pass Through Funding Total	**£ -**	**£ 6,200,000**	**£ 10,430,000**	**£ 3,000,000**	**£ 19,630,000**
Total Programme Funding	**£ 45,130,000**	**£ 78,300,000**	**£ 82,859,608**	**£ 84,200,000**	**£ 290,489,608**
Expenditure (Actuals and/or Forecast)	£41,126,082	£75,899,734	£75,845,539	£ 77,276,033	£270,147,388
Total Expenditure	**£ 41,126,082**	**£ 75,899,734**	**£ 75,845,539**	**£ 77,276,033**	**£ 270,147,388**
Programme Over + / Under (-) spend	**£ (4,003,918)**	**£ (2,400,266)**	**£ (7,014,069)**	**£ (6,923,967)**	**£ (20,342,220)**

Figure 4: Funding breakdown

As can be seen in the table, there has been an average underspend of c£5m per annum contributed to by a variety of factors, including delays in annual funding approvals and the split of capital and revenue. This funding has been split between central programme activities and support for the National and Regional SDEs as shown in the figure overleaf.

Portfolio	2022/23 Actual	2023/24 Actual	2024/25 Actual	2025/26* Forecast	4 yr Total Act/F'cast
Central Mgmt Op Model (&Transition 25/6)	£ -	£ 1,349,114	£ 669,000	£ 2,942,201	£ 4,960,315
External Affairs & Public Trust	£ 379,115	£ 1,884,290	£ 1,107,225	£ 589,737	£ 3,960,367
Programme	£ 1,857,440	£ 2,351,130	£16,800,517	£12,885,095	£ 33,894,182
Data Enabled Clinical Trials & Cohorts	£ 9,617,504	£ 8,800,000	£ 6,857,976	£ 6,842,000	£ 32,117,480
Central Total	£11,854,059	£14,384,534	£25,434,718	£23,259,033	£ 74,932,344
East Midlands	£ 273,000	£ 1,700,000	£ 2,800,000	£ -	£ 4,773,000
East of England	£ 273,000	£ 5,300,000	£ 4,821,000	£ 4,705,000	£ 15,099,000
KMS	£ 273,000	£ 2,000,000	£ 2,600,000	£ 3,529,000	£ 8,402,000
London	£ 3,623,000	£ 8,320,000	£ 6,625,000	£ 6,058,000	£ 24,626,000
NENC	£ 873,000	£ 4,300,000	£ 3,625,000	£ 3,576,000	£ 12,374,000
North West	£ 3,623,000	£ 5,500,000	£ 5,925,000	£ 5,253,000	£ 20,301,000
South West	£ 273,000	£ 1,800,000	£ 2,300,000	£ 3,347,000	£ 7,720,000
TVS	£ 3,623,000	£ 4,900,000	£ 4,425,000	£ 5,165,000	£ 18,113,000
Wessex	£ 273,000	£ 4,000,000	£ 3,525,000	£ 5,097,000	£ 12,895,000
West Midlands	£ 3,623,000	£ 5,300,000	£ 2,600,000	£ 2,955,000	£ 14,478,000
Yorkshire & Humber	£ 273,000	£ 2,400,000	£ 3,100,000	£ 3,752,000	£ 9,525,000
National SDE	£11,824,023	£10,500,000	£ 7,420,821	£10,580,000	£ 40,324,844
+Additional SDE services	£ 445,000	£ 5,495,200	£ 644,000		£ 6,584,200
SDE Network Total	**£29,272,023**	**£61,515,200**	**£50,410,821**	**£54,017,000**	**£ 195,215,044**
Grand Total	**£41,126,082**	**£75,899,734**	**£75,845,539**	**£77,276,033**	**£ 270,147,388**
Variance	(£4,003,918)	(£2,400,266)	(£7,014,069)	(£6,923,968)	(£20,342,220)
Pass Through Funding		£6,200,000	£10,430,000	£3,000,000	£19,630,000
Direct Programme Total	**£41,126,082**	**£69,699,734**	**£65,415,539**	**£74,276,033**	**£ 250,517,388**

Figure 7: Spend Profile

* 25/26 – A Transform budget has been created for this year only. This is a pot of money to be split amongst SDEs once they had submitted their business plans. Additional allocations over the Baseline run and maintain allocations were based on these plans.

+ Across the programme some funding has been provided on a pass-through basis which is not part of the core programme funding (i.e. funding for Chair of Community of Practice). Some of this has been included in the Additional SDE Services line but other sums have been wrapped into Portfolio lines. The totals by year for are shown in the bottom line of the table.

When looking at the way in which the money has been spent, we can comment on central Programme expenditure but not that of either the National or Regional SDEs. This is due to both the way in which the Programme operates, and also in how it is structured.

At a central level the Programme complies with required commercial guidance on any procurement carried out directly, which is managed through the PMO team (with the commercial team resources focussed on driving behavioural and procedural standardisation across the Network). Financial monitoring and reporting is carried

out within the Programme for all central activities and projects with outline monitoring of wider spend.

The Programme has suffered significantly from ongoing uncertainty over annual funding and the fact that it has a limited lifespan. This has meant that resourcing on a permanent basis has been a continuing challenge and there are significant FTE vacancies frequently in excess of 25%. In order to support activity, the Programme has been heavily reliant on both external and CSU resourcing leading to a higher cost for resourcing than permanent FTEs. The basis on which the Programme has been funded makes this inevitable.

Whilst badged as a single programme it would be more accurate to describe there as being a central co-ordinating unit which runs the central activities and projects and which then commissions work and provides funding to SDEs, to deliver against agreed KPIs in the individual Memorandums of Understanding (MOUs). The Regional SDEs are run by NHS Trusts on their own or in conjunction with Health Innovation Networks (HINs). The SDE architecture is hosted on Trust platforms and, in many cases, will use staff from these parent bodies to deliver the services. While SDEs are required to provide annual bids outlining their plans for the year to secure specific funding, the funding provided does not cover the full cost and will be accounted for as a contribution towards the wider costs that support SDE delivery. This means that there is not a stand-alone reconciliation of how the funding provided through the SDE programme is spent available to the Programme.

The National (NHS) SDE while being part of the central organisation is at one remove from the Programme and is a commissioned service with a multi-year role. This remove, and the lack of common governance, means that the National SDE does not have significant oversight from the programme team and, despite being within NHS England, it shares with the Regional SDEs the ownership of delivery rather than being a core part of the Programme.

The Programme leadership is aware of the weaknesses that exists in terms of the ability to track and manage spend more accurately and for 25/26 has introduced, or is in the process of introducing for next year, the following:

- For the current year it has introduced the concept of splitting funding bids into Baseline and Transform categories with Transform representing discrete

projects to improve capability and capacity which can be more actively managed through the new Account Management function.

- As part of the planning for 2026/27 there is significant work being put into developing agreements which specifically increase the obligations on the SDE in terms of specific reporting on expenditure.
- Engagement has commenced to understand the necessary business systems including standardised CRM tool with linkages to finance systems and how this can be centrally provided and rolled out.
- The Programme is also commissioning work to develop a comprehensive performance management framework together with the supporting information required to monitor the proposed metrics.

Recommendation – the work on increasing transparency and accuracy of regional spend should be continued together with the ongoing discovery on the systems needed to automate the reporting of MI, increasing transparency and reducing the reporting load.

Recommendation – As part of the work to support the previous recommendation, a clear direction needs to be set out on the basis of the need and purpose of all MI and how it will be used both to provide information to stakeholders and to provide insights which can help the SDEs to develop.

Recommendation - While the temptation to take a more command-and-control approach will be strong, HDRS should be mindful of the structure of the regional SDEs and the risks inherent in forcing specific behaviours, including the potential for them to walk away. At this time, we are not aware of increased statutory or legislative power to expressly mandate behaviours or actions, although it is expected that strong political support will be available.

8.4 Quantified Benefits

It is not possible to assess the benefits delivered to date against the original case in a quantified way as the Programme does not currently have that information. The original PBC included a quantified benefits analysis for the preferred option, with a value of £1.7Bn over a 10-year period. With the reduction in funding, this was revised down to £1.4Bn and then, in January 2024, due to progress on the Programme, revised again, this time upwards to £1.6Bn, as shown below.

Benefit area	Type	22/23	23/24	24/25	25/26	26/27	27/28	28/29	29/30	30/31	Total
Patient outcomes: improved cancer treatment	Societal	0	627	2,653	8,523	18,441	25,041	24,764	22,063	19,656	**121,768**
Patient benefits: AI-enabled cancer diagnosis	Societal	0	806	3,408	10,951	23,951	33,552	33,941	30,238	26,939	**163,786**
Patient benefits: risk stratification and improving CVD outcomes	Societal	0	228	963	3,095	6,769	9,484	9,593	8,547	7,614	**46,293**
NHS Benefits: reduced cancer and CVD treatment costs	Non-cash releasing	0	1,893	8,007	25,725	55,663	75,582	74,748	66,593	59,328	**367,539**
NHS benefits: reduced readmissions	Non-cash releasing	0	368	1,556	4,998	10,816	14,686	14,524	12,940	11,527	**71,415**
NHS benefits: reduced imaging spend	Non-cash releasing	0	175	739	2,375	5,196	7,279	7,363	6,559	5,844	**35,530**
Clinical trials: increased volume and reduced cost of trials - industry cost savings	Societal	0	10,437	16,953	28,951	45,670	63,528	80,383	95,931	142,351	**484,204**
Clinical trials: increased volume and reduced cost of trials - NHS revenue	Cash-releasing	0	6,009	8,640	14,014	17,585	20,191	20,822	19,995	17,499	**124,755**
Industrial growth: Growth in the UK life sciences sector	Societal	0	5,473	11,586	14,789	18,354	22,313	26,702	31,559	36,608	**167,384**
All benefits total	-	**0**	**26,016**	**54,505**	**113,421**	**202,445**	**271,656**	**292,840**	**294,425**	**327,366**	**1,582,674**

The work carried out to assess the potential benefits was detailed and took into account a number of factors when considering the value, including:

- Benefits were adjusted down based on the application of a confidence grid, reflecting both the level of dependency and uncertainty regarding assumptions. This typically reduced benefit by 40-50%.
- A maximum of 50% of the total benefit was attributed to the investment. This reflected the additional role of other individuals and organisations, including researchers and individuals involved in implementation, in delivering benefits.

The benefits in the case were backed up by an outline theory of change framework looking at inputs, throughputs, outcomes and impacts.

The Programme has struggled to measure metrics over time, due to the nature and attributed values of the individual benefits, the immaturity of the SDE Network and its data capture and reporting and some of the initial assumptions. As a result, a review was commissioned during 2025, the key findings and areas for improvement are shown below.

- Benefits statements captured within the FY 2022-25 Programme Business Case and FY 2025-26 Programme Business Case Addendum ignore the fact that the Programme's role is primarily that of an enabler, limiting the ability to demonstrate measurable impact.
- The most clearly attributable benefit is income generated from the SDE Network, which is currently captured in metrics however, this information

requires validation and further detail is required from the SDEs to improve tracking of this benefit.

- Additional benefits such as productivity gains, reduced duplication, improved processes, and regional standardisation have been discussed but remain undocumented.
- Gaps in governance, standardisation, and supporting structures hinder consistent benefits management across the Programme.

8.4.1 Opportunities for Improvement

- Strengthen governance and establish a dedicated benefits network.
- Standardise frameworks, templates, and reporting processes across the Programme.
- Redefine benefits statements to reflect measurable, attributable outcomes.
- Expand tracking to capture currently unrecorded benefits.

Following this piece of work a revised set of benefits and approach to capturing them has been developed and initial work to develop quantified value targets is underway with the initial outputs shown overleaf. Work on the revised framework being implemented is still underway and the values in the table (£20.177m) are the current estimate for 2025/6, with it not being possible to determine values for earlier years at this time.

Ref	Description of Benefit	Value Assumptions to calculate benefits	Impact/Outcome category	Benefit Type (e.g. Societal, Quality, CR, NCR)	Value (For the year of the OBO)	Comments (benefits)
OBO1 B1	Improved time to access data for research	Reduction in average time - baseline current position and evidence assumptions Reduction in staff time spent - Financial impact of reduced resource implications Total Time Saved = Baseline Time – New Time Cost Saving = Total Time Saved × Staff Cost per Hour	Reduced operating costs/save staff time (admin)	NCR	£3,275,245.47	This will cover the full process of accessing research data and demonstrating the time saved from having the SDE network in place. There is a cost saving to be applied on top of the time saved. We are currently working with existing MI and have requested additional data and assumptions from SDEs to calculate this.
OBO1 B2	Increase in the attraction of research applications	Increase in number of applications % of conversion rate = No of research enquiries out of No of applications x 100	Growth	Societal	£1,216,272	This demonstrates the USP of the SDE network by reflecting the number of applications. We are currently working with existing MI and have requested additional data and assumptions from SDEs to calculate this. * current pipeline non-contracted revenue (£2,533,901.03) as the baseline:
OBO1 B3	Increased numbers of research papers published that have used data from SDE's	No of papers published with SDE data quoted as reference source (Search tools and citing apps available)	Industry growth	Societal	TBC	Reflects the outputs from the researches using the SDE data for research and development. We are currently working with existing MI and have requested additional data and assumptions from SDEs to calculate this.
OBO1 B4	Increase in Public trust in NHS data usage	% of data access requests publicly listed # of citizens engaged per year - stretch target YoY Avg. survey trust score (1–5) # of upheld data complaints % of projects with public benefit statements - 100%	Preserve* or increase trust	Quality	£1,000,400	The programme is underpinned by public trust in data usage. This is imperative to ensure public trust in data usage is increased Meeting with PPIE team to refine further. *assumes a 5% growth in public trust
OBO1 B5	Increased operational efficiency - cost saving	Total amount of sub benefits in cash savings The time saved efficiencies should be used to calculate the costs	Reduce operating costs	CR	TBC	The programme has delivered cost savings as a result of the activity happening with the SDE network. This benefit reflects the cost savings generated by productivity gains. We are currently working with existing MI and have requested additional data and assumptions from SDEs to calculate this.
OBO1 B6	Increased operational efficiency - Time saved	Total Time saved due to operational efficiency gains	Save staff time (Admin)	NCR	TBC	The programme has delivered cost savings as a result of the activity happening with the SDE network. This benefit reflects the cost savings generated by productivity gains. We are currently working with existing MI and have requested additional data and assumptions from SDEs to calculate this.
OBO1 B7	Increase in revenue through SDE income	Total income - through commercial activity (not funding)	Revenue generation	CR	£4,623,816	This benefit is true financial cash income through commercial activity from the SDEs. This had previously been calculated not taking into account the mobilisation of the SDEs and assumed income in year one. We are currently awaiting a P&L return from SDEs 24/11/25 to use to calculate actuals and projected values. * reflect only commercial research activity, not NHSE funding.

Ref	Description of Benefit	Value Assumptions to calculate benefits	Impact/Outcome category	Benefit Type (e.g. Societal, Quality, CR, NCR)	Value (For the year of the OBO)	Comments (benefits)
OBO1 B8	Increased growth and investment	Growth %= total Value for all SDEs this quarter - Total Value for all SDEs last quarter/Value last quarter×100	Financial growth	NCR	£2,530,000	this % represents the growth of the SDE network financially and will provide a progress indicator on growth. Awaiting P&L return to calculate. *Financial returns indicate a potential 40% growth
OBO1 B9	Increase in value of assets	Total cash value of assets in £ Increase in Value =Current Value of Assets−Baseline Value of Assets	Revenue generation	NCR	£1,926,589.92	The SDEs have produced multiple assets such as NHS owned platforms. Re-usable processes/policies. Reuseable data assets. This benefit captures the value of the assets across the network
OBO1 B10	Increased growth of data availability at scale	% increase in data availability	Improved patient outcomes	Quality	£4,640,000	This will provide more high-quality NHS data available—securely, responsibly, and at scale—so that research, service improvement, innovation, and decision-making can be more powerful & reliable * f the SDE network experiences the projected 40.8% increase in data availability, and project value scales proportionally with availability (as supported by the increase in pipeline volume), then:
OBO1 B11	Increased job opportunities linked to research within the SDE	Define Job growth metrics - show an increase in roles within SDE networks over a define period of time	Improve business continuity resilience*	Societal	TBC	The programme will ensure that the growth of the SDE infrastructure creates a sustainable, skilled workforce that strengthens NHS research capacity, supports innovation, improves regional economies, and ultimately accelerates
OBO1 B12	Expansion of research partnerships across the SDE Network	Total of increase Baseline number vs new number	Reduce operating costs	Quality	£860,000	Expanding research partnerships across the SDE Network enables more collaborative, high-quality, and innovative research by bringing together diverse expertise, increasing access to representative data, and accelerating the
OBO1 B13	Decrease in data sharing breaches (measured in decrease in cost and number of	Trend in number of data breaches/incidents and financial £ / metric	Reduce operating costs	CR	£60,000	This protects patient confidentiality, maintains public trust, ensures regulatory compliance, and lowers legal, financial, and reputational risks, enabling safer use of NHS data for research and innovation
OBO1 B14	Increase in data security and consistency by offering secure online access instead of offline copies.	% of data provided via access vs offline copies sum = total number of projects accessing data vs secure access / total number of projects	Reduce vulnerability to cyber attack*	Quality	£44,200.00	Ministerial priority to provide access to research data as opposed to providing data sharing or the data being taken away. We intend to utilise the DARS/DAC metric already provided however there is an issue with data quality. Currently requesting info from SDEs and working with MI team *Cost avoidance of all current projects being accessed securely and online. Ave
OBO1 B15	Increase in the quality of healthcare data/research ready	Data quality indicators	Reduce operating costs	Quality	£3,275,245.47	Further modelling required in collaboration with the SDE to agree the common metrics.
OBO1 B16	Improved patient outcomes through the adoption of research-informed interventions	Number of research projects by category and link case studies to show the impact. We will also look into calculating societal £ value at a later stage (P2)	Improved patient outcomes	Societal	TBC	Next phase will capture the value associated with the research outcome and applying the attribution model
					£20,176,523.39	

While not disagreeing with the key findings of the internal review we believe that there is a need to consider a number of further factors in more detail.

The purpose of the Programme: The Programme was set up to create a collaborative ecosystem supporting research. At best it could be said to be building a foundation from which benefits could be delivered using existing structures at different levels of maturity and building on a “brown field” site at a variety of pace. The creation of the Network is still at a relatively early stage despite the progress being made.

The role of the Programme: The Programme is intended to facilitate the ability to access high quality homogenous data from across care settings to support research across 6 primary use cases rather than to deliver end benefits itself.

The structure of the Programme: The central programme team has neither the mandate nor the leverage to make the SDEs behave in a structured way which, aligned with the varying maturity levels, means that the chances of successfully eliciting large amounts of complicated MI on benefits across the full system is limited.

Taken together, these exacerbate the underlying problems of the business case benefits basis:

Several of the benefits which were set out make assumptions, very possibly based on what were current areas of concern about where research would be focused. While cancer was and still is a significant concern the actual areas of research are significantly broader.

The case assumes that the Programme can influence, measure and deliver benefits when the Programme is in fact at one or more likely multiple removes from the delivery of the values, meaning that none of the listed benefits are direct benefits to the Programme. The only direct benefit so far seen would be income from providing the data and tools where it exceeds the direct cost of delivery, which was not included initially.

While attempts were made to reduce the level of the initial calculated values based on the linkage of empirical evidence to a causal chain as well as considering external factors it is not clear if the currency of the data, its specific relevance to the delivery

of the benefit in the specific use case context, the quality of the data and the range and consistency if multiple sources existed were considered.

The timings of delivery for the benefits, in most cases, seem to be significantly faster than would normally be seen in a healthcare environment where changes in practice can take 6+ years to be adopted, and changes in treatment can take well in excess of 9 years to be tested and cleared. Whilst the benefits from clinical trials might be expected to deliver the soonest of those identified, including a quantified value in year 2 of a foundational programme seems excessive.

Additionally the case assumed that the existence of the programme would make things better in the chosen areas and deliver benefits when the findings from experience have suggested that in some areas such as Digi-Trials the initial impact of the work has been to identify challenges which had not been previously known and highlighted weaknesses in data governance and access which need to be overcome before the undoubtedly significant benefits can flow.

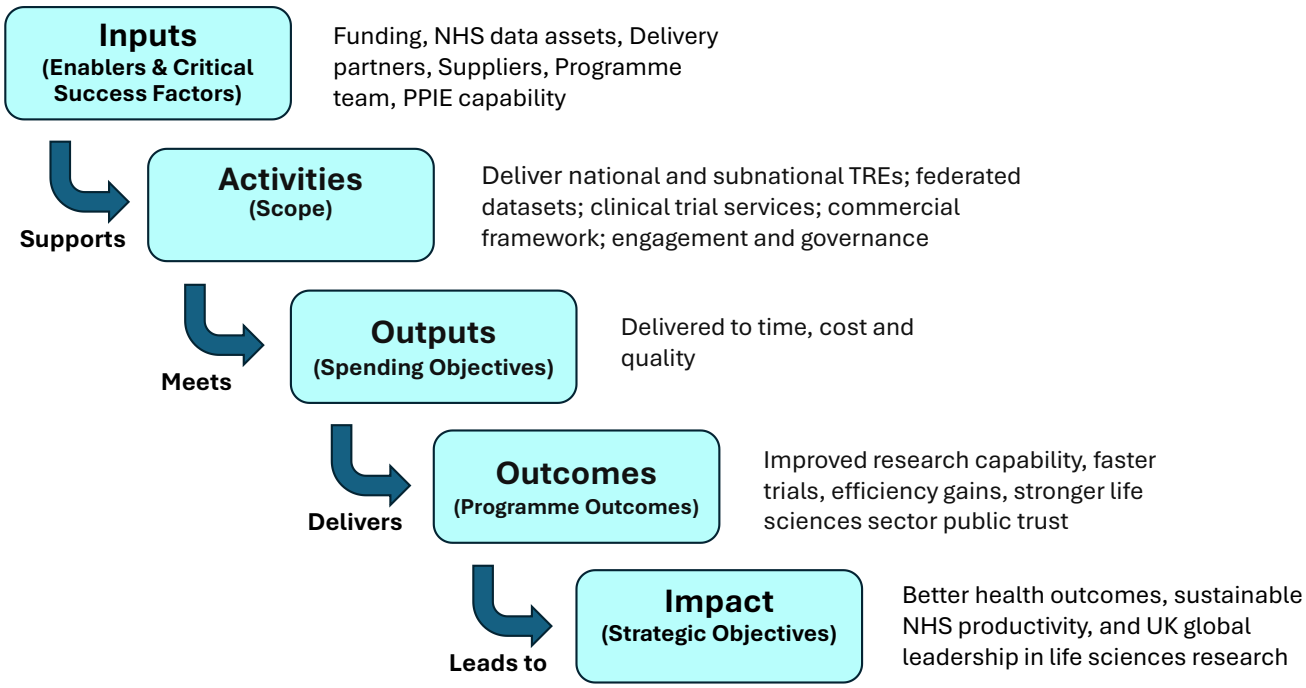
Recommendation – Further work should be undertaken to reflect in the benefits targets the specific nature of the research work being undertaken across the various use cases, in other words benefits should be linked to actual activities being supported rather than potential activities.

Recommendation – The programme should consider the concept of whether a benefit is Created (only exists because of what Data for R&D has done) is Enabled (Data for R&D has done something which allows another party to deliver a benefit) or is Influenced (an activity contributes or steers a party at a remove or outside the public sector to deliver value). This could be supported by more nuanced “nested” Theory of Change assessment which considered the ownership of various stages of the journey to value delivery. The programme can still measure its progress towards completing its part of the journey but cannot be held responsible for the success of subsequent stages.

Recommendation – We would caution against assuming significant levels of theoretically potential benefits which can be delivered at pace, when the first 3 years or so of activity will still predominantly be taken up with maturing the ecosystem, its data and its processes. This has been up to now, and will continue for some time to be, an investment for the future.

8.5 Qualitative Achievements

The 5-case model structure for Business Cases uses a hierarchical flow but separates the elements out into the 5 cases. For the programme these were:



Whilst the programme was set up with a 3-year initial lifespan (although we are now over a year past that) the case was structured for a 10-year lifespan and therefore the more strategic elements (Programme Outcomes and Strategic Objectives) were set out for the medium and longer term.

When looking at what has been achieved at this point in time it is therefore more appropriate to look at the Spending Objectives, achievements to date and examples of where the SDE data is being incorporated into wider data analysis ecosystems with the potential to deliver value as well as understanding what still needs to be done.

These are the primary objectives that were intended to be directly funded and delivered by the programme.

8.5.1 NHS-owned data infrastructure (SO1)

Develop an England wide ecosystem of secure, NHS owned and managed data infrastructure providing access to high-quality, linked datasets.

- National data platform expanded to support >400 users

- Network of 11 regional SDEs covering ≥80% of England
- National SDE

Achievements to date:

- Development of a national Network of SDEs, all of which are operational.
- Established a national, scalable operating model for safe, sustainable, and trusted health data services, aligning with the NHS Long-Term Plan, Life Sciences Vision, and Sudlow Review.
- Development of a tested, interoperable approach (operational, commercial, technical and governance) which allows for projects to be conducted across multiple SDEs.
- Delivery of a "single front door" through the HDR UK Gateway, where researchers can search for the data available, conduct cohort discovery and apply for multiple datasets through one process.
- Launch of Research Powered by Data site, hosted within the NHS England website hierarchy, providing information on the SDE Network, case studies demonstrating the projects delivered, and information on service offering.
- Over 500 datasets available across the Network, the majority of which were not available or not easily available to researchers three years ago.
- Adoption of the OMOP data model across the Network, meaning that data is able to be easily linked and grouped for analysis across multiple SDEs.
- Agreement to enable to single workspace per project for researchers, through a system of a "lead SDE" which hosts all the data needed for a project.
- Over 500 projects completed or in progress across the SDEs, with more than 300 in pipeline.
- Developed a Health Data User Group and built-up membership to allow for close working with stakeholders to codesign and develop new services. Comprehensive stakeholder engagement approach has seen positive testimonials from users.
- Secured increased collaboration with life sciences and industry partners, including AstraZeneca and Pfizer.
- All but one of the SDEs have Section 251 approval i.e. a legal basis to process and provide access to identifiable data without consent.

- Consistent governance committees and processes to increase objectivity and standardisation applied across the Network.
- Secured £6.4m in Government funding for separate and complementary new data infrastructure projects to advance cancer research and AI model training.

8.5.2 Increased clinical trials capacity and capability (SO2)

Use NHS data to improve trial setup, recruitment and delivery.

- 50% increase in trial recruitment by March 2025
- Improved diversity of trial participants
- Concierge support for high priority and innovative trials

Achievements to date:

- Enabled the design and delivery of large-scale clinical trials, inviting over 25 million citizens to participate in research studies, bolstering public engagement and trust.
- Supported recruitment of over 1 million volunteers for five major trials, including the world's largest study (Our Future Health) and the UK's fastest recruiting trial (Galleri)
- Reduced feasibility insight generation timelines from months to hours through a feasibility tool with self-service opportunities.
- The EOI in FY 2023/24 attracted interest from ~50 potential trials with the Recruitment Service selecting 8 for piloting. These are progression at different speeds through the systems with the Lessons Learned to be summarised in Q1-2025. A further EOI will be launched before end FY 2024/25 with a longer time open to better attract industry studies and testing the model for other use cases (most will be smaller than the unusually large trials that NHS DigiTrials has serviced initially).
- Behavioural science initiatives as embedded methodological research initiatives are being implemented to improve recipient decisions-making and to facilitate recruitment to trials from under-represented groups, supporting Our Future Health's national priority recruitment targets and helping ensure that trials are representative of the UK population.

8.5.3 Federated access to genomics datasets (SO3)

Enable interoperable and federated access to genomics datasets across multiple Trusted Research Environments (TREs).

- Single point of access to datasets from UK Biobank, Genomics England, Our Future Health and others
- Larger sample sizes and increased analytical power.

Achievements to date:

- Advanced the Prostate Progress virtual registry, incorporating clinical and patient-entered data to improve prostate cancer care.
- Delivered the world's largest genomics data research initiative, covering 6,000 cancer patients and integrating 75,000 radiology and 100,000 pathology images.

8.5.4 Fair financial returns to the NHS (SO4)

Apply a coherent commercial framework to generate financial and nonfinancial returns.

- NHS share of UK clinical trial revenues exceeds 13% by March 2025
- Demonstrable efficiency and cost avoidance benefits

Achievements to date:

- Delivery of an agreed pricing structure across the Network which recovers the costs of project delivery and derives additional value for the NHS determined by the downstream value of usage of data.
- Progress in the development of a single contracting process to underpin the commercialisation of the service and increase speed of contracting.
- Established outline aggregated profit and loss monitoring for the ongoing monitoring of the Network and to support cross Network transparency.
- Break even modelling completed identifying commercial requirements for achieving break even by end of annum 27/28.
- Bi-lateral and multi-party non-disclosure agreement (NDA) templates in place for use to support cross-SDE delivery.

- Early discovery work into investment opportunities for the Programme and for HDRS.
- Proposed approach to multi-SDE delivery models.
- Risk adjusted pipeline revenue for 25/26 forecast to be c£10m (not all in year however)

8.5.5 Positive patient and public support (SO5)

Maintain and enhance public confidence in the use of NHS Data for R&D.

- Continuous PPIE embedded at programme and project level
- Measured through engagement, feedback and research

Achievements to date:

- Over 5,700 members of the public have been involved in PPIE work on health data over the past three years. This has been through a combination of large-scale public deliberations, work commissioned through understanding Patient Data and local PPIE work to support the development of regional SDEs.
- Development of a Community of Practice, which brings together expertise from across the Network to problem solve and to work together on issues which affect the Network. The groups provide an additional delivery resource to the Programme and focus on Tech and Data; PPIE, IG and ethics; and Communications.
- Data use registers will be available across all SDEs by the end of the financial year, increasing transparency.

8.6 Summary of Key Points affecting VFM

- Funding uncertainty and delays have had a material impact on the programmes ability to deliver to original milestones.
- Financial reporting is not strong or consistent enough to fully analyse wider spend but the programme has stayed within its funding envelope.
- There is ongoing work to increase the transparency and granularity of information together with reporting metrics relevant to objectives together with implementing suitable systems and tools to automate the process, and this work should be supported and continued.

- Original benefits were inappropriate and overstated and, as they were for a 10-year programme, it is too early to assess in detail.
- The original intent for collaborative benefits management has not worked in a loosely federated system with differing levels of maturity.
- The programme is still foundational at this point and is enabling rather than end-value delivery in nature. It should monitor its creation of capability, potential and opportunity rather than just specific outcomes.
- The specific challenges in setting up and running the network were over-simplified and time and money has needed been spent on further work to understand them. This is an ongoing process but critical for sustainability.
- Material achievements have been made but the work to create a stable system with consistently high levels of maturity is still a work in progress with significant standardisation activity still to be completed.
- The programme structure as a federated network from which services are commissioned does not support easy direction and co-ordination. This will not be different in the future, and any new operating model will need to be designed with this in mind.

8.7 Appendix E: Benefits

Revised Benefits following internal review

REF	DESCRIPTION OF BENEFIT	VALUE ASSUMPTIONS TO CALCULATE BENEFITS	IMPACT/OUTCOME CATEGORY	BENEFIT TYPE
OBO1 B1	Improved time to access data for research	Reduction in average time - baseline current position and evidence assumptions Reduction in staff time spent - Financial impact of reduced resource implications Total Time Saved = Baseline Time – New Time Cost Saving = Total Time Saved × Staff Cost per Hour	Reduced operating costs/save staff time (admin)	NCR
OBO1 B2	Increase in the attraction of research applications	Increase in number of applications % of conversion rate = No of research enquiries out of No of applications x 100	Growth	Societal
OBO1 B3	Increased numbers of research papers published that have used data from SDE's	No of papers published with SDE data quoted as reference source (Search tools and citing apps available)	Industry growth	Societal
OBO1 B4	Increase in Public trust in NHS data usage	% of data access requests publicly listed # of citizens engaged per year - stretch target YoY Avg. survey trust score (1–5) # of upheld data complaints % of projects with public benefit statements - 100%	Preserve* or increase trust	Quality
OBO1 B5	Increased operational efficiency - cost saving	Total amount of sub benefits in cash savings The time saved efficiencies should be used to calculate the costs	Reduce operating costs	CR
OBO1 B6	Increased operational efficiency - Time saved	Total Time saved due to operational efficiency gains	Save staff time (Admin)	NCR

REF	DESCRIPTION OF BENEFIT	VALUE ASSUMPTIONS TO CALCULATE BENEFITS	IMPACT/OUTCOME CATEGORY	BENEFIT TYPE
OBO1 B7	Increase in revenue through SDE income	Total income - through commercial activity (not funding)	Revenue generation	CR
OBO1 B8	Increased growth and investment	Growth %= total Value for all SDEs this quarter - Total Value for all SDEs last quarter/Value last quarter ×100	Financial growth	NCR
OBO1 B9	Increase in value of assets	Total cash value of assets in £ Increase in Value =Current Value of Assets−Baseline Value of Assets	Revenue generation	NCR
OBO1 B10	Increased growth of data availability at scale	% increase in data availability	Improved patient outcomes	Quality
OBO1 B11	Increased job opportunities linked to research within the SDE Network.	Define Job growth metrics - show an increase in roles within SDE networks over a define period of time Increase = New Value / Old Value / Old Value x 100	Improve business continuity resilience*	Societal
OBO1 B12	Expansion of research partnerships across the SDE Network	Total of increase Baseline number vs new number	Reduce operating costs	Quality
OBO1 B13	Decrease in data sharing breaches (measured in decrease in cost and number of breaches)	Trend in number of data breaches/incidents and financial £ / metric	Reduce operating costs	CR
OBO1 B14	Increase in data security and consistency by offering secure online access instead of offline copies.	% of data provided via access vs offline copies sum = total number of projects accessing data vs secure access / total number of projects	Reduce vulnerability to cyber-attack*	Quality
OBO1 B15	Increase in the quality of healthcare data/research ready data	Data quality indicators	Reduce operating costs	Quality

REF	DESCRIPTION OF BENEFIT	VALUE ASSUMPTIONS TO CALCULATE BENEFITS	IMPACT/OUTCOME CATEGORY	BENEFIT TYPE
OBO1 B16	Improved patient outcomes through the adoption of research-informed interventions enabled by enhanced access to research ready data.	Number of research projects by category and link case studies to show the impact. We will also look into calculating societal £ value at a later stage (P2)	Improved patient outcomes	Societal

8.8 Appendix F: Benefits Mapping

8.8.1 Benefits Mapping Table with Delivery Status and 4Es Alignment

Programme Objective / Outcome	Linked Benefit Ref	Benefit Description	Measurement Approach	Current Delivery Status	4Es Category
Improved time to access data for research	OBO1 B1	Reduction in time to access data	Baseline vs new time: cost saving = time saved × staff cost per hour	Partially Achieved – regional improvements, national delays	Efficiency
Increase in attraction of research applications	OBO1 B2	Growth in research applications	Number of applications; conversion rate (%)	Partially Achieved – strong regional uptake, uneven nationally	Effectiveness
Increase in published research papers using SDE data	OBO1 B3	Evidence of research impact	Count of papers citing SDE data	Emerging – early outputs, pipeline growing	Effectiveness
Increase in public trust in NHS data usage	OBO1 B4	Transparency and engagement	% of projects with public benefit statements; survey trust score	Achieved – strong PPIE engagement	Equity
Increased operational efficiency – cost saving	OBO1 B5	Reduced operating costs	Aggregate cash savings	Not Yet Measurable –	Efficiency

			from efficiency gains	benefits remain backloaded	
Increased operational efficiency – time saved	OBO1 B6	Reduced admin burden	Total time saved due to process improvements	Partially Achieved – onboarding delays persist	Efficiency
Increase in revenue through SDE income	OBO1 B7	Commercial sustainability	Total income from commercial activity	Emerging – early revenue streams, needs validation	Economy
Increased growth and investment	OBO1 B8	Financial growth	Quarterly growth % across SDE Network	Emerging – regional variation	Economy
Increase in value of assets	OBO1 B9	Asset appreciation	Current vs baseline asset value	Not Yet Measurable	Economy
Increased growth of data availability at scale	OBO1 B10	Expanded data coverage	% increase in data availability	Partially Achieved – secondary care strong, GP/MH gaps	Effectiveness
Increased job opportunities linked to research	OBO1 B11	Workforce development	Job growth metrics across SDE Network	Emerging – early signs in regional hubs	Equity
Expansion of research partnerships across SDE Network	OBO1 B12	Collaboration growth	Baseline vs new number of partnerships	Achieved regionally, national coordination weak	Effectiveness

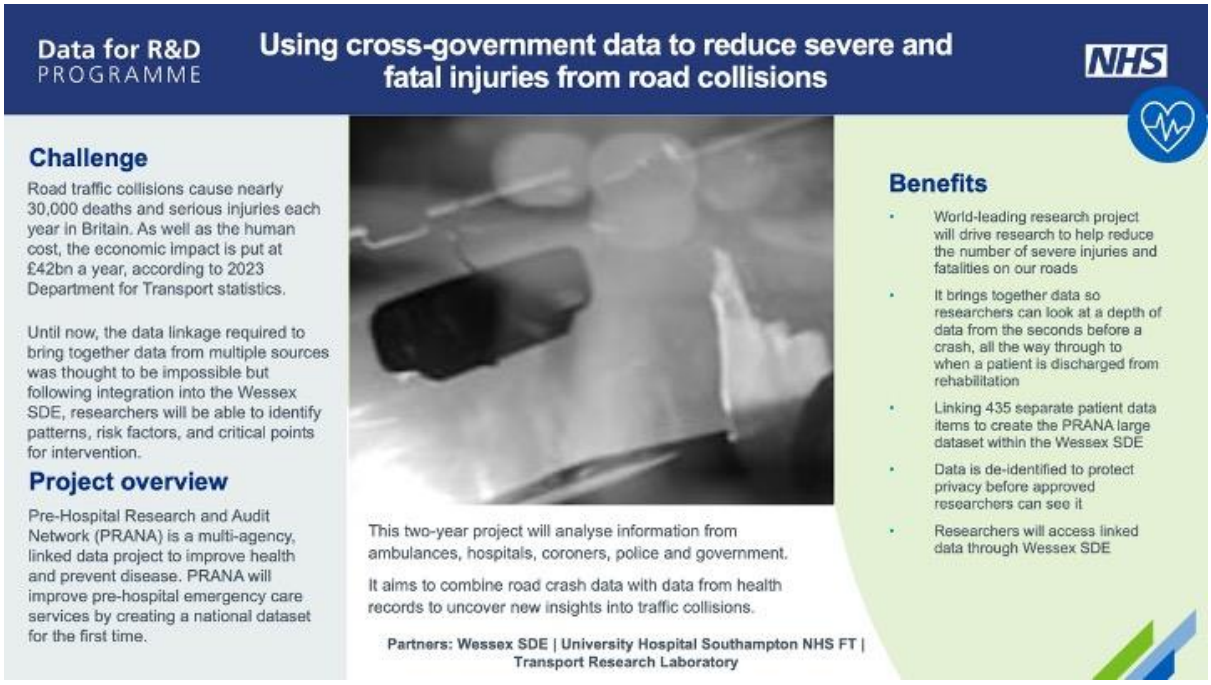
Decrease in data sharing breaches	OBO1 B13	Improved security	Trend in breaches and associated costs	Achieved – secure environments in place	Efficiency
Increase in secure online access vs offline copies	OBO1 B14	Cybersecurity resilience	% of projects using secure online access	Achieved – TRE model adopted	Efficiency
Increase in quality of healthcare data	OBO1 B15	Research-ready data quality	Data quality indicators	Partially Achieved – OMOP adoption strong, but completeness varies	Effectiveness
Improved patient outcomes through research-informed interventions	OBO1 B16	Societal impact	Number of research projects linked to improved outcomes	Not Yet Measurable – long-term benefit	Effectiveness

8.9 Appendix H: Lessons Learned

The full table of lessons learned, recommendations, Where / How to Apply and mapping to Gateway 5 themes is supplied as an additional excel spreadsheet.

8.10 Appendix I: Example Case stories

These are examples of some of the great work that has been enabled by the Programme. These were collated separately by the Programme team and showcase some of the research projects and the benefits they are starting to deliver.



Data for R&D PROGRAMME

SDE data to reduce unplanned hospital admissions

NHS

Challenge

- There's an urgent need to reduce avoidable hospital admissions and attendances.
- There are over 5 million patients on NHS treatment waiting lists, with 400,000 waiting for over a year.
- NHS England estimates 24% of unplanned hospital admissions and 40% of unplanned hospital attendances could be avoided.
- Routine data is not usually linked across services making research less effective. This delays interventions and reduces their impact as it doesn't fully reflect the patient journey or wider system. This data needs to be linked and accessed in a secure and scalable way.

Project overview

This project will facilitate broad data access through multiple SDEs to explore whether enhancing existing tools and platforms, by bringing together data from across the patient journey (e.g. ambulance services, NHS111), could help improve the identification of people needing preventative care and reduce unplanned hospitalisations.

Benefits

- Reduced mortality
- Reduction in unplanned urgent care attendance
- Increased ability to forecast unplanned Urgent and Emergency Care demand
- Improvement in physical and mental health of patients
- Released bed capacity and staff time
- Reduction in health inequalities
- Reduced costs

Partners: Yorkshire & Humber Sub National SDE | London Sub National SDE | University of Sheffield | London Ambulance Service | Health Innovation Yorkshire and Humber | Health Navigator

Data for R&D PROGRAMME

Protecting immunocompromised patients from COVID-19

NHS

Challenge

COVID-19 represents an ongoing threat to immunocompromised groups and people with certain underlying health conditions.

Researchers need secure access to near real time health care data from the whole of the UK population to test potential solutions.

Project overview

The project used linked national healthcare datasets in the NHS England SDE to give actionable insights for the NHS.

This involved characterising and describing the risk of severe COVID-19 within immunocompromised demographics, as the pandemic evolved into an endemic stage.

The NHS England SDE provided secure access to near real-time data from 25% of England's population for the study.

This data included pseudonymised, routinely collected electronic healthcare record data from primary and secondary care, which was linked to national data on COVID-19 surveillance, vaccination status, primary care medication dispensations, and mortality.

Benefits

- Provided crucial data to identify the most vulnerable immunocompromised individuals, enabling targeted preventive interventions for maximum impact
- Despite receiving ≥3 vaccine doses, immunocompromised groups were up to 13 times more likely to suffer severe COVID-19 outcomes (hospitalisation, ICU, and death)
- Immunocompromised individuals require extra preventative measures to reduce risk of severe COVID-19
- Offered valuable insights to inform policy decision-making
- Results published in the Lancet Regional Health and cited in >10 abstracts and presentations

Partners: England SDE | Evidera PPD | AstraZeneca