NDG National Data Guardian for health and social care

The National Data Guardian for Health and Social Care

Annual report 2024-25

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1 Introduction by Dr Nicola Byrne

This report covers our work during the 2024-25 financial year and highlights key developments from the drafting period (April to December 2025) that have contributed to shaping our plans into 2026-27.

As I present my fourth annual report, we find ourselves once again in a period of profound change for the NHS. This year marked the launch of the government's 10 Year Health Plan for England: fit for the future, which sets out bold ambitions for digital innovation and data-driven care. The plan commits significant investment to modernising health and care services, with a clear focus on prevention and community-based interventions. Alongside this, preparations are underway for a major structural shift: the abolition of NHS England and the transfer of its remaining functions to the Department of Health and Social Care. This represents a seismic change, particularly coming so soon after the dissolution of NHS Digital. The implications for data and digital within the NHS are still unfolding, but one thing is certain: strong, coherent leadership will be critical to the success of these reforms.

Amid major reforms, safeguarding public trust whilst enabling access to data is both complex and critical. Health and care data is deeply personal, and views on its use vary widely, making transparency and meaningful engagement essential. Without trust, digital initiatives risk costly setbacks, abandonment and missed opportunities. Drafting policy in this space – where trust can be fragile – is inherently challenging and its difficulty should not be underestimated. People hold firmly rooted and often conflicting views about data shaped by personal experience, cultural values, and trust in institutions. As a result, full consensus on data-related matters is unlikely. Decisions must carefully balance people's control over their data with the practical needs of running safe, effective and sustainable health services.

Our role is to help navigate this complexity by providing clear, principled advice grounded in the Caldicott Principles, patient confidentiality, and drawing on evidence of public expectations. These foundations ensure that data use is not only lawful and efficient but also ethically sound and aligned with the values of those who rely on the health and care system.

In the following section, I want to consider some of these major programmes and policy commitments shaping the future of health and care data. These initiatives will profoundly influence how data is used to improve care, research, and system efficiency. Each brings opportunities and challenges, and my role – as ever – is to help ensure they are implemented in ways that build trust and bring benefit to the public.

Opt-out reform: revisiting patient choices

I have welcomed the opportunity to engage with the Department of Health and Social Care on the complex challenge of opt-out reform. The task is difficult but clear: create a choice that is genuine and workable, whilst ensuring the information needed to run a modern, increasingly data-driven health and care system safely and effectively is available.

The current National Data Opt-out, introduced in 2018, has been taken up by over three million people. However, exemptions granted for essential planning and operational work mean it no longer reflects what many believe it offers. This risks undermining trust. It also reflects a simple truth: the NHS cannot function in ways the public should be able to expect without reliable information. This information helps shape safe, effective, sustainable services and improves the care people receive. Being open about this reality, clear about the safeguards that protect people's data and ensuring these are strong and credible, remains vital if we are to maintain public confidence.

I welcomed the public engagement undertaken to inform opt-out policy reform. I was encouraged by the dialogue's thoughtful design, which aimed to ensure a balanced perspective. Whilst views were mixed amongst those new to the topic, participants who had time and information to understand how data supports the NHS recognised that comprehensive data is essential for safe, effective and fair care.

As discussions with the Department progress, my goal is to ensure any future opt-out model is honest, pragmatic, and trusted. To support this, I will continue to advise on the importance of clarity, coherence, and timing: aligning potential changes with wider system developments such as COPI regulation reform, the Health Data Research Service, and considerations around the Type 1 opt-out. I will also emphasise meaningful, proportionate transparency and authenticity, ensuring communications explain choices and limitations clearly, including why some data uses are essential and how confidentiality is safeguarded.

Health Data Research Service

In April 2025, the Prime Minister announced the Health Data Research Service (HDRS), a joint initiative between the UK Government and the Wellcome Trust. The service is intended to provide a single point of access to UK health data, aiming to reduce duplication and improve efficiency in medical research and clinical trials. It is expected to simplify data access and address complexity in the current landscape through changes to governance, clearer funding and charging structures, and mechanisms for safe linkage of datasets where there is demonstrable public benefit.

It is important that this new service delivers not only for research, but also in ways that are acceptable to patients and the public, whose trust is essential and who ultimately stand to benefit from better, faster, and safer use of health data. To this end, I have engaged with the Department of Health and Social Care as it develops the early principles shaping the HDRS. My advice has focused on encouraging the embedding of public benefit at the heart of decision-making, ensuring commercial benefit is assessed transparently, and being clear about funding and charging arrangements. I have also stressed the importance of strong safeguards, transparency, and sufficient authority for HDRS to succeed in an already complex data access landscape.

As this work progresses, I will continue to advocate for simpler access for projects delivering public benefit, robust protections for patients and the public, and clear communication about how HDRS operates and the mechanisms that keep data safe.

NHS Single Patient Record

Announced in late 2024 and now embedded in the NHS 10-Year Health Plan, the Single Patient Record (SPR) aims to create a unified health and care record accessible across settings. Its purpose is to reduce duplication, improve patient experience, and enable clinicians to make safer, faster decisions by ensuring the right information is available when needed. If delivered effectively, it could transform care by supporting better coordination, thereby reducing delays caused by missing information and, crucially, improving outcomes.

However, making health information more widely available across the country brings important considerations. Public engagement on the SPR shows strong support for the principle, but only if conditions around security, transparency, and choice are met. Clear and precise language will be vital to avoid unrealistic expectations, for example, phrases like "patient-owned and controlled" risk confusion about rights and responsibilities. Clinician engagement must also be central; their input and daily use will determine whether the record works in practice. If it meets clinicians' needs, benefits for patients will follow. Building trust through early communication, robust safeguards, and clarity on how SPR integrates with tools like the NHS App is critical. Finally, inclusivity matters: digital solutions should enhance care without disadvantaging those who cannot or choose not to use technology.

These principles are essential to earning trust and making sure the Single Patient Record delivers for everyone, clinicians included. As plans develop, I will continue to champion clarity, transparency, and inclusivity, and ensure that the voices of clinicians and patients shape a system that will hopefully deliver real benefits without compromising safeguards or equity.

NHS Federated Data Platform

We have also continued to advise on the development and implementation of the NHS Federated Data Platform (FDP), which is intended to help NHS organisations use the data they already hold more effectively to better manage people's care. Over the past year, we have provided both strategic and practical information governance input, participating in key oversight groups and contributing to work with members of the public on NHS FDP communications.

Our office has supported NHS England in determining when data protection impact assessments (DPIAs) are required, including developing a screening questionnaire to assess whether data is genuinely anonymous. We have also reviewed template DPIAs for local and national use, as well as specific DPIAs for early projects such as virtual wards and antimicrobial resistance. This work has helped to ensure clarity, consistency and appropriate safeguards across the system as the programme’s implementation and benefits realisation continue to develop.

Health Service (Control of Patient Information) Regulations 2002 (COPI)

The Health Service (Control of Patient Information) Regulations 2002 (COPI Regulations) are a set of statutory rules made under Section 251 of the National Health Service Act 2006. They provide specific legal gateways that allow confidential patient information to be processed without breaching the common-law duty of confidentiality in defined circumstances, such as for public health purposes, medical research and other medical or public interest uses, subject to specified safeguards and approvals. Modernisation is needed to reflect the changing ways in which health data is used including for planning, research and service improvement. We have advised the Department of Health and Social Care on early proposals to modernise the regulations, ensuring they continue to support timely and proportionate data use and that the protections currently afforded to patient information are not inadvertently diminished. We will continue these discussions in the coming year.

Supporting public engagement on key policy areas

Understanding what matters most to people is crucial when planning major changes that rely on their data. With complex initiatives already under way and significant reforms ahead, it is important that decision makers know what the public and professionals think, and what is and is not acceptable to them.

I therefore welcomed the large-scale public engagement programme led by NHS England and the Department of Health and Social Care, which included structured dialogue on key policy areas, and agreed to chair the steering group that advised this programme. My team supported this work with practical input, and the insights generated will help ensure that policy decisions reflect the priorities of those who rely on the health and care system. I will continue to advocate for further conversations with the public and professionals where key policy questions remain and warrant exploration.

Other work

In addition to supporting these high-level policy initiatives, my team and I have also worked on a wide range of activities in 2024-25, many of which are featured in this report. Much of our work is reactive, responding to immediate demands, but we also take on longer-term, self-initiated projects. Over the past few years, we have worked on one such project, our mixed-methods research project: Can communications create reasonable expectations about uses of health and care data? Insights from co-design and public testing. We are pleased to have published the report from this research and look forward to working with stakeholders to implement the findings.

This research explored how health and care organisations can set accurate expectations around certain uses of confidential patient information beyond individual care through communications, so that these uses do not come as a surprise to people. Although the public generally supports data being used for public benefit, such as improving services or planning care, many people remain unaware of these routine uses. To address this, we worked with two NHS programmes (the Screening Quality Assurance Service and local Population Health Management) to co-design clear, accessible communication materials with members of the public and tested them through workshops, focus groups, and a large-scale survey.

The findings show that well-designed materials can successfully inform people and set accurate expectations, even for complex uses of data. Most participants understood the materials and felt reassured by the safeguards described, and they valued transparency even if they were not personally interested in detailed information. Our report provides practical insights for organisations on how to communicate clearly and concisely about data use, supporting the principle that there should be “no surprises” for patients and service users. It also contributes to the ongoing debate about whether the legal concept of a “reasonable expectation of privacy” can help determine when health and care data can be used legitimately for public benefit without breaching confidentiality.

To conclude

I am proud of what we have achieved, thanks to the dedication of my team and panel of experts. I also recognise that there is more to do across the areas set out in this report, and the priorities section explains what I will focus on for the remainder of my term, until I leave office in 2027.

To end, I’d like to thank the many individuals and organisations we have worked or connected with over the past year – in particular Understanding Patient Data, use MY data, medConfidential, the Information Commissioner’s Office, the Health Research Authority and its Confidentiality Advisory Group, the Advisory Group on Data, the General Medical Council, the British Medical Association, NHS England and the Department of Health and Social Care. Our work is strengthened by collaboration and a range of perspectives, and we continue to benefit from the insight and experience of digital, data and clinical experts, as well as the perspectives of patients, the public and health and care staff.

Dr Nicola Byrne
National Data Guardian for Health and Social Care

2 About this report

The Health and Social Care (National Data Guardian) Act 2018 requires that the National Data Guardian (NDG) submit an annual report detailing the advice provided and guidance issued in the previous fiscal year, along with upcoming priorities. This report fulfils these requirements, highlighting the NDG's work from 1 April 2024 to 31 March 2025, and includes some key activities from the drafting period. It outlines the progress in priority areas set by Dr. Nicola Byrne, the National Data Guardian, in last year's report, as well as the unforeseen and reactive work that occupies much of her and her team's time.

Throughout the reporting period, the NDG was supported by a small team of staff (the Office of the National Data Guardian) and an independent advisory group known as the NDG panel. Biographies of panel members, the panel's terms of reference, and minutes from panel meetings are available on the NDG's website.

3 What the NDG does and how

3.1 Vision

To improve the quality and sustainability of health and care through the safe, appropriate, and ethical use of people's health and social care information.

3.2 Mission

To provide leadership, expertise and insight on the use of health and social care data, advocating for policies, practices and principles that build and maintain trust in data use and the confidentiality of our health and social care services.

3.3 Strategic objectives

Three strategic objectives support the delivery of this mission:

1. Improving health and care staff and patient access to healthcare information
2. Encouraging the ethical and legal use of data for public benefit through research, planning and innovation, in line with people's expectations
3. Supporting health and care organisations to uphold the Caldicott Principles and make well-informed decisions about data

This report details our work undertaken in support of each objective. Most of our work cuts across multiple objectives.

4 Objective 1: Improving health and care staff and patient access to healthcare information

Healthcare teams, social care providers and care coordinators all need timely access to people's information to deliver the safest, most effective care. However, for many reasons, this is not always available when needed. Supporting and empowering staff to share information confidently and appropriately is therefore crucial, including across organisational boundaries, where it ensures continuity of care and prevents missed opportunities for people receiving the right care where and when they need it.

Additionally, there is growing public expectation for access to medical records and online health services, allowing us all to take a more active role in managing our health.

Furthermore, cyber events are now a fact of life. These events can have serious consequences: for privacy when data is compromised, as well as clinically when critical information systems are down for extended periods, leaving health and care teams without access to essential clinical tools and patient information. The system must actively work to reduce both the frequency and severity of these incidents and their impact by ensuring strong mitigatory controls are in place.

Through working to explore and address the above, I am committed to ensuring that health and care teams and the individuals they care for have secure and appropriate access to the information and systems they need to effectively manage people's treatment and care.

In 2024-25, I set the following work priorities under this objective:

I will work with national organisations and health and care leaders to:

- provide advice and guidance to the system that encourages the better use of health and care data to improve the quality and sustainability of people's care and treatment and addresses barriers to information sharing
- explore ways in which we can ensure that organisations have sufficient support to build and maintain their cyber-security and improve organisational resilience to better cope with cyber-events when they do happen

I have delivered the following work in support of the first priority, work to support the second is covered under strategic objective 3.

4.1 Input into AI scribe guidance for the NHS

AI scribe software uses artificial intelligence to assist clinicians by automatically recording and summarising patient consultations and other direct care interactions. These summaries are subsequently reviewed and signed off by the clinician. This technology has the potential to reduce the administrative burden on healthcare professionals, improve the accuracy of clinical records, and ultimately support more efficient and effective delivery of care. NHS England is producing information governance guidance on the implementation of AI scribes, and we have supported this work throughout by providing detailed advice and expertise. This will be published in early 2026.

4.2 Guidance on reflective practice as integral to safe care

Reflective practice is essential for ensuring safe, high-quality care. However, professionals across many settings often cannot access confidential patient information after care is delivered, limiting their ability to understand outcomes and improve future practice. This is at odds with the fact that reflective practice is a mandatory requirement for professional registration.

Programmes designed to allow health professionals access to patient information to reflect on the impact of the care they have provided have traditionally required approval under Section 251 from the Health Research Authority’s Confidentiality Advisory Group. Whilst effective, this process can create an administrative burden for work that is essential for improving patient care.

Following engagement with the Health and Care Professions Council, Social Work England, the Nursing and Midwifery Council, and the General Medical Council we drafted a position statement setting out that the NDG considers enabling health and social care professionals to undertake reflective practice to be integral to the delivery of safe direct care. To understand public attitudes towards health professionals accessing data to reflect on the care they have provided, we surveyed 2,558 UK adults; 97% agreed that health and care professionals should have access to information about how their care impacted patients in order to support reflective practice.

Our position that reflective practice falls within implied consent for direct care removes the need for Section 251 approval, reducing bureaucracy and enabling professionals across health and care settings to access patient data where this is essential for reflecting on their practice. We have worked with NHS England to translate this position into practical guidance for the NHS Information Governance portal, outlining the limitations and safeguards required when accessing patient information for reflective purposes.

This work highlights our commitment to removing barriers to safe and effective data use for direct care and demonstrates our support for all regulated health and care professionals in delivering safer, higher-quality care.

4.3 Ensuring proportionate access in the Pharmacy First initiative

Pharmacy First is a government initiative aimed at expanding the clinical role of community pharmacists, enabling them to treat more common conditions and help ease pressure on general practice. We strongly support its ambition to improve access to care and make better use of pharmacists' skills. The GP Connect programme underpins this by seeking to provide pharmacists with timely access to the information they need from patients' records, so they can deliver the Pharmacy First programme safely.

This year, we advised the GP Connect team on the appropriate use of data to support Pharmacy First. We were greatly supportive of phase one, which allows pharmacists limited access to key information from GP records, such as medications, to help them deliver safe, effective care in the Pharmacy First programme. We were also supportive of some further expansion, such as allowing access to allergies data.

However, we raised concerns about aspects of phase two, which proposes sharing further sections of the GP record, including free-text notes. We advised that this level of access appeared disproportionate for the purpose and lacked sufficient evidence of public or professional support from primary care. We also stressed the importance of accountability and governance, recommending appropriate updates are made to the national data protection impact assessment (DPIA) template to support a consistent approach to assessing and managing risks across implementing organisations.

We remain committed to supporting Pharmacy First and its potential to improve patient care and will continue to engage with GP Connect to ensure that any future information sharing developments are necessary, proportionate, and informed by meaningful engagement with patients and primary care professionals about what level of access is necessary and acceptable. We support the programme's restriction of the use of Pharmacy First to qualified pharmacists and pharmacy technicians, who are only able to use the product in the restricted area of a pharmacy.

5 Objective 2: Encouraging the ethical and legal use of data for public benefit through research, planning and innovation, in line with people's expectations

Using health and care data for reasons other than direct delivery of care is essential. It allows us to identify where there are problems with the quality of care, to learn from where things are going well, and to unlock insights that can lead to new or improved treatments and sustainable services that benefit everyone.

I will uphold the principle that data should be used ethically as well as legally when doing so. This means promoting a culture of transparency, fairness, equity, and accountability amongst those who use data to plan our services, monitor their quality and sustainability, or to conduct research that benefits the public.

As the NHS continues to introduce important new technologies to provide better data access and use, as well as the policies, processes, and ways of working that support them, it's important to ensure that these advances happen in a way that people can accept and trust. Those making system-level decisions about health and care data must always recognise and respect the human element behind that data: that it is private information entrusted to health professionals in times of sickness and vulnerability. I will urge decision-makers to place the views of patients and service users at the centre of their deliberations, so they never forget where data comes from and why people are concerned about how it is used and by whom.

I set the following work priorities under this objective:

I will continue to offer advice and guidance to the government and health and social care system to help build public trust in secondary uses of data. The goal is to attain and maintain public support for uses of data in planning, research and innovation by making sure that data use is demonstrably trustworthy. My key focus areas will include:

- contributing to new data policy and scrutinising proposed policy changes
- reviewing information governance arrangements for data programmes
- promoting the importance of transparency around data use, including around risks, safeguards and public benefits
- fostering open and honest communications and engagement about data use

- ensuring patient and public involvement in the formation of new data policy and in data policy decision-making

5.1 Reasonable expectations: informing and engaging the public

5.1.1 Background

In November 2025, we published the findings from our reasonable expectations project, which explored whether the public can be informed about the use of health and care data in ways that set clear expectations and maintain trust in how health and care data is used. Although this publication falls outside the reporting period for this report, we felt it important to mention it here, as much of the work to deliver it took place during the reporting period.

5.1.2 The project

The project tested communication materials co-designed with members of the public to explain why data is collected, who can access it, how it is used, and the safeguards in place. The research focused on two specific NHS uses of data: Screening Quality Assurance Service (SQAS), focusing on bowel cancer, and local population health management. Both are essential uses that currently operate with Section 251 support to protect confidentiality.

Findings show that well-designed communications can help people form accurate expectations, so that specific uses of data are understood and accepted, reducing the expectation of privacy around those uses. This aligns with the legal concept of a reasonable expectation of privacy, which is the threshold courts rely on when determining if a breach of confidence or misuse of private information has occurred.

5.1.3 Key insights

The research revealed that people’s engagement with information varies. Many participants reported low spontaneous interest in how their data is used and were unlikely to read longer materials. Despite this, transparency and reassurance were consistently valued. Trust in the NHS influenced comprehension, with lower trust linked to reduced understanding.

For communicators, the project provides important insight into how people think about and process communications on health and care data. Feedback showed that most people preferred brief initial information, with further detail available for those who wish to explore it. This approach ensures communications meet public needs without overwhelming those with lower interest, whilst still supporting informed expectations and trust.

5.1.4 Next steps

These findings provide evidence that carefully designed communications can create conditions in which specific uses of health and care data are understood and expected. This evidence enables us to drive debate about when the concept of 'a reasonable expectation of privacy' might serve as an adequate legal basis for determining how data collected within a health and care relationship can be legitimately used for public benefit without breaching confidentiality.

The full report, including insights and implications for organisations using health and care data, is now published and available to inform future policy, communications, and practice.

5.2 Advising the NHS Federated Data Platform programme

The National Data Guardian continues to support the NHS Federated Data Platform's objectives (NHS FDP) and advises on its development and implementation to ensure it maintains public trust. The NHS FDP programme is a government initiative designed to bring together data from across the health system to improve care. It will deliver a secure software system that allows NHS trusts and Integrated Care Boards to connect and access data they already hold (such as bed capacity, waiting list volumes, staff rosters, and supplies) without creating a central data store. Each organisation maintains its own instance, with strong technical and privacy controls, enabling better coordination, planning, and streamlined service delivery.

Since our last update, implementation and benefits realisation has continued to grow. We will continue to engage with the programme's updates, learning and feedback, including data on benefits realisation, whilst also listening to feedback and any concerns from digital leaders, users and implementers across the system.

Over the past year and beyond, we have contributed to the programme through strategic input and practical information governance advice. This has included participation in three key oversight groups: focused sessions on NHS FDP information governance with the NDG and the Information Commissioner's Office; the NHS FDP Check and Challenge Advisory Group; and the NHS FDP External Information Governance Advisory Group. We also take part in the Health and Social Care Data Public Panel, joining members of the public to provide early feedback on NHS FDP communications and related plans.

5.2.1 Supporting NHS England in identifying when a DPIA is necessary

A key part of our work has been advising the programme on when a data protection impact assessment (DPIA) is required. We helped develop a screening questionnaire to determine whether the data is genuinely anonymous. This tool helps the programme quickly and clearly decide if a DPIA is necessary. Whilst DPIAs are always required for personal data, much of the NHS FDP data is aggregated, with identifiers removed, and cannot be linked to individuals. The questionnaire has made the process more focused and efficient, saving time and resources.

5.2.2 Reviewing DPIA templates and specific DPIAs

In addition, our office has continued to review NHS FDP template DPIAs, examining them in depth. These are categorised by data type (such as pseudonymised or identifiable data) and by scale of use (national or local). Trusts and ICBs will use the local templates to support data use within their NHS FDP instances, whilst NHS England will use the national templates.

Early in the year, we also reviewed specific completed DPIAs (including those for virtual wards and antimicrobial resistance projects) to assess how the templates were working in practice. Our reviews have provided clarity on the legal basis for data sharing, ensuring consistent application aligned with the National Data Opt-out framework.

5.2.3 Right to object: establishing a clear position

In conjunction with other stakeholders, our office has also supported the system to reach a clear and consistent position on patients' right to object to their data being processed in the NHS FDP. This had been an area of initial uncertainty, but through continued dialogue across organisations, the programme has now agreed a uniform approach with consistent language. This clarity is helping to embed a robust and patient-centred position across multiple guidance documents and operational policies.

5.3 Supporting national public engagement on the use of health and care data

The NDG continues to chair the independent steering group supporting NHS England and the Department of Health and Social Care's large-scale public engagement programme. The programme, announced in September 2023, has gathered public views on key aspects of digital and data policy in the NHS in three cohorts (with a fourth planned):

1. Principles of data use and access
2. The Single Patient Record and secondary uses of the GP data
3. The opt-out landscape

The ONDG has contributed by reviewing and helping to shape the questions to consider materials used in public deliberation sessions, including workshop discussion guides. A NDG panel member also sits on the steering group to provide additional independent input. The NDG has meanwhile actively participated in engagement sessions as a subject matter expert, both speaking directly to public participants and recording a video that was shown during the workshops.

5.4 Supporting opt-out reform

5.4.1 Engaging the public about opt-out reform

In March 2024, DHSC colleagues attended a NDG panel meeting to provide an update on their opt-out reform plans, with a particular focus on public engagement. They confirmed their intention to run a large-scale engagement exercise, with one group of the public focused solely on the opt-out landscape. The NDG panel offered pointers on shaping the engagement, which DHSC welcomed as valuable input ahead of the design phase.

Reforming opt-out systems remains a complex task within a constantly evolving health data and IT landscape. Any solution must be 'future-proofed': flexible enough to remain fit for purpose whilst not creating barriers that hinder future innovations benefiting the public. We welcome this commitment to seeking public views to inform data policy and remain ready to offer further guidance and support as needed.

5.5 National Data Opt-out exemptions: patient experience surveys

National patient experience surveys provide valuable insight into people's views of their recent care, helping to identify where health and care services are working well and where they could be improved. Because the teams developing these surveys cannot see who has opted out via the National Data Opt-out (NDOO), they are unable to adjust the results to ensure they are representative of the wider population. This means the findings (statistical results) would have an inherent bias if the opt-out were applied. For this reason, when a new survey is being developed, the NDG is asked to support an exemption from the NDOO to allow access to the data needed to invite participants.

We believe that when people opt out of their data being used for research and planning – that is, for purposes beyond their own care – they generally do not expect this to prevent the NHS from asking them about their own care experiences.

In July 2025, the office responded rapidly to a request to support an exemption from the NDOO, enabling the identification and invitation of people to participate in the Neonatal Care Experience Survey. The NDG supported this exemption on the basis that everyone who has experienced this care should have the opportunity to share their views.

5.6 Supporting robust information governance in regional SDEs

The government's 2022 Data Saves Lives strategy committed to moving the NHS from a model of "data sharing" to "data access as default" for analysing health and care data, including social care, for secondary purposes. Supported by the 2022 Goldacre Review, this shift is being implemented through secure data environments (SDEs). These are secure platforms that allow approved users to access relevant health data for research and analysis without the raw data leaving the environment. There are currently 12 SDEs forming the NHS Research SDE Network: the NHS England SDE and 11 regional SDEs.

Last year, we provided advice to two regional SDEs – the East Midlands Secure Data Environment and the London Data Service – on developing and refining their information governance approaches. Our guidance helped them think through complex decisions, align with data protection principles, and strengthen data access processes – ensuring the safe and appropriate use of health data whilst maintaining public trust.

5.7 NHS Constitution consultation response

During 2024-25 we submitted a response to the Department of Health and Social Care's statutory consultation on the ten-year review of the NHS Constitution. The consultation sought views on proposed updates to the Constitution to ensure it continues to reflect current priorities for the NHS, including patient rights and responsibilities, equality and inclusion, sustainability, and the integration of research into care.

Our response focused on the proposals' implications for the use of confidential patient information (CPI). We welcomed the overall aims of the review, particularly the emphasis on reducing health disparities and strengthening research participation across the NHS. However, we noted that several of the proposed changes would depend on clear and consistent processes for accessing and using CPI. We recommended that the revised Constitution should recognise the essential role that CPI plays in understanding local health needs, supporting research, and delivering coordinated, person-centred care.

By contributing to the consultation, we aimed to support a version of the NHS Constitution that enables appropriate use of data to improve care and outcomes, whilst maintaining public confidence in the handling of personal information.

5.8 Embedding clinical AI in national screening programmes

In February 2025, the Office of the National Data Guardian participated in a workshop hosted by the NIHR Incubator for AI & Digital Healthcare and the UK Centre of Excellence for Regulatory Science and Innovation in AI & Digital Health (CERSI-AI) to look at embedding clinical AI in national screening programmes. The workshop brought together clinical, academic, industry, and regulatory experts to explore how AI can be embedded in national screening programmes, focusing on validation, commissioning, implementation, and monitoring. A short policy output based on the workshop conversations will be published on the CERSI-AI website to support wider engagement and visibility.

5.9 Digital (Use and Access) Act 2025

The Digital (Use and Access) Act 2025 received Royal Assent on 19 June 2025.

Throughout the development of the legislation, the NDG provided advice on aspects of the Bill that impacted our ongoing commitment to transparency, public trust, and the responsible use of health and care data.

We particularly welcomed provisions to support the development and adoption of information standards in adult health and social care, including those set out in Schedule 15. These have the potential to enable greater consistency in data handling and contribute meaningfully to initiatives such as the development of a single patient record.

In our engagement on the Bill, we strongly advocated for the importance of maintaining transparency obligations when data collected directly from individuals is subsequently used for research. Our view remains that transparency should be interpreted broadly, including a range of communication techniques (such as public notices and layered messaging) rather than individual notifications. The Act now includes provisions under Clause 77 for situations where providing information might involve disproportionate effort, we note the continued requirement for data controllers to take appropriate measures to safeguard individuals' rights and freedoms, including by making information publicly available.

5.10 Work with Understanding Patient Data

Understanding Patient Data works to make the use of patient data more visible, understandable, and trustworthy for patients, the public and professionals. Its vision closely aligns with that of the NDG, and we have collaborated over the years to support each other's work. We serve as an advisor on the UPD Steering Group and, during the year, provided practical input to some of their projects.

We would like to amplify UPD's research findings from the past year, given their insights may be relevant to those reading this report.

- Public attitudes towards patient data for planning and population health (8 May 2024)
- Language to use when explaining secure data environments (SDEs) / trusted research environments (TREs) to the public (16 May 2024)
- The use of data in integrated care systems (ICSs) (5 June 2024)
- Secure data environments survey update / SDE evidence summary (November 2024)
- Public attitudes and information needs about GP record data (8 May 2025)
- Understanding health data security in direct care (22 May 2025)

We continue to engage with UPD's work, drawing on their public attitudes research insights to inform our own policy advice and initiatives.

6 Objective 3: Supporting health and care organisations to uphold the Caldicott Principles and make well-informed decisions about data

I am committed to improving health and care organisations’ ability to handle and share information securely, confidently, and in compliance with the National Data Guardian’s Caldicott Principles: eight good practice guidelines introduced to ensure people’s information is kept confidential and used appropriately. From the frontline to the boardroom, I will strive to cultivate a culture of awareness and understanding of the safe, appropriate and ethical use of data, and why this matters to patients and the public.

Everyone working in health and care, at all levels, needs to feel supported and well-informed when it comes to making decisions about people’s health and care information. In many instances, leadership around these activities falls to Caldicott Guardians. By resourcing and actively participating in the work of the UK Caldicott Guardian Council, I will increase the availability of information and support to help those upholding the Caldicott Principles.

I set the following work priorities under this objective:

- I will sponsor and actively participate in the work of the UK Caldicott Guardian Council, to ensure that Caldicott Guardians have the support and resources they require to provide effective leadership to their organisations regarding the handling and use of confidential patient information in line with the Caldicott Principles
- I will look for opportunities to support staff awareness and understanding of information governance good practice at all levels, to ensure that patient confidentiality is maintained whilst ensuring data is used appropriately for both patient care and public benefit.

I have delivered the following work in support of this:

6.1 Developing better IG guidance for health and care

As part of the Health and Care Information Governance Panel (HCIGP) working group, run by the NHS England IG Policy Engagement Team, the Office of the National Data Guardian has contributed to shaping national guidance available on the NHS Transformation Directorate Information Governance portal.

The portal provides clear, consistent guidance to help staff use information appropriately in supporting care, with dedicated sections for patients, frontline staff, and information governance professionals. The HCIGP working group reviews and refines draft guidance produced by its members before it is approved for publication.

From April 2024 to November 2025, the following guidance was published on the portal:

- Updated Open SAFELY FAQs and data analytics service DPIA
- Guidance on information sharing with the Department for Work and Pensions
- Guidance on sharing information relating to Infected Blood Compensation Authority claims
- Subject Access Request (SAR) form template (linked via our existing SAR guidance)
- Guidance on information risk and impacts to individuals following personal data breaches
- Guidance on sharing information during major incidents and emergencies
- Guidance on Freedom to Speak Up
- Updates to guidance on sharing information with the police
- Guidance on requesting information from a public body: freedom of information
- A just culture guide for IG and cyber security
- Update to guidance on access to the health and care records of deceased people
- Update to guidance on Subject Access Requests (SAR)
- Update to guidance on personal data breaches and related incidents
- Managing Subject Access Requests (SAR) training
- Becoming an Information Asset Owner training
- FAQs about the Equality, Diversity and Inclusion in Health and Care Research pilot
- Training: Handling freedom of information requests
- Using information for reflective practice
- Access to the health and care records of deceased people
- Cyber incident IG checklist and template notification letter
- O365 migration DPIA templates
- Sharing information relating to Infected Blood Compensation Authority claims

6.2 Supporting the NHS Data Security and Protection Toolkit

The Data Security and Protection Toolkit (DSPT) is an online self-assessment tool used by health and care organisations to demonstrate how they are meeting data protection and information security requirements.

It was originally aligned with the National Data Guardian's (NDG) 10 data security standards, which set a framework for how the security of patient information should be maintained. In September 2024, the DSPT began its transition away from the 10 data security standards, beginning instead to use – for some larger organisations – the National Cyber Security Centre's Cyber Assessment Framework (CAF) as the underpinning assessment mechanism.

The CAF is a national framework that provides a structured approach to assessing cyber security across all sectors. Whilst comprehensive, the CAF is deliberately sector-neutral, meaning it does not always reflect the specific responsibilities of health and care organisations. Our role has been to help adapt the CAF within the DSPT, ensuring that it continues to meet the NDG's data security and protection expectations, and remains appropriate for the unique needs of health and care.

The CAF aligned toolkit is currently only used by organisations identified as needing to meet enhanced DSPT standards. These are typically large or complex organisations with significant data-sharing and governance responsibilities, such as integrated care boards and NHS foundation trusts.

6.2.1 Embedding health and care priorities into the framework

Introduction of objective E

A key contribution this year was supporting the development of Objective E: Using and sharing information appropriately. This objective was introduced in addition to the existing CAF objectives specifically for health and care organisations to carry forward important elements of the NDG's 10 data security standards that were not fully addressed in the CAF. We worked closely with the DSPT delivery team through multiple rounds of feedback and review. The result was an objective that reinforces the responsibilities of health and care organisations to protect confidentiality, maintain public trust, and ensure that information is used safely to deliver care.

6.2.2 Strengthening guidance on cyber resilience

Following the launch of the CAF-aligned DSPT, we supported the refinement of guidance materials. We focused on: Objective B: protecting against cyber attacks and data breaches and Objective D: minimising the impact of incidents

Our input emphasised strengthening organisational planning for cyber incidents and improving recovery processes.

Ensuring the clinical perspective

Drawing on lessons from the Synnovis cyber attack, we highlighted the need to embed a senior clinical voice within incident response and business continuity planning. This helps ensure that potential risks to care are fully understood and addressed, recognising that significant disruption to clinical services can persist long after technical systems are restored.

The DSPT team responded positively to our contributions, adopting our recommendations and working with us to interpret and apply them effectively. Our aim was to ensure that the CAF-aligned DSPT is not only technically robust but also tailored to the specific needs of health and care, safeguarding patient data whilst supporting the safe delivery of services in the event of any incident.

6.3 Clarifying engineers’ access to confidential patient information

We frequently receive questions from across the health and social care system about when engineers can access confidential patient information (CPI) within health and care information systems. In response to these recurring queries, the NDG developed a position setting out the circumstances in which technical staff carrying out maintenance on electronic patient record systems can be considered to be acting under the 2013 definition of direct care established in Dame Fiona Caldicott’s Information Governance Review.

Given that the definition of direct care is owned by the NDG, it is important that we provide clarity on matters such as this. Without it, health and care organisations and researchers may be uncertain about when implied consent applies, when alternative legal bases are required, and how to ensure compliance with the common law duty of confidentiality.

Our position sets out three scenarios: maintenance for systems used for direct care; maintenance of systems that support both direct care and research; and maintenance of systems used specifically in research. By outlining this position, the NDG gives organisations confidence that they can continue to use and maintain systems safely whilst meeting their legal and ethical obligations. We are already applying this position to provide consistent responses to the queries we receive, and it is also being used by the Confidentiality Advisory Group when advising on applications for Section 251 support.

6.4 National guidance on instant messaging for direct care

In 2025, concerns were brought to the National Data Guardian about the use of instant messaging platforms to communicate with patients for direct care. In exploring these concerns, the NDG identified that there was no definitive guidance in place to provide clarity and assurance across the health and care system.

Acting on this, the NDG worked with national partners to address the gap. In collaboration with our office and other stakeholders, NHS England is now developing new guidance on texting, emailing and messaging patients and service users. This guidance provides clarity on the distinction between contact preferences and objections to receiving messages in certain ways, and confirms the lawful bases required to comply with UK GDPR and satisfy the Common Law Duty of Confidentiality.

The NDG supported this work to promote greater consistency and transparency in patient communications across the system.

6.5 Information Commissioner's Office anonymisation guidance

In March 2025, the Information Commissioner's Office (ICO) published long-awaited anonymisation guidance, following consultations on the draft guidance, to which we contributed reviews, clarifications and suggestions. The guidance provides much-needed clarity on what constitutes anonymous and pseudonymous data. It is hoped this technical document will reduce inconsistent practice across the health and social care sector.

We welcome the ICO's clear position on terminology within this guidance, specifically their approach of discouraging use of the term 'de-identified' as a synonym for 'anonymous' or 'pseudonymous'. This term has long caused confusion in the health and care sector due to its lack of definition. The guidance highlights that, without specificity, 'de-identified' is ambiguous and unhelpful, particularly in technical documentation. By promoting greater precision in language, it supports a shared understanding and more consistent practice.

6.6 NHS Continuing Healthcare: information sharing template

The NDG provided feedback on a draft consent form developed by NHS England and the Department of Health and Social Care's Adult Social Care Directorate. This form is used to obtain explicit consent from individuals undergoing NHS Continuing Healthcare (CHC) assessments before sharing their personal information with family members, friends, or other representatives. Such consent is legally required, as sharing personal data with third parties without it would breach data protection and confidentiality regulations.

7 Priorities 2025-27

The National Data Guardian will continue to progress the core programme of work aligned to each strategic objective through to March 2027.

As we move into 2026-27, there will also need to be a strong transitional focus in readiness for Dr Nicola Byrne's departure at the end of March 2027 when her tenure as National Data Guardian concludes.

As Dr Byrne reflects in her introduction, there is profound change underway, notably plans to integrate NHS England into the Department of Health and Social Care by April 2027; and the delivery of the NHS 10 Year Health Plan – which sets out a bold ambition for a health and care system in England underpinned by data.

Whilst the health and care landscape will continue to evolve, and policy developments may arise that require additional work, the report has set out in detail a number of 'big ticket' areas summarised in the table below where sustained focus will be maintained:

Opt-out reform to continue to advise through next phase of development, in particular on the importance of clarity, coherence, and timing: aligning potential changes with wider system developments.	**Health Data Research Service** to continue to advocate for simpler access for projects delivering public benefit, robust protections and choices for patients and the public, and clear communication about how HDRS operates and the mechanisms that keep data safe.	**NHS Single Patient Record** to champion clarity, transparency, and inclusivity, and ensure that the voices of clinicians and patients shape a system that will hopefully deliver real benefits without compromising safeguards or equity.
NHS Federated Data Platform to continue to advise on the development and implementation of the NHS FDP, to ensure clarity, consistency and appropriate safeguards across the system as the programme's implementation and	**Health Service (Control of Patient Information) Regulations 2002 (COPI)** to continue discussions with the Department of Health and Social Care on early proposals to modernise regulations with focus on timely and proportionate data use and protections.	**Supporting public and staff engagement** to shape next steps following publication of our report Can communications create reasonable expectations about uses of health and care data? Insights from co-design and public testing. We will also explore the feasibility of working with the

benefits realisation continue to develop.		UKCGC on a staff-facing communications campaign to promote good practice in maintaining patient and service user confidentiality.

8 Supporting the system through board and panel membership

The NDG provides much of its advice and guidance through regular meetings and participation in different boards, panels, and groups. In the year 2024-25, the NDG or delegated representatives attended the following:

Title	Attendee
Cyber Futures Programme Board	Rob Shaw
Health and Care Information Governance Policy Group	Dr Nicola Byrne
Digital Social Care Advisory Group	John Carvel
Health and Care Information Governance Working Group	Dr Vicky Chico
Professional Record Standards Body Advisory Board (PRSB)	John Carvel
Health and Social Care Data Public Panel	Layla Heyes
Data Access and Delivery Forum	Dr Vicky Chico
Federated Data Platform Check and Challenge Group	Dr Nicola Byrne
Data Strategy Advisory Panel	Dr Nicola Byrne
The Federated Data Platform Information Governance group	Dr Vicky Chico
NHS England's Large-Scale Public Engagement Steering Group	Dr Nicola Byrne is the Chair; Jenny Westaway also attends
Consent for Research Assurance Group (CRAG)	Dr Nicola Byrne
Understanding Patient Data Steering Group	Layla Heyes

9 Financial statement

The National Data Guardian (NDG) is a non-incorporated office holder who does not employ staff, hold a budget, or produce accounts. The Department of Health and Social Care (DHSC) holds the budget and reports expenditure through the DHSC Annual Report and Accounts.

The budget meets the costs of:

- The Office of the NDG, hosted by NHS England
- the work of the NDG and their advisory panel
- the work of the associated UK Caldicott Guardian Council
- events, public engagement, and legal advice
- the remuneration of the NDG

Except for the NDG’s remuneration (the NDG is paid as a public appointee), the NDG has the flexibility to determine the allocation of the available budget according to in-year priorities.

For 2024-25, the budget was £900,000 which included funding to cover the cost of the NDG’s public engagement project for 2024-25.

10 Appendix A: NDG panel members

The following panel members supported the NDG during 2024-25:

- Dr Natalie Banner
- John Carvel
- Professor Ian Craddock (left July 2024)
- Dr Arjun Dhillon (Outgoing UK Caldicott Guardian Council Chair) (left May 2025)
- Claire Delaney-Pope (joined September 2024)
- Dr Edward Dove (left September 2024)
- Dr George Fernie (New UK Caldicott Guardian Council Chair) (joined November 2024)
- Dame Moira Gibb (left March 2025)
- Dr Fiona Head
- Dr Jeffry Hogg (joined March 2025)
- Mr Adrian Marchbank
- Dr Jess Morley (joined June 2024)
- Maisie McKenzie
- Professor Daniel Ray (joined June 2024)
- David Sharp (joined January 2025)
- Rob Shaw
- Jenny Westaway
- Professor James Wilson

Read NDG panel member biographies.