Department of Health & Social Care

Data saves lives

Reshaping health and social care with data

Published 13 June 2022

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Ministerial foreword

The use of NHS data was at the forefront of this country's fight against coronavirus (COVID-19), helping us to remove restrictions and return on the path to normal life.

Now that we are living with COVID-19, we must keep this momentum going, and apply it to the long-term challenges ahead of us, including tackling the COVID backlog and making the reforms that are vital to the future of health and care.

Earlier this year, I made a [speech setting out my 4 priorities for reform in health](#):

1. Prevention.

2. Personalisation.

3. Performance.

4. People.

We cannot deliver the change that we need to see – and our 10-year plans for [cancer](#), [dementia](#) and [mental health](#) – unless we embrace the digital revolution and the opportunities that data-driven technologies provide.

There is so much more to do if we are to make the NHS and social care more data driven, and reassure people that their data will be handled safely and ethically.

This strategy shows how we will use data to bring benefits to all parts of health and social care – from patients and care users to staff on the frontline and pioneers driving the most cutting-edge research.

It is backed by a series of concrete commitments, including:

- investing in secure data environments to power life-saving research and treatments

- using technology to allow staff to spend more quality time with patients

- giving people better access to their own data through shared care records and the NHS App

This is on top of the huge investment that we have already made – for instance, investing £200 million in our Data for Research and Development programme.

Last year, we published this strategy in draft so we could gather views from far and wide. I'd like to thank the hundreds of people and organisations who shared their views, which were invaluable in shaping this final product.

I'd also like to thank Professor Ben Goldacre for his work on the review of how we could make better, safer use of health data for research and analysis (known as the Goldacre review), which was published in April, and made a compelling case for how data can drive innovation and improve healthcare. I fully support his recommendations and this strategy shows how we are already taking them forward.

The title of this strategy says it all: data saves lives. If we put this plan into action, and unlock the incredible power that data possesses, we can bring the future forward, and make us all healthier and safer.

– The Rt Hon Sajid Javid MP, Secretary of State for Health and Social Care

NHS England Transformation Director foreword

The future of the NHS depends on improving how we use data for 4 related purposes:

1. For the direct care of individuals.

2. To improve population health through the proactive targeting of services.

3. For the planning and improvement of services.

4. For the research and innovation that will power new medical treatments.

Data helped power the NHS through the pandemic. The NHS Datastore has helped us get ventilators sent to where they are most needed, data helped us recruit 46,000 patients into the RECOVERY trial to test treatments for COVID-19, and data allowed the sharing of advanced care plans with ambulance and A&E staff to enable more complete assessment, safer care and speedier discharge.

Better use of data will be critical to the new integrated care systems. They will be responsible in their local areas for:

- improving population health and care

- tackling unequal outcomes and access

- enhancing productivity and value for money

- supporting broader social and economic development

All of this will require good quality data and data systems to underpin effective working across multiple local organisations.

The NHS Long Term Plan sets out our aspiration to make digitally enabled care mainstream across the NHS, and this strategy – along with What Good Looks Like, Who Pays for What and the Unified Tech Fund – provides the guidance and support integrated care systems need to make this a reality.

At a national level, the merger of NHS Digital and NHS England and NHS Improvement (NHSEI) will allow us to make the most of NHS data while maintaining safeguards so the public and staff have confidence that data is safe and being used appropriately.

The joining of these NHS bodies will also improve co-operation and provide the strong national leadership that is needed to support the recovery of NHS services, address waiting list backlogs, and support hardworking staff, all while driving forwards an ambitious agenda of digital transformation and progress.

All of us within the NHS are dedicating ourselves to bringing the benefits of data to the service of better care, improved outcomes, and more efficient services.

– Dr Tim Ferris, National Director of Transformation, NHS England

1. Improving trust in the health and care system's use of data

Our vision: the public have confidence in how their data will be handled, and are happy for their data to be used to improve the care that they and others receive

As someone using health and adult social care services, I and those who support me will have:

- confidence that my data is being handled in a way that is safe and secure

- a good understanding of how my data is being used, both for my individual care, and for improving population health, planning, innovation and research

- greater access to my own health and care data, and the power to choose how it is used

Why this matters

Up-to-date information about our health and care is critical to ensuring we can:

- plan and commission services that provide what each local area needs and support effective integrated care systems

- develop new diagnostics, treatments and insights from analysing information so the public have the best possible care and can improve their overall wellbeing

- stop asking the public to repeat their information unnecessarily by having it available at the right time

- assess the safety and quality of care to keep the public safe, both for their individual care and to improve guidance and regulations

- better manage public health issues such as COVID-19, health and care disparities, and sexual health

- help the public make informed decisions about their care, including choosing clinicians, such as through patient-reported outcome measures (PROMs) that assess the quality of care delivered from a patient's perspective

When it comes to handling personal data, [the NHS has become one of the most trusted organisations in the UK by using strict legal, privacy and security controls](#). Partly as a consequence of this track record, the National Data Guardian's recent report [Putting Good Into Practice](#) found that participants were supportive of health and social care data being used for public benefit. This reflects [previous polls, which show most respondents would trust the NHS with data about them](#) (57% in July 2020 and 59% in February 2020).

During the pandemic, we made further strides in harnessing the power of data:

- identifying patients who could take part in trial treatments

- delivering vaccines to the most vulnerable first

- creating both the [Coronavirus Dashboard](#) and the [NHS COVID Pass](#)

However, we cannot take the trust of the public for granted. In the summer of 2021, we made a mistake and did not do enough to explain the improvements needed to the way we collect general practice data. The reasons for these changes are to improve data quality, and improve the understanding of the health and care system so it can plan better and provide more targeted services. We also need to do this in a more cost-effective way as the current system using ad hoc collection processes is more expensive and inefficient, and has been criticised by the National Audit Office and the House of Commons Public Accounts Committee.

Not only did we insufficiently explain, we also did not listen and engage well enough. This led to confusion and anxiety, and created a perception that we were willing to press ahead regardless. This had the unfortunate consequence of leading to an increase in the rate of individuals opting out of sharing their data. Of course, individual members of the public have the right to opt out and always will. But the more people who opt out, the greater the risk that the quality of the data is compromised.

This is why the then-Minister for Primary Care wrote to GPs and explained the actions we were going to take to put this right in the short term. We acknowledged that more work needed to be done and set a number of conditions that would need to be met before the primary care data collection would start. We also promised Parliament we would learn the lessons, and work to maintain public trust and confidence.

In this data strategy, which differs from the [draft we published last year](#), we are putting public trust and confidence front and centre of the safe use and access to health and social care data. The data we talk about is not an abstract thing: there is an individual, a person, a name behind each piece of data. That demands the highest level of confidence. It is their data that we hold in trust and, in return, promise to use safely to

provide high-quality care, help improve our NHS and adult social care, develop new treatments, and, as a result, save lives.

The GP Data for Planning and Research programme provides a blueprint we can build on. Already the programme is demonstrating a much-improved way of working with, and listening to, stakeholders and the public to shape the overall approach. This ensures patients and the public are engaged in the conversation, can input into the design and are made aware of the future changes.

We need to build on this to demonstrate that the health and care system is a trustworthy data custodian, and we will do this in 5 ways:

1. Keep data safe and secure.

2. Be open about how data is used.

3. Ensure fair terms from data partnerships.

4. Give the public a bigger say in how data is used.

5. Improve the public's access to their own data.

At the heart of this new approach will be a new pact with the public, which will reset the conversation on health data. We will develop it in concert with patients, stakeholders and the healthcare professions. It will set out rights and responsibilities, and will rightly hold us to account.

On wider efforts to improve trust and transparency, we have made some progress already and some of this activity is described below in 'Progress so far'.

Progress so far

We have:

*   continued to safeguard personal information through the common law duty of confidentiality so personal information shared in confidence must not be disclosed without legal authority or justification

*   to support public trust in data use, placed the National Data Guardian on a statutory footing to act as an independent advisor on safe and appropriate use of people's confidential health and care information

- referred data requests to independent groups that provide robust scrutiny of the use of patient data such as NHS Digital's [Independent Group Advising on the Release of Data](#) and the NHS Health Research Authority's [Confidentiality Advisory Group](#)

- given the public the ability to choose to opt out of their health and care data being used for service planning and medical research purposes, and committed to regularly publishing [data on how many members of the public have opted out](#)

- established the [Centre for Improving Data Collaboration](#) to provide guidance and support to NHS organisations, and ensure data partnerships maximise benefits to the public we serve and the health and care system

- asked the public if and how data should be used, including a [2021 Citizens' Jury reviewing the use of data-sharing powers during the pandemic response](#)

- published [all data releases since 2012 through NHS Digital](#)

- created the [Coronavirus Dashboard](#) providing members of the public with up-to-date local and national data (19 million weekly views)

- transformed the public's access to a range of health and care services, and trusted anonymised information within the [NHS App](#) – 26 million users can now access services including the NHS COVID Pass, repeat prescriptions, organ donations and national data opt-out

Taking this further

Keeping data secure and safe

The government, the NHS and the adult social care system are committed to keeping the public's data safe. We will always uphold the public's rights in law, including those enshrined in the [Data Protection Act 2018](#) and the common law duty of confidentiality.

To build the public's trust that their health and care data is only accessed in ways that are secure and safe, we will bring in new privacy-enhancing technologies that help us keep personal information safer than ever. As noted by the [Centre for Data Ethics and Innovation](#), privacy-enhancing technologies include:

- federated analytics

- homomorphic encryption

- differentially private algorithms

- synthetic data

Most importantly, we will establish secure data environments as the default route for NHS and adult social care organisations to provide access to their de-identified data for research and analysis.

Secure data environments

Secure data environments – a subset of which are known as trusted research environments – are a big step forward in how data can be accessed securely in a virtual setting. Analysis takes place within a secure online platform rather than data being shared and distributed.

In secure data environments, access to data is granted to authorised researchers in a controlled and recorded manner. This will put an end to the routine sharing and distribution of healthcare data for research purposes. Users' interactions with the data will be recorded and monitored, and the information they can extract will be assessed and with personal identifiers removed. As no data that can be linked to an individual leaves the server, and all access to the data and analysis is monitored, we will greatly reduce the risk of data breaches or other misuse.

We will be mandating the use of secure data environments for NHS data, and engaging with the public, both to demonstrate their inherent benefits and to understand any remaining concerns.

Subject to HM Treasury approval, the GP Data for Planning and Research programme will be a flagship example of a service where data will only be accessible via a secure data environment. This programme is being co-designed with other data and technology experts, researchers, NHS analysts and patients to make sure it delivers a robust, safe and secure service. For further information on the GP Data for Planning and Research programme, see section 2, 'Giving health and care professionals the information they need to provide the best possible care', and for more on secure data environments, see section 5, 'Empowering researchers with the data they need to develop life-changing treatments, diagnostics, models of care and insights'.

In 2023, NHS England will – subject to parliamentary processes – assume responsibility for NHS Digital's functions. As part of the transfer, we will create a statutory safe haven for health and care data in NHS England. NHS England's use of data, including how it shares data externally, will be subject to independent scrutiny.

This will ensure transparency and the continuation of the high standards of data security exemplified by NHS Digital.

Our commitments

By December 2022, we will work with expert partners and the public to implement secure data environments as a default across the NHS. We will do this by delivering:

- a clear public guide to secure data environments and our overarching policy guidelines for the use of secure data environments

- a robust accreditation regime to ensure our high standards for secure data environments are implemented. This will include not only accreditation requirements for secure data environments but also guidance and oversight on users of the environment, as well as the process to monitor and assess implementation

- a full technical specification, drawing on industry best practice, including requirements to ensure interoperability, cyber security and the use of privacy enhancing technologies

- a comprehensive roadmap to ensure all partners across the system know how to implement our framework, with clear indicative timescales and expectations for those at different readiness levels. This will include not only those delivering the transformation in the NHS but also software providers, academic and industry researchers, as well as funding agencies

Being open about how data is used

We recognise the importance of transparency in building trust and retaining public confidence in government decisions. This was one of the key findings in the [Office for Statistics Regulation's recent report on lessons learned from the COVID-19 pandemic](). Transparency and working in the open also improves accountability, and helps ensure that the end product is better designed for users.

As well as improving transparency, we will explain more clearly how data is being used across the health and care system. We need to make clear to the public about how and why data is used. We need to build a broader understanding of how data can help us support individual care, how the system works, and how we develop new ways to improve everyone's care. This includes:

- accessible information about the benefits and risks of data use

- the safeguards we have in place to keep their information safe

- how they can opt-out of sharing their data for purposes other than their individual care

We will give the public the opportunity to have their say on data issues and take part in engagement activities that help inform our decision-making. We will make sure that we are regularly checking in with the public about what they need and their expectations around the use of data.

We will also be transparent about the latest data developments in health and care, including regular updates from data programmes such as shared care records and GP Data for Planning and Research, which are still subject to HM Treasury approval.

Our commitments

We will:

- work with the public to establish, for the first time, a data pact that will set out how we will use health and care data and what the public has the right to expect – by December 2022

- co-design a transparency statement, as part of a regularly updated online hub, setting out how publicly held health and care data is used across the sector – by December 2022

- lead the work of the Health and Care Information Governance Panel to develop additional information governance guidance, including the first part of the information governance frameworks for integrated care covering individual care and standards (such as data sharing and transparency), so the public can be confident in our handling of their data, to be published on the information governance portal – completed December 2021

- establish an expert advisory group, drawn from a wide range of stakeholders from across health and adult social care, with whom we will co-design a robust and detailed plan for rebuilding public trust, including commitments set out in this strategy, and provide a check-and-challenge function to make sure we never fall below the ambition and standard set out in this strategy – by June 2022

- agree, with the expert group, how we will transparently measure and monitor levels and drivers of public trust so that all organisations using health and care data have up-to-date information about the public's attitudes to data use – by December 2022

A data pact

A data pact or charter between the public and the health and care system will set out shared expectations on both sides in simple, clear and accessible language.

It will provide clarity and certainty about what does – and does not – happen to health and care data, and give the public confidence that the health and care system is a trustworthy custodian of data.

This will be co-designed through public dialogue, and with the advice and support of experts including the National Data Guardian.

Depending on public views, it could include pledges such as:

* "We ask that you provide us with complete and accurate information, and inform us when that needs updating…"

* "Your data will be used in the following ways…."

* "We make the following commitments to strong governance, security and transparency…"

* "The choices you have are…."

To get involved and help shape this initiative, register your interest on our online hub.

Ensuring fair terms for data partnerships

Data partnerships between health and care partners, charities, academia or industry organisations (such as life science companies) are essential. Providing researchers, industry, charities and other partners with access to data enables us to:

* improve the care we provide through clinical trials, and the development of treatments and medicines

* support colleagues to do their jobs by creating diagnostic or decision support tools and technologies that free up staff time and improve accuracy

* improve our health and care system by using insights from analytics platforms

* provide more care and invest in services by bringing funding into the system on fair terms, such as reduced costs for drugs or treatments, or a return for contributions to the development of intellectual property

We have heard the concerns about third parties having access to health and care data. We will ensure that data partnerships are developed in a way that is safe, lawful, ethical and transparent.

The public has a right to know if and how data about them is being used, and by whom, and that their privacy and rights are safeguarded throughout. That is why we have developed 5 principles (set out in the box below titled 'The 5 principles to help the NHS realise benefits for patients and the public in data partnerships') to help us to seize the opportunities for data-driven innovation and ensure they are based on fair terms, but only in a way that is safe, secure and transparent.

The Centre for Improving Data Collaboration is leading work to develop a value-sharing framework that will support the health system to deliver good data partnerships by providing:

- a minimum standard to meet the 5 principles, and clarifying where there is room for local flexibility

- guidance on how to design and manage successful data partnerships

- case studies and practical examples from across the system, including for public and patient involvement and engagement, in line with the data standard for engagement

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The 5 principles to help the NHS realise benefits for patients and the public in data partnerships

In 2018, the second Life sciences: Sector Deal set out 5 draft principles to realise benefits for patients and the NHS where data underpins research and innovation.

The 5 principles were tested and refined following an extensive period of engagement with the NHS, medical research charities, public and patient engagement advocates, healthcare professionals, researchers, regulators and industry experts. A revised version was published in July 2019.

1. Any use of NHS data, including operational data, not available in the public domain must have an explicit aim to improve the health, welfare or care of patients in the NHS, or the operation of the NHS. This may include the discovery of new treatments, diagnostics, and other scientific breakthroughs, as well as additional wider benefits. Where possible, the terms of any arrangements should include quantifiable and explicit benefits for patients that will be realised as part of the arrangement.

2. NHS data is an important resource and NHS organisations entering into arrangements involving their data, individually or as a consortium, should ensure they agree fair terms for their organisation and for the NHS as a whole. In particular, the boards of NHS organisations should consider themselves ultimately responsible for ensuring that any arrangements entered into by their organisation are fair, including recognising and

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safeguarding the value of the data that is accessed and the resources that are generated as a result of the arrangement.

3. Any arrangements agreed by NHS organisations should not undermine, inhibit or impact the ability of the NHS, at a national level, to maximise the value or use of NHS data. NHS organisations should not enter into exclusive arrangements for data held by the NHS, nor include conditions limiting any benefits from being applied at a national level, nor undermine the wider NHS digital architecture, including the free flow of data within health and care, open standards and interoperability.

4. Any arrangements agreed by NHS organisations should be transparent and clearly communicated in order to support public trust and confidence in the NHS and wider government data policies.

5. Any arrangements agreed by NHS organisations should fully adhere to all applicable national level legal, regulatory, privacy and security obligations, including in respect of the National Data Guardian's data security standards, the UK Data Protection Act 2018 and the common law duty of confidentiality.

Our commitments

We will:

- develop a central portal for data partnerships guidance for healthcare leaders, and seek feedback ahead of a wider roll-out – in testing from January 2022

- publish the value-sharing framework, which will support the health system to deliver good data partnerships – by March 2023

- update the 5 principles to include the adult social care sector – by March 2023

- develop commercial principles to ensure that partnerships for access to data for research and development have appropriate safeguards, and benefit the public and the NHS, and NHS Digital's template contracts for access to data will be reviewed to ensure they are consistent with these principles – by December 2023

Giving the public a bigger say over how data is accessed and used

Meaningful engagement is an integral part of building trust in how data and information is used to improve health and care. If the public have not had a say in how data is used, they will feel disenfranchised and distrustful. We must change how we operate, clearly explaining and engaging the public, patients, service users, staff and stakeholders on how data is used.

This does not mean just broadcasting intentions after decisions have been made. It means a 2-way conversation, where we take the time to explain in accessible language how and why data could be used, and then we listen to the public's views and act on their feedback. This is the approach the GP Data for Planning and Research project has taken in recent months, working closely with patient groups and stakeholders to test their thinking before deciding on next steps.

To make sure we have a consistent approach when engaging with the public, we will agree on a standard for how organisations using health and care data effectively engage with the public and staff. This work will be part of wider plans to set agreed standards – mandated through legislation – such as standards for the collection and storage of data (as stated below in section 6, 'Working with partners to develop innovations that improve health and care').

This standard will set out best practice and expectations for health and care organisations, and any other body using NHS data, including research organisations. As the Goldacre review highlighted, researchers need access to practical guidance so they can help build public understanding.

As well as being able to influence future uses of data, it is also very important that individuals have an active say in how their data is used and can opt out of sharing their data beyond their individual care, should they choose to do so.

We agree with the National Data Guardian's recommendation that there should be more focus on improving how opt-out mechanisms work in practice, and engaging with the public to ensure choices are clear, coherent and simple.

Simplifying the opt-out

We want to simplify the opt-out process so that it is accessible, simple to action and easily explained.

Patient choice should be offered in one place, whether that relates to data leaving a GP practice or to other patient information.

The digital journey needs to evolve and improve to offer this – for example, the NHS App could display the different choices the public have in a simple and easily understandable 'tick box' format, so that citizens are clear what they are opting out of, and how their data will be used as a consequence.

To do this, we will listen to stakeholders and the public to ensure opt-outs are displayed in a user friendly and simple way, and that we are clear what choice is being offered to individuals, while making sure the NHS can continue to provide safe and effective care.

Our commitments

We will:

- develop a standard for public engagement, setting out best practice for health and care organisations, and any other body using NHS data, to engage appropriately with the public and staff across the system on data programmes and issues – by December 2022

- undertake in-depth engagement with the public and professionals, through forums such as focus groups with seldom-heard groups, and large-scale public engagement on topics and questions that are high priority or particularly complex, including how we deliver secure data environments and the future of the national data opt-out, and working closely with regions to understand local needs – from July 2022

- work with local health and care systems, and partners including integrated care systems, co-designing regional engagement to make sure that we understand the needs, concerns and opportunities for different communities across England – commenced from April 2022

- work with the public, the expert advisory group, the National Data Guardian and other stakeholders to ensure that we have a simple opt-out system in place that provides clarity and choice, giving patients confidence and ensuring data continues to support the functioning of the health and care system – from July 2022

Improving individuals' access to their own health and care information

We want to make sure that the public are active partners in their care, with access to the right information to inform their decision-making. By empowering the public to access their data and manage their care, we can deliver better outcomes, improve the public's experience and increase efficiency.

We are also looking at how we can make it easier for patients to access their own data and GP records, including mandating access as they have done in the United States. We have made significant progress in giving the public the ability to access their own data. For example, research shows that increasing numbers of patients want easy access to their health records and personal information, including 80% of the 25 million NHS App users.

However, the level and ease of access is not uniform across England, and we need to do better.

It is also important to enable parents, carers and healthcare professionals to access information about the children and young people they care for in a digital format, which is why we will look to develop the capabilities to support a digital personal child health record to enable safe, efficient and responsive services for children.

Operating in a way that supports individuals to be active partners in their care also means that digital tools to support care should not exacerbate health and care inequalities. Digital services should be inclusive for all communities and requirements, and should always be part of a multi-channel offering with appropriate support (including face to face) available to those who need it.

Our commitments

We will:

- improve access to GP records in the NHS App by giving patients access to their latest health information (November 2022), and provide patients with the ability to digitally request historic coded information including diagnosis, blood test results and immunisations – by December 2023

- continue to develop the NHS App so that 75% of the adult population will be registered to use the NHS App and NHS website, and content and services produced on these national channels will be tailored to a person's needs and choices, making it easy to self-serve and provide choice in the ways they interact with us – by March 2024

- continue to support local systems to roll out shared care records across England (subject to HM Treasury approval), providing the necessary data and API infrastructure to enable the public to access their records through national and local solutions – by December 2025

2. Giving health and care professionals the information they need to provide the best possible care

Our vision: staff will have easy access to the right information to provide the best possible care

As a member of health and adult social care staff, I will have:

- systems that provide quick and easy access to information about the individuals in my care, even if they have been treated or supported elsewhere. This will give me the data to make the right decisions and recommendations about their individual care, and reduce the time looking for information so I can spend more time with the individuals I am caring for

- all relevant information about individuals in my care, including if they wish to share information about their sleep or physical activity from wearable devices, so I can have informed conversations about their individual care

- confidence about when and how I should access data, giving me the assurance that I am respecting data privacy so that I feel empowered to access data for the benefit of individuals in my care and for the running of the system, such as for wider population health and proactive care

- full information about other professionals or unpaid carers involved in supporting individuals in my care so that I understand the whole situation and I can have the right conversations about care

Why this matters

We need to give staff up-to-date information about the person in front of them so they can provide the best possible care by:

- making more accurate diagnoses

- understanding their preferences to offer more personalised care

- keeping them safe

Frontline health staff spend large amounts of time collecting data – usually because information isn't accessible to them and they need to collect it again. When information is not available, they must find workarounds or look through paper-based documents. We want to make sure that the data is immediately available on the systems they use to do their jobs. We also have many data analysis tools, helping us identify patterns and trends, diagnoses and treatment possibilities at high speed.

If we get this right, we will not only deliver benefits to the public we serve, but we can also free up staff time to focus on what they do best, giving the best possible care to everyone, whilst respecting data privacy.

Progress so far

To support the COVID-19 pandemic response:

- NHSX issued one page of simple information governance guidance to help staff access data with confidence, with the support of the Information Commissioner and the National Data Guardian

- government used the Health Service (Control of Patient Information) Regulations 2002 to issue notices requiring public sector organisations to share patient information to support the COVID-19 response – find out more on the NHSX website

- NHSX, with NHSEI, established a single front door for anyone requesting data for COVID-19 response purposes

100% of integrated care systems now have a basic shared care record in place, and we have published the Information Governance Framework for Integrated Health and Care: Shared Care Records to support local implementation.

We have also:

- tripled the use of NHSmail in the social care sector, extending it across 10,000 care homes, and enabled nearly 4,000 domiciliary care sites, 4,200 dental practices and 2,300 optometry contractors to securely access data across secure email

- created the information governance portal to act as a single point of access for guidance for health and care staff, the public, and information governance professionals, including a new interactive search tool to let users quickly find specific records and retention times in the Records Management Code of Practice 2021

- published new information governance guidance to help health and care organisations deal with personal data breaches

- established the Data Alliance Partnership and board to reduce the burden on the frontline, including agreeing data and standards requirements, increasing data access and reuse, and delivering the best outcomes

- invested in new technologies, such as robotic process automation, to automate appointment bookings or situational reporting to free staff up to spend more time with patients and members of the public accessing care and support

Taking this further

Simplifying and transforming information governance

Information governance is about how to manage and access information safely and securely. However, information governance is perceived as technically difficult, complex and something to be feared. This interpretation often results in risk aversion and an inability to change.

We ran user research to further understand:

- staff perceptions of information governance

- the ways they access information governance guidance

- how it could be communicated more effectively

The research confirmed that frontline staff have great concern about the potential repercussions of a mistake or breach, and, in contrast to information governance professionals, require written guidance to be extremely concise and unambiguous.

Feeding into the risk-averse culture is the variance in the skillset of those in information governance roles. Many information governance professionals are highly competent whereas others may lack expertise or the ability to apply their knowledge in practical health and care situations. There are no common competency frameworks or job families for staff working in information governance across health and care.

In attempts to ensure compliance with the law, national bodies and regulators have created checklists, audits and reporting tools that now dominate the duties of information governance staff. However, there needs to be a recognition that the duty to share personal information can be as important as the duty to have regard for patient confidentiality. We need to leverage maximum benefit from information to enhance patient care and improve services, in accordance with the law. This can be achieved by working in multi-disciplinary informatics teams to solve problems and find solutions.

Case study: Carl Starbuck, Leeds and York Partnership NHS Foundation Trust

Carl said:

"Speaking as an information governance professional, an NHS employee and senior manager, and perhaps most importantly as a UK citizen, I have both welcomed and valued the timely, focused and concise information governance advice provided by NHSX throughout the COVID-19 emergency."

The simplified information governance guidance enabled Carl to:

- maintain support to his community of mental health patients via video conferencing when face-to-face contact was unsafe under lockdown

- quickly and confidently select the right, secure solutions so that individual care was not impacted by delays

- feel empowered, as an information governance professional, to select solutions in the best interests of service users

- ensure staff could feel confident that the NHS information governance leadership 'had their back'

He added:

"In short, at a time of great turmoil across the health and social care system, NHSX empowered information governance professionals to clear the path for our clinical colleagues to do the day job without fear of information governance or data protection come-back."

Awareness of information governance is not just important for experts. All health and care staff need the confidence to appropriately access data to support and deliver people's care.

Just as we are encouraging digital skills across health and care organisations, we must make sure the whole workforce, and the public, understand the important role information governance plays. A change of mindset is required to drive and build confidence in information governance as an enabler.

To achieve that requires a focus on new ways of working, and defined skills and abilities for new entrants into the profession. We need to change the experience of those who work in information governance and those who work with information governance so they perceive it as integral to excellent care.

We will accomplish the change by:

- influencing and creating a more dynamic, credible and professional workforce who are committed to driving a transformation of approach and behaviours across the sector

- championing the appropriate use of information to make a difference in setting competencies

- reviewing the skills and knowledge required, putting in place career paths, and creating communities of practice to rebuild a credible and self-respecting profession

To achieve maximum impact, the information governance profession must realise that they are part of a larger disciplinary team. While they need to major in information governance, they need to also understand the basics of cyber security, data analytics and ethics, and work closely with colleagues in those areas to resolve information problems.

Although a duty to share data across health and social care for an individual's care already exists (in Section 251B of the Health and Social Care Act 2012), staff still find it difficult to share information about individuals. This is the case between primary care (GPs and pharmacies) and secondary care (hospitals), between health and social care, or for administrators.

The Goldacre review recommendations on information governance, ethics and participation also envisage a simplified system with a consistent approach for managing data access requests, built on a common understanding, templates and standards.

We need to give our staff clear, simple guidance on what information they can access, who they can give access to, and for what purpose. This guidance must be appropriate and accessible for the range of organisations and individuals relying on it. We need to change the culture in which the rules are seen as a barrier. We need to shift the focus from a concentration on legal compliance to leveraging maximum benefit from information, enhancing patient care and improving the service, while still meeting legal obligations.

Information governance is multidisciplinary and analytics, IT, ethics and information governance teams must work together to achieve that overarching aim. Staff need to receive training on information governance throughout their careers, including during initial training, with an emphasis on why appropriate data-sharing is important, and how to ensure safe and secure access to data.

Our commitments

We will:

- improve information governance guidance so staff are confident in sharing individuals' data for their care, including publishing the [Information Governance Framework for Integrated Health and Care: Shared Care Records](#) – completed December 2021

- action the findings of the user research to embed the [information governance portal](#) as the one-stop shop for help and guidance, as evidenced by an increase in the number of visits to the online portal – commenced from April 2022

- working with the Health and Care Information Governance Panel, create fit-for-purpose rules around different types of data (such as pseudonymised), so that staff can clearly understand them, addressing concerns around pseudonymised data as raised by the Goldacre review – by July 2022

- develop a national information governance transformation plan, focusing on practical data-sharing situations, creating professional standards and addressing training for frontline staff – by December 2022

- establish a head of profession to ensure the development of competency frameworks, standards, job families and appropriate professional accreditation for information governance staff working in health and care – commenced from April 2022

- lead the development and implementation of information governance as part of a multidisciplinary function for informatics and champion the work of information governance professionals – by December 2022

- review the [Data Security and Protection Toolkit](#) and its language to bring it into line with our work to simplify information governance – by July 2022

Case study: Kelly Brow, speech and language therapist, Bradford District Care NHS Foundation Trust

Kelly said:

"Returning from maternity leave at the start of a major pandemic, I did expect to see fundamental changes.

"My first week back started with a session to fit my personal protective equipment (PPE). I was also told I'd take a video-first approach to my patients… We needed to get to grips with video-calling tools."

The simplified guidance [Video conferencing with colleagues](#) gave Kelly confidence to:

- provide video care and assessments to service users ranging in age and level of disability

- spend time with patients instead of issuing and chasing individual video call consent forms

- undertake in-depth video and telephone triage of swallowing difficulties to give instant advice over the phone where appropriate, and make follow-up calls more quickly

- easily share tools and exercises with patients for use during the video session or to refer to between appointments

She added:

"NHSX guidance has helped staff and trusts to quickly recognise that we are covered appropriately to use video-calling tools."

Sharing anonymous health and social care information

We want to drive a change in the culture towards data-sharing across the health and adult social care sector. We want to make sure that information is shared appropriately for the benefit of everyone using health and care services, and the running of the system as a whole.

As well as improving information governance guidance, we will introduce a new power allowing health and adult social care organisations to require anonymous information from each other and from commissioned private providers. This will help to ensure that anonymous information will be more effectively and seamlessly shared across the system. Before we enable the use of this power, we will undertake an assessment of its impact and use secondary legislation to ensure that it does not create an undue burden on organisations.

This new power will only apply to information that is in a form that does not identify any individual or enable the identity of any individual to be ascertained – information that is not subject to the UK General Data Protection Regulation, Data Protection Act 2018 or the common law duty of confidentiality. There is more detail about this in paragraphs 74 to 79 and 730 to 736 of the Explanatory Notes on the Health and Care Bill.

Organisations will not be required to anonymise information for the purpose of providing it and they will only be required to provide information that they already hold.

We will also introduce a power to make regulations setting out exceptions to the requirement to provide anonymous information. Issues such as minimising the burden on

providers and protecting commercially sensitive information may be taken into account when introducing exceptions. It is intended that the requirement will not come into force until regulations are made.

Our commitments

We will:

- introduce a statutory power to enable health and adult social care public bodies to require anonymous information that relates to the provision of health and adult social care services in England – delivery date subject to Parliamentary processes

Delivering shared records

We want a world where every person and the health and care professionals involved in their care can draw information from, or put information into, the same shared care record in a safe and straightforward way.

To make this vision a reality, we are extending our shared care records programme. These make it possible for staff that use different data systems, or record their data in different ways, to see a person's information in one shared record. This will help us put the public's safety and care first, and break down the barriers that exist between health and care.

The programme is focusing first on linking general practice and hospital trusts, working towards comprehensive record-sharing by 2024 (in line with the NHS Long Term Plan and allowing the public to make their own contributions into that shared care record.

We are also working to make the data categories captured within the shared care record responsive to need, as revisions are made to the core information standard 1.0 with input from professionals and the public.

Our commitments

We will:

- ensure that each integrated care system has a basic shared care record in place to enable sharing of key information between GP practices and NHS trusts – completed March 2022

- support every integrated care system to ensure that all organisations are able to access a shared care record that meets the requirements set out in the standards roadmap, enabling individuals, their approved caregivers and their care team to view and contribute to the record – by December 2024

Reducing the data collection burden

Requests for data can often be burdensome to both the NHS and social care frontline. In November 2020, the Department of Health and Social Care (DHSC) published a [report on excessive bureaucracy in the health and social care system](#). The results were striking, showing how collecting data can pull staff away from providing health and care.

Clinicians can be asked to record every instance of a particular procedure, or managers to pull together counts of bed or care home occupancy. It is important that this information is collected to make sure that services run properly, but we need to do so in a smarter way.

Reducing the data burden on staff has benefits by being able to give them time back. By moving from manual data collection to automated systems, staff can spend more time using data to do their jobs rather than collecting it.

Understanding where we already have the right amount of data collection means we can prioritise the areas where we urgently need more data – for example, across adult social care. It will help:

- eliminate duplication

- save unnecessary costs

- make sure that we have the right data we need for the health and care system to work at its best

The new [Data Alliance Partnership](#), made up of organisations from across health and social care, is focused on placing a minimal burden on the frontline. Its remit includes:

- accountability: working on behalf of the whole system when collecting and sharing data, and reporting on progress to the Secretary of State for Health and Social Care

- streamlining data collection setting sharp, measurable targets for reducing the burden on frontline staff

- preventing 'collection creep': new collections may not be mandated if the alliance's board does not agree to put them on the list

- encouraging data sharing: sharing data across the alliance, using existing powers, and in accordance with agreed criteria for different categories of data and in compliance with data protection legislation

- building for the long-term: agreeing an architecture that reduces the burden over time

- advocacy: communicating the work, so colleagues can see what is being done and the value of the collections that remain

Secure data environments, where data is accessed and analysed in situ, provide opportunities to maximise and streamline the use of these data sets. This will significantly reduce the volume of separate data collections that are currently required, and reduce the burden on health and care staff.

The GP Data for Planning and Research (GPDPR) collection is an example of this. Its implementation will mean that data is collected once in a secure manner and used many times to improve health and care, when it is appropriate, safe and legal to do so.

Once fully operational, the service will provide a secure and efficient data service via a secure data environment so that planners and commissioners can make informed decisions without GP practices having to deal with data requests from different bodies.

Researchers and analysts will be able to go to just one place to securely access the information they need to develop new medicines and treatments, and the patient-level data does not leave the secure environment.

Access to this data will only be granted for specific health and care planning, and research purposes, to those who have a legal basis and legitimate need to use the data. Access will be fully auditable, with independent oversight of any data access requests and information about all data access being published.

Our commitments

We will:

- put in place a system-wide target for the rationalisation of data collections to reduce the time spent by health and care staff inputting and processing data for national use – by end of 2022 and reviewed annually

The UK Health Security Agency (UKHSA) will:

- put FAIR (findability, accessibility, interoperability and reusability) principles at the heart of its data strategy, designing institutional capabilities and processes that reduce burdens on public health system stakeholders while responding to user needs – by September 2022

Harnessing remote monitoring data

Remote monitoring can give health and care staff access to robust, real-time data to inform their decisions, prevent illnesses and support recovery. Access to this data allows

staff to provide high-quality and safe care to the public at home, freeing up time for them to focus on those who need care in a clinical setting.

This includes allowing the public to safely and securely permit clinician access to data from wearables and trackers, where this data is of sufficient accuracy and reliability to add value to a diagnosis.

Case study: digital cardiac pathway

The [Barts Health NHS Trust](#) Heart Centre is the largest cardiac centre in the UK, with 3,500 outpatient appointments and diagnostics weekly. Timely follow-up of patients enables identification of symptomatic recurrences or late complications. However, the hospital was experiencing delays in patient follow-up and low rates of medication dosage increases following a heart attack.

Barts deployed a digital system that helps patients and their clinicians to connect through virtual appointments using a computer or mobile phone, rather than face to face. The system captures biometric data including blood pressure, heart rate and [PROMs](#) to intervene if needed by communicating directly with patients through the service.

Patients also have access to data, such as medical documentation and clinical notes, that supports the management of their long-term conditions at home.

The data involved helped to increase appropriate medication dosage levels from 11% to 88% of patients, follow-up times were reduced from 3 months to 8 weeks, and data collected from continuous monitoring reduced appointment times from 20 minutes to 6 minutes. Use of the portal also increased appointment attendance rates to 88%. All of this supported the improved experience, outcomes and safety of the patients.

Our commitments

We will:

- scale up our digital home care projects to support 740,000 members of the public with care at home, including those who are resident in care homes, improving their health outcomes – completed March 2022

3. Improving data for adult social care

Our vision: members of the public and their care teams will have access to timely, high-quality data to improve care quality and inform choices about their care and support

As someone who draws on care and support, I will:

- have access to my own information about my own individual care

- be able to give access to that information to everyone supporting me, including friends and family, so they have the full picture about my needs and preferences

- have access to data about the type and quality of local care services so I can make better informed choices about my care and preferences

- be reassured that my data will be held with the highest respect for privacy

As an adult social care professional, I will:

- have access to information about the needs of those I support and the care they have received across the system, so I can provide seamless person-centred support

- have operational and client-level data to support proactive care, smoother transitions between NHS services and social care, and to plan and oversee future services

- have the confidence and capability to use the most appropriate technology to collect better data to improve care, understand the public's needs, and plan, commission and improve services

- be able to easily and securely record and access information about those in my care, making the best use of new technology

As someone providing unpaid care, I will:

- have access to comprehensive and up-to-date individual care information through a digital social care record that helps me to understand that person's preferences and care needs

- have access to user-friendly and up-to-date information about local services that will provide respite care and support for me

- if I choose, include in my own care and health information that I care for someone, making it easier for me to have conversations about the support I need

Why this matters

The public should be able to access care and support in the place that is most appropriate for them, whether in their own home or in another type of care setting.

Individuals and their families should not have to repeatedly provide information in either health or social care settings. It is vital that all professionals involved in a person's care can access the most up to date information – this will ensure individuals only have to tell their story once, and that their care and support networks are co-ordinated around them to provide personalised care.

Staff across adult social care need to be able to safely access the information they need, whenever and wherever they need it. Staff, individuals who draw on care and support, and their carers need to be relieved of the burden of chasing health updates and discharge summaries, and accessing locally held paper records. Instead, they need to be enabled to use data to make better decisions, such as engaging the most appropriate physiotherapy option, and delivering more personalised care that focuses on their preferences and needs.

Technologies like remote monitoring tools are also being used successfully to provide more targeted care, such as for individuals with dementia living at home, preventing or delaying escalating care needs and reducing the need for more formal care provision.

We want to work with local authorities and care providers to make sure we all have the technology and systems that help us access data safely and securely, respect privacy, and improve the experiences of individuals who draw on care and support. Technical and data standards will be an underpinning factor in enabling a more seamless flow of information, as well as making it easier for national and local leaders to use the data to improve services.

Accurate, safe and timely access to data – including information on quality, costs and workforce requirements – can be used to plan an individual's care services, and for planning and commissioning services. This is essential to make sure that the social care system is working for those who use it, helping them lead more fulfilling lives with better experiences of their care.

Progress so far

We:

- published, in December 2021, the Department of Health and Social Care published [People at the Heart of Care](#), which set out a vision for reform of the adult social care system as well as making available at least £150 million funding to drive rapid digitisation in the sector

- published, in February 2021, the health and care white paper [Working together to improve health and social care for all](#) to improve data collection to support health and adult social care integration, with an enhanced assurance framework and improved accountability within the social care sector

- have created an initial use-case blueprint through the [Yorkshire and Humber Care Record](#) programme of what the future model of care could look like for members of the public with frailty, with a single integrated care record that brings together data from across health and social care

- continue to enable [GP Connect](#) to support authorised clinical staff (registered nurses) in care provider settings to have access to information held within GP systems. Authorised non-clinical staff are also able to view appropriate levels of information from GP records within their own local care management system, with a filtered view using role-based access control

- have created a list of assured digital social care record suppliers whose systems will integrate into shared care records in the future

- for regional and national level data requirements, are refreshing the Adult Social Care Outcomes Framework. The [Association of Directors of Adult Social Services](#) (ADASS) led the initial work and we are now working together to finalise our approach. This will help us to understand what data we need to demonstrate the delivery of high-quality services for everyone

- to manage the pandemic, have collected data from providers via the [Capacity Tracker](#) tool and developed an Adult Social Care COVID-19 dashboard, allowing critical data to be viewed in real time at national, regional and local levels by national and local government

- have begun to collect client-level data from local authorities through a voluntary collection process – this will give us more detailed adult social care data, which we can then link to health data sets to better understand and improve outcomes for individuals drawing on care

Taking this further

Improving access to information for adult social care providers

At present, very few adult social care providers have online access to information about the individuals in their care. Only 45% of social care providers use a digital social care record, and [research published in December 2021 showed that 23% of care home staff could not access the internet consistently at work](). In addition, it found that 45% of providers expressed concern that care staff lacked digital skills. Care providers who are not fully digitised will not be able to realise the benefits of digital services for the public they support.

DHSC's recent white paper [People at the Heart of Care]() set out a vision for technology to transform care and support services, helping the public to live happy, fulfilled lives in their homes and communities. Digital tools can also be used to:

- identify risk

- prevent incidents from occurring

- ensure quick and appropriate responses to avoidable events such as falls, urinary tract infections, medication errors and pressure ulcers

We will work with the sector to help providers, including those at the beginning of their digital journey, to improve their internet connections and access to devices. We will also deliver a comprehensive learning offer so that care staff have the confidence and skills to use digital tools to provide outstanding care.

Digitising social care will improve quality and safety by giving carers, managers and regulators access to the latest information about the individuals they support in a secure way, including relevant data from the NHS where appropriate. This will ensure that the public receive the right care at the right time and will support a move towards more preventive models of care.

The COVID-19 pandemic has reinforced the need for access to regularly updated and high-quality data to improve the development of policy at a local, regional and national level, and identify emerging issues. It exposed large gaps in social care data and inconsistencies in the quality of this information, such as workforce absences, PPE levels and numbers of people in receipt of care.

The Office for Statistics Regulation's 2020 report [Adult Social Care Statistics in England]() further highlighted that the social care system is likely to benefit from making

more comprehensive and accurate data available to commissioners and central government.

We understand that data needs are different for individuals, their families, social care staff, local authorities and commissioners, providers, the voluntary and community sector, regulators, policymakers and other national bodies. We want to agree these differing data needs, and ensure there is a recognised core of data that can be collected and easily accessible to all those who need to use it. Simplifying data collection is also crucial to improving the ability to identify and support unpaid carers. We will therefore look to increase the voluntary use of noting someone as an unpaid carer in their NHS electronic health record.

Projects underway to collect client-level data from local authorities can deliver positive changes to the way local authorities and central government are able to understand the pathways and interactions of clients within social care.

These projects will also link client-level data from local authorities to health data, which will be a key step in achieving the government's vision for a highly integrated health and care system. These linkages will underpin insights into the interactions between health and care that will in turn drive up quality and innovation.

Work underway to develop an enhanced assurance framework and improved data collection will also improve accountability within the social care sector.

Case study: data to support planning for adult social care

As the sector adopts digital technologies, the collection and sharing of data will become increasingly automated, helping make data more accurate and less resource-intensive for staff to collect. This data will ensure everyone involved in a person's care has the information needed to plan, evaluate and deliver outstanding care.

During COVID-19, DHSC led a significant amount of work with the sector to address long-standing gaps in care data and provide a near real-time view of the impact of the pandemic. The NHS England North of England Commissioning Support Unit's capacity tracker was repurposed to cover:

- care home outbreaks

- COVID-19 cases

- bed occupancy

- workforce absence

- PPE supply

At the early stages of implementation in spring 2020, response rates were low at between 41% and 61% for care homes, and between 73% and 77% for homecare. Sector coverage has increased, with over 95% of care homes and over 85% of home care providers submitting data at least once by May 2022.

Staff at Kirklees Care Home were among those who welcomed the support it provided at a difficult time:

"The new business continuity features of the Capacity Tracker enabled the local authority and clinical commissioning groups to identify those providers who were in need of the most support.

"Those providers who had identified themselves as 'red' or 'amber' are contacted first by the contracts team in order to identify and understand the challenges being faced by these providers."

Our commitments

We will:

- continue to pursue the collection of pseudonymised client-level data rather than aggregate data from local authorities as set out in the adult social care reform white paper. This will ensure we have regular and comprehensive data to enable person-centred, sustainable innovation for adult social care. We will use the NHS number to ensure data can be appropriately linked and plan to make client-level data collection mandatory with all local authorities expected to commence data flows by 2023 to 2024 – from April 2023

- develop an easily accessible data-sharing solution with local authorities and providers over the next 3 years that supports real-time decision making at local, regional and national levels, building on the learning from the pandemic, and seek to ensure different actors in the system have access to the same rich data sets – from June 2022

- develop, in collaboration with Skills for Care, a digital skills framework that will support the improvement of the digital capabilities of everyone working in the adult social care sector (phase one completed March 2022), supported by the delivery of an inclusive approach to training opportunities to improve the data and digital literacy of the adult social care workforce – commenced from April 2022

Integration of health and social care data

When patients are discharged from hospital, information about their health is usually received by social care providers through hospital discharge summaries, which are often incomplete or need a further conversation with the GP. Information across other health settings such as community and primary care is not always accessed by social care when required, and vice versa.

To ensure better integration of health and social care, we want to make sure that data is only collected once and flows better across health and social care so that services can meet the needs of users without multiple conversations.

We are developing our plans to support the adoption of digital social care records and proven care technologies that can reduce escalation of care needs. Increased use of care technologies offers greater opportunities to inform real-time care and support by using information generated during their use. At the same time, the development of integrated care systems provides an opportunity to bring together data and knowledge to deliver improved outcomes for and co-ordinate care around individuals.

The adult social care digital transformation programme aims to support Care Quality Commission-regulated social care providers to:

- capture real-time information

- view relevant information from the NHS record

- enable more effective quality management

This information has the potential to transform care outcomes and provide greater personalisation of care planning that focuses on the individual. Digital social care records that can interoperate with shared care records will mean the care workforce is equipped with the information they need to provide the right care, and will help drive better integration between health and social care.

In addition, we plan to standardise the approach to gathering individual consent to access data that is stored in a digital social care record so that anyone registering with a social care provider can determine who their data is accessed by – for example, a family member or friend who supports them.

Our commitments

We will:

- ensure that at least 80% of social care providers have a digitised care record in place that can be connected to a shared care record and we will reinforce the use of the NHS number universally across adult social care to support this – by March 2024

- introduce a power to require information from all adult social care providers (both public and private) so that we can build a better picture of the delivery of adult social care services across England – delivery date subject to Parliamentary processes

- establish a data framework for adult social care setting out what data the sector needs to collect, the purpose of those collections and the standard to which it is collected. We will engage with the sector, including local authorities and providers, to develop the framework, which will set out how we will improve the quality of data and rationalise collections so that we minimise the collection burden. We will:

  - share our proposed approach with the Data Alliance Partnership – by June 2022

  - work with the sector on its detailed design – from July to November 2022

  - publish the framework – by December 2022

- continue to promote NHSmail – or other appropriate services that meet the government's secure email policy requirements – to all providers to enable secure information sharing, and will work with the sector to identify a long-term and sustainable approach – by March 2023

- work with our partners to evaluate the impact of the solutions currently in place for access to primary care data – for example, the recent expansion of a restricted view of GP Connect to specific community and social care staff. Over the next year, we will explore further options for appropriate access to information to deliver high-quality care – by March 2023

- publish a [standards and capabilities roadmap for digital social care record solutions](#) (completed May 2022), which assured suppliers providing digital social care records are required to comply with. Its development will be co-designed with the adult social care sector, and will include data and reporting standards that will allow providers and commissioners across the NHS and adult social care sector to access information. This will begin by developing a process to consolidate existing social care terminology standards – by March 2023

- work with the telecare sector ahead of the telecoms industry-led transition from analogue to digital phone lines by 2025, and issue an action plan to support those who commission, deliver and supply telecare services and equipment – by July 2022

Case study: developing a minimum research data set for care homes

A 4-year National Institute of Health Research (NIHR)-funded research study is aiming to enhance how researchers and health and social care services can use existing data to improve the care and quality of life for care home residents, families and staff.

The £2.2 million [Developing research resources and minimum data set for care homes' adoption and use (DACHA) study](#) is led by the University of Hertfordshire. Researchers are aiming to address the need to develop robust systems that support how all the different services and individuals – such as care staff, NHS professionals, family, regulators, and social services – work together for the benefit of residents.

The study team is reviewing how current health and social care systems work, and exploring the evidence on how to integrate data and test what a minimum data set would need to contain to be the key resource for all those working in and for care homes.

The findings have the potential to deliver a step change in how we understand the needs of individuals living in care homes and this could be a resource that supports the provision of high-quality care across England.

Expanding the use of data from care technologies

Greater digitisation of social care will give the public a more seamless experience of the health and care system. We want individuals to be able to use their own health and care data for greater insights into their health and care needs, and support them to live independently at home and in their communities for longer.

Digitisation will also enable easier social care data collection – for example, automated digital collection of information through APIs (APIs are mechanisms that enable 2 software components to communicate with each other).

To support digitisation, funding will be provided to help care providers to adopt technologies that will:

- enable information to be captured at the point of care

- provide access to appropriate NHS data

- enable easier data-sharing between settings

There are some compelling examples of the data from assistive technologies (such as room sensors, activity monitors and alarm systems) providing 24-hour background support

while enabling the individual to live independently, and giving unpaid carers and family members reassurance about their wellbeing and safety.

Case study: assistive technology

Hampshire County Council has made assistive technology a mainstream part of its work in adult social care, integrating alarms, sensors and medication reminders into the care packages they provide.

It became the first local authority to trial the use of Amazon Echo technology to help older people live independently in their homes for longer. It provided 50 adult social care clients with a modified version of the device to remind individuals when to take medication or check when their carer is due to arrive, as well as connecting to other technology in their homes such as movement sensors.

Results from the trial showed that 72% of users believed the voice-activated assistant would improve their daily routine, with 68% agreeing it would help maintain their independence. 62% of users also felt the device helped relieve their feelings of loneliness and isolation.

The council calculates that implementation of assistive care technology across the local authority area has saved more than £14 million in contract costs and through delaying admissions to residential settings.

In client surveys, 94% of responders said care technology has:

"increased their feelings of safety and security".

We will work with a range of partners to focus on the challenges and opportunities that will have the greatest impact in driving digital transformation in social care. We will establish at the outset how the data generated can be accessed and used to improve the quality of care. We will use data to build the evidence for the adult social care sector as a whole to support wider adoption and scale of successful care technologies within all care settings.

The Local Government Association has worked in collaboration with NHS Digital to fund innovative projects using technology to collect and provide safe and secure access to information. These have included work on apps in Southwark Council to prevent and manage falls by older people in community settings and in North Somerset Council to improve hydration for care home residents, and in Kirklees the council has developed a self-service care account that gives individuals access to their data and information 24 hours a day.

We will continue to work with the social care sector through integrated care systems and local authorities to support the use of care tech and approaches to commissioning innovation. We will test and learn from digital initiatives, scaling those that have proven effective.

Case study: the public, private and voluntary sectors supporting the public

Jointly is Carers UK's care co-ordination app that was developed with carers themselves, Tech for Good and UK Research and Innovation (UKRI).

Jointly enables families, friends and neighbours to create a circle of care with or around an individual to keep all the information they need in one place and manage the support being provided. It includes a dedicated medical management page which can connect with an automatic pill dispenser developed by Pivotella.

A recent development funded by NHSEI allows carers to create a contingency plan to use in case of emergency. This can be exported from the app in Word or PDF format, allowing access to anyone outside the caring circle, including a health or social care professional.

Our commitments

We will:

- support care providers in adopting proven technologies that can transform quality of care and safety, and fund implementation support within each integrated care system, to rapidly digitise social care as set out in the People at the Heart of Care white paper – commenced from April 2022

4. Supporting local and national decision-makers with data

Our vision: leaders and policymakers in every community will have up-to-date sophisticated data to make effective decisions, and help the health and care system run at its best

As a local decision-maker, I will have data about our current service delivery and our local population to:

- take a population health and proactive care approach, with interventions and resources targeted at those people and groups who most need them

- plan, commission, oversee and improve services to suit local needs, including areas that need support or improvement

- evaluate services and care, including capacity and demand, safety risks and good practice

- manage vital management functions such as workforce planning

As a national decision-maker, I will have:

- information about the operation of health and adult social care organisations to support them by planning national programmes and targeting areas that need support, intervening where there are serious failings; spot emerging risks and issues, and respond to national emergencies such as COVID-19; manage population health and proactive care by understanding current health and care needs, and predicting future ones; and commission specialised services

- data to develop national policy and produce guidance and standards, improvement, and regulation

Why this matters

The insights and analysis drawn from data are vital for leaders to plan, commission and improve their services. These services are supplied by a range of public, private, voluntary and community providers to meet the needs of the populations they serve. If decision-

makers are using inaccurate information – for example, an underestimate in those at risk of developing diabetes in their area – they will not be able to provide enough resources to support those individuals.

We must balance the benefits of providing high-quality data to decision-makers and leaders with a respect for individual data privacy and address concerns that members of the public have around data access.

As we move to a place-based health and social care system, the availability of accurate data is vital for managing population health, including to identify those who are most at risk of adverse clinical outcomes, and individuals who are most likely to benefit from different health and care interventions, including preventative measures. Data also provides valuable insights into the wider determinants of health – such as housing, employment and education – shining a light on health disparities and enabling the delivery of more effective population health management.

Insights and evidence drawn from data gives leaders an accurate understanding of the health and care system to develop better policy and guidance, and provide better oversight and national assurance. The shared experience of the COVID-19 pandemic has highlighted the critical role data has to play for these leaders to make decisions.

As set out in the Digital Clinical Safety Strategy, the effective flow of data between health and care settings is essential to ensure patient safety. It is particularly important to ensure that data collected and analysed about safety incidents in individual providers or programmes is shared to develop more comprehensive intelligence on clinical safety.

We have talented data analysts and professionals on hand throughout the health and care system, and local and national government. We must harness their skills to seize this opportunity and expand our use of data to drive continuous improvement.

Progress so far

As set out in our design framework for integrated care systems, all integrated care systems are creating intelligence functions that bring together data, analytical and intelligence teams across health and care partners to support data-led decision-making and local approaches to population health management and care co-ordination.

The NHS COVID-19 Data Store ensured the health and care system had the data it needed to manage extraordinary demand during the pandemic, and ensured the system could make effective use of data for the benefit of patients and service users

AnalystX, a data and analytics community, was created as a platform to begin collaborating, sharing tools, methodologies and best practice – this is one of the largest

online communities of practice in the world for data and analytical professionals working in health, with over 16,000 members to date.

The [Fingertips service](#) provides data that supports commissioning to improve health and wellbeing, and reduce health and care disparities.

Discovery work has begun on a data science and analytics specialist academy to ensure the learning needs for this profession are met, working with the AnalystX community and the Data and Analytics Board to develop the content and course structure.

Case study: NHS COVID-19 Data Store and data platform

To effectively respond to the COVID-19 pandemic, decision-makers need access to accurate, real-time information to enable effective planning and protect population health.

To achieve this, NHSX and NHSEI established the [NHS COVID-19 Data Store](#), which brings together multiple data sources from across the health and care system in England into a single, secure location.

In a matter of months, the NHS achieved what would have taken much longer under normal circumstances. The government used the 2002 [COPI regulations](#) to issue time-limited notices requiring public sector organisations to share patient information to support the COVID-19 response. In this case, data from the NHS COVID-19 Data Store is integrated into a single data platform where it is cleaned, harmonised and analysed to develop the single version of the truth that is needed to support decision-making and improve outcomes for patients at a time of immense pressure.

This data ecosystem was built to protect data by design. Patient data is pseudonymised by NHS analysts using a technique that replaces or removes information in a data set that identifies an individual. The data is controlled by the NHS at all times. A single front door process was established to manage applications for access to data in the NHS COVID-19 Data Store and purpose-based access controls in the data platform mean the right users have access to the right data at the right time. No more and no less.

A number of dashboards and tools have been developed within the data platform. These include the Strategic Decision Makers Dashboard, which aids senior national figures to make strategic policy decisions, and the NHS Operational Dashboard for local and regional NHS leaders, and local government officials. Analytical tools and products have also been developed that support ministers and system leaders to make effective, data-led decisions through effective use of data collection, analysis and insight generation.

NHS teams have been given access to predictive technology to help them save lives by forecasting COVID-19 hospitalisations. Using these forecasts, NHS providers can plan and

oversee how to use their available capacity for both COVID-19 patients, and routine care and operations, with the benefit of knowledge of how the need to care for more or fewer patients with the virus might change over the coming 1 to 3 weeks.

Overall, the NHS COVID-19 Data Store and data platform has helped us to:

- understand and oversee how the virus is spreading and identify risks to particularly vulnerable populations

- proactively increase health and care resources in emerging hot spots

- ensure critical equipment is supplied to the facilities with the greatest need

- divert patients and service users to the facilities that are best able to care for them based on demand, resources and staffing capacity

- support clinical research and innovation to understand more about the virus and the impact it is having

- manage the delivery of the largest vaccination programme in NHS history

- support elective recovery by providing NHS providers with functionality and modules to cleanse their elective waiting lists, and optimise theatre scheduling and capacity

Taking this further

Integrating local care systems with a culture of interoperability by default

NHSEI published a consultation on integrated care systems in November 2020, which made clear that being an effective local system means having the best-quality data possible.

Traditional divisions between hospitals and GPs, physical and mental health, the NHS and council services, and statutory and voluntary sector bodies created divisions of data across these organisations. This not only meant that care has been disjointed, but that it has been difficult for local and national leaders across health and care to effectively plan, commission and develop policy.

As set out in the integration white paper, an integrated health and care system will mean data flows seamlessly between staff, patients and their carers. The insights generated will be used to:

- make decisions more quickly, responsively and safely

- tailor services to the needs of populations

- enable more personalised care

- reduce unnecessary interventions

We are creating a more co-ordinated local approach with integrated care systems at the heart of our plans. Integrated care systems are new partnerships that meet health and care needs across an area, co-ordinating services across local organisations, and planning in a way that improves population health and reduces inequalities between different groups.

Integrated care systems will lead on deciding how the data they hold benefits their populations. For example, Our Dorset has introduced the Dorset Care Record. This enables community pharmacists to access relevant information about patients, which can help pharmacists support their management of long-term conditions, preventing future hospital admissions.

Integrated care systems will help the NHS join up data and delivery more seamlessly, working with local government, third-sector partners, social care providers, and the wider health and care system to address long-term challenges. Each integrated care system will be expected to use digital and data to drive systems working, connect health and care providers, improve outcomes and put the citizen at the heart of their own care.

Our commitments

We will integrate social care records into local shared care records within 6 months of a provider's digital system going live. Based on current forecasts for digital roll-out, this will mean 80% of providers will be integrated – by September 2024.

Building analytical and data science, management and engineering capability

There are estimated to be around 10,000 data and analysis professionals in the NHS, as well as a government analyst profession across DHSC, UKHSA and Care Quality Commission. There are also data and analysis professionals in primary care and local government.

The NHS has been building on existing approaches to data and analytics, replacing traditional high-effort, low-value processes. Through the use of analytical approaches,

including machine learning and natural language processing, we can drive better analytics to improve decision-making, policy-making and performance management.

During COVID-19, the data and analytical community mobilised to provide quick and robust analysis to inform decision-making, including tracking the virus, predicting outbreaks and managing bed capacity. Colleagues at both national and local levels were relied upon to convert raw data into useful information and insights. The pandemic has been a case study in the importance of expertise in data and analytics, and the necessity of encouraging this talent in the future.

We will build the profile of data and analysis as a profession in line with the wider vision that will be set out in the forthcoming digital workforce strategy. This will include consistent and appropriate competency frameworks, networks, training, career opportunities and status.

This approach to building data and analysis as a profession is identified as a priority in the Goldacre review and its recommendations will be used to help inform the development of the data and analytical community. Our work with the Association of Professional Healthcare Analysts (AphA) has led to a report to give structure and support to uplift the analytical workforce. We will work with AphA, stakeholders in higher education and training, as well as research and NHS environments, to ensure these skills are being developed effectively.

It is important that this profession can use data to harness insights that can be used directly for care or to support frontline staff. Clear data visualisations are an efficient way of enabling time-pressured staff to see the benefits of changes made based on the data they have provided.

Data also forms the basis for published statistics, which help us understand the overall picture of the health and care system at a national, regional and local level. Statistics are not just for decision-makers. The pandemic has shown us how important it is for the public to understand what is happening across the country, and there has been huge public interest in the aggregate picture of issues through engagement with the Coronavirus Dashboard. We will work to make sure that statistical data is accessible to continue to inform the general public on health and care issues.

Providing high-quality tools and training to colleagues for visualising data means they can provide health and care staff, and the public with information presented in a clear and accessible way.

By doing all of this, we are creating a profession that is a powerhouse for data science and modern analytical techniques, and that works openly and transparently. This community

will develop new partnerships with academia to expand its innovative analytics and build capability on a massive scale.

Case study: AnalystX – connecting and empowering the data and analytics community

The COVID-19 pandemic was a galvanising moment for the analytical community. The NHS faced a surge in demand for sophisticated analysis and game-changing insights. The analytical community worked in unprecedented ways, collaborating across organisations, and using tools and approaches that were previously confined to academia or other industries.

Building on this, NHSX and NHSEI established AnalystX, a social movement led by a community of data professionals and analysts to provide support to help health and care teams in England to battle the pandemic. This network now has over 16,000 members, committed to common principles of adaptability, innovation at pace and working in new ways.

To enable collaborative working at scale, we leveraged the FutureNHS platform and created a workspace that is a mixture of 4 components:

1. Community-curated and indexed data and analytical resources such as dashboards, web applications, evidence syntheses and insight reports to support planning, oversight and service improvement.

2. Discussion forums to regularly exchange ideas, form virtual cross-organisational teams and come together to solve a common challenge.

3. An analytics market exchange to match requests for support with surge analysts and relevant partners within our ecosystem.

4. An analytics champions programme with a focus on developing the analytical leaders of the future.

Data skills are not just important for data professionals. These skills are necessary in all roles and at all levels, and so we need to promote these skills across our health and care system. Just as we are encouraging digital skills across organisations, we need to encourage data skills in national and local government, and across the whole health and care workforce, and make sure data and analytics expertise is represented at board level.

The Goldacre review highlights the need to support leaders to be data literate "to help them make better use of data in their day-to-day jobs", and we will work to ensure there are readily available resources for leaders to use.

The pandemic response has created momentum, and we need to build on it.

Our commitments

We will:

- develop a workforce observatory, including an annual census, to inform how to better harness the professional skills of analysts and data managers, engineers and scientists, and support their professional learning and development – completed March 2022

- develop an online [Analytics Hub](#), working with AnalystX, to share, promote and endorse training, events and other resources aimed at analysts and non-analysts across all career levels – completed December 2021

- grow the AnalystX community and build the team of future analytical leaders through a champions programme – completed March 2022

- continue to encourage innovation and collaborative working through a data and analytics accelerator by promoting the use of open data, and working with a plurality of solutions and teams. The principles of the accelerator will be tested through hackathons and real business cases – by September 2022

- develop and roll out a unified set of competency frameworks aligned to the government analysis function skills and the digital, data and technology profession – by December 2022

- through the Developing Data and Analysis as a Profession Board:

  - agree frameworks, guidelines and policies to support the analytical community and address the concerns raised in the Goldacre review

  - build the ecosystem of the profession through communities of practice (local, regional, national and virtual)

  - signpost and provide development opportunities for analysts in both health and social care – by March 2024

Improving the data analytics ecosystem

The NHS does not lack data. However, we suffer from siloed data from multiple sources. The lack of consistent and timely access to data will limit integrated care systems in achieving their goals. A good data and analytics ecosystem is essential if we want to use

data-driven decision-making to achieve the priorities set out in the NHS Long Term Plan, and to support NHS recovery.

The data architecture of any such ecosystem should be supported by a technology infrastructure that will:

- streamline operational and performance data collection from providers

- facilitate rapid development and sharing of analytics across integrated care systems and support operational improvement

- maintain integrated care system data control

- enable appropriate provider data to be accessible and visible to local, regional and national bodies for improved operational planning

Lessons learned from our COVID-19 response, vaccination programme and elective recovery have provided us with the expertise and experience to address the key underlying causes of the problem. We need to continue to improve the way that data is managed and used by the system. That is why we are looking to develop a federated data platform which will be a system of connected platforms, placed in, and ultimately determined by, individual NHS organisations.

The ambition is that every trust and integrated care system will have their own platform that protects data to the highest standards of privacy and security, in accordance with the secure data environment requirements, which can also interact with regional and national platforms when they need to fulfil specific, predetermined use cases.

COVID-19 SMART response and recovery

North West public health and data science teams co-produced the world's first evidence on large-scale, voluntary rapid antigen testing, which became national community testing policy and underpins the new World Health Organization guidance. This action-research culture and platform also enabled the first COVID-19 risk-mitigated reopening of mass gatherings in the Northern Hemisphere.

The University of Liverpool responded to a call from Liverpool City Council and government in October 2020 for urgent research into the feasibility of large-scale COVID-19 risk-mitigation with rapid antigen testing. An agile, data-led response was possible because NHS, local authority and university partners had formed the Combined Intelligence for Population Health Action (CIPHA) system.

CIPHA was conceived pre-pandemic in planning the UK's first civic data co-operative, supported by Liverpool City Region Combined Authority. This civic partnership delivered world-first evidence and shaped COVID-19 testing policies nationally and internationally.

The aim of the Liverpool COVID-19 SMART (systematic, meaningful, asymptomatic, repeated testing) pilot was to reduce transmission of the virus while tackling the harms to health and social or economic wellbeing from COVID-19 restrictions. The objectives were to generate understanding of:

- how offering large-scale testing would be received by the local community

- how lateral flow testing would perform in large-scale asymptomatic testing

- whether large-scale testing would help to contain the pandemic, reduce adverse health outcomes, such as hospital admissions, and support social and economic functions

CIPHA is now sustained as an NHS England programme that is core to COVID-19 recovery and the building of data-led integrated care systems. It is enabling new research and innovation that links population health management and clinical workflow, and in doing so generates a world-leading environment embedding more preventive, predictive and personalised care.

We will work to create a data and analytics architecture that supports the NHS to operate flexibly. The architecture builds on a data platform product supported by common central data management services, cloud-based technologies and elements of existing architecture within the NHS. The platform will be open and enable 2-way sharing of data and products that enable effective care management at integrated care system level.

Through this approach, regions and the centre will receive access to analytics using the same data to better plan, support, and collaborate. This approach will enable faster development, enabling learning and innovation developed in one part of the system to be quickly adopted by others to accelerate roll-out.

Our commitments

We will:

- have initiated a national pilot on improving care co-ordination via the Improving Care Coordination for Patients programme – completed March 2022

- be able to showcase replicable archetypes of national data and analytics technology infrastructure based on the maturity of integrated care systems – completed March 2022

- have a federated data platform that will provide the connectivity needed to transform care and improve outcomes for patients – by April 2023

Working in the open

Public services are built with public money, and so [the code they are based on should be made available across the health and care system](#), and those working with it, to reuse and build on.

Analysts and developers should be encouraged to think from the start of a project about how work can be shared or consider 'coding in the open' – for example, through the use of open notebook science. This will include sharing technical skills and domain knowledge through sites like Cross Validated and Stack Overflow, while sharing code and methodology through platforms like GitHub will build high-quality analytics throughout the system.

We are developing an open analytics policy, which will be informed by the Goldacre review recommendations. This will provide a basis for engaging with relevant sectors such as research funders, higher education and other government departments on how we can derive the benefits that greater openness and code-sharing can deliver. As part of this, we will explore the:

- impact and benefits of modern, open working methods of data management and analysis such as Reproducible Analytical Pipelines (RAPs), which is particularly recommended by the Goldacre review

- opportunities for promoting these and embedding them in practice

We recognise, support and will help maintain the excellent open-source work produced to date by our analysts and developers. We encourage more of our staff to contribute in the future.

As we foster an increasingly open culture, we will progressively ask for more open-source ways of working in our procurement and contracts, with clear policies that build towards open by default across the NHS.

Our commitments

We will:

- begin to make new source code that we produce or commission open and reusable by default (with clear exceptions) and publish it under appropriate licences to encourage further innovation (such as [MIT](#) and [OGLv3](#), alongside suitable open data sets or

dummy data). Subject to consultation, the relevant policies will also aim to be open and reusable – commenced from December 2021)

- consult with the UKRI and NIHR to consider how outputs from research they fund involving health and care data can follow open and reusable code principles – commenced from March 2022

Providing access to data for wider purposes

The ability to see the current position and trends in health and social care data, and use analysis to understand the drivers of those trends, is critical. This allows us to understand the effectiveness of previous actions that have been taken, or what challenges and opportunities the system faces.

Currently, there is a lack of clarity about when personal information can be accessed to support the health and care system. This can create a barrier to the effective sharing of information for work vital to the operation and improvement of health and care services, such as:

- commissioning and planning services for local communities

- analysing data to develop policies

- having the right information for risk management

Not having data for these essential functions has a negative impact on giving the public the best care possible by making it difficult to continually improve services. Additionally, this lack of information acts as a barrier to effectively identify, prepare for, and respond to future health and care needs. This must change.

The response to COVID-19 has been supported by the timely sharing of data under the COPI regulations 2002. Subject to specified safeguards (limitations, exclusions and approval processes), these regulations provide a legal basis for the sharing of confidential patient information, setting aside the common law duty of confidence for anything that is necessary for the purpose of processing confidential patient information in accordance with the regulations.

The regulations also allow the Secretary of State to issue notices requiring the sharing of confidential patient information for the recognition, control and prevention of communicable disease and other risks to public health. Notices issued in early 2020 were instrumental in ensuring that information was accessed where and when it was needed for the response to COVID-19.

These regulations were developed in 2002. While they facilitated the sharing of information for COVID-19 purposes, they do not reflect the developments in the past 20 years for purposes to support the management and development of the health and care system. We want to ensure that, for all purposes, the arrangements support the health and care system in providing the best possible services to the public.

Any use of confidential patient information should be proportionate and appropriate, and it is essential that there should be safeguards in place to ensure that. What we want to do is to allow for the appropriate use of data in a way that minimises delay while maintaining confidence in how confidential patient information is protected.

Our commitments

We will amend the 2002 COPI regulations to ensure that they facilitate timely and proportionate sharing of data, engaging with stakeholders and the public by the end of 2022 to make sure that changes are implemented transparently – delivery date subject to Parliamentary processes.

Reduce health and care disparities

There are shocking disparities in health outcomes and experiences in the UK according to geography, ethnicity and income, as the COVID-19 pandemic exposed. To better understand where disparities in health outcomes and experiences exist by population group, their root causes, and how to tackle them (both at a policy and clinical level), the health system needs to better harness data.

It is vital that, when data is collected and analysed, this data is broken down (disaggregated) by indicators of disparities (such as ethnicity, age, sex, income or economic status, geography and disability). Without breaking down health and care service data in this way, understanding of where disparities in health outcomes and experiences exist by population group, their causes, and how to tackle them (both through policy and clinical interventions) will be limited.

It is particularly critical that research data sets used to design new medical innovations and treatments are representative of different population groups. Otherwise, we risk inadvertently worsening health disparities as new medical innovations and treatments are rolled out. This is a particular risk where artificial intelligence and predictive analytics tools are used.

Currently, the quantity and quality of disaggregated health and health service data remains variable. Limited ethnicity data at sufficient granularity, limited data broken down by the determinants of deprivation (such as income, employment and housing), and limited data

on inclusion health groups have been highlighted as particular gaps in health data sets and subsequent understanding of disparities.

It is also important that opportunities to access and link data across the health system and wider public services (where appropriate, safe and legal) are harnessed to improve the richness of data on health disparities within population groups – particularly given we know that the causes of health disparities are many and complex. Data-sharing and linkage is central to population-health management (a core strategic aim for integrated care systems) and for holding the system accountable for action on health disparities.

The forthcoming health disparities white paper will set out the government's overarching approach to breaking the link between individuals' backgrounds and their prospect for a healthy life, reducing the gap in health outcomes between different places and communities across the country. Among other things, it will highlight the importance of shifting the system's focus to prioritise action on disparities – including ensuring data is harnessed more effectively to identify, measure and act on health disparities where they occur.

As we implement the commitments in this data strategy, we will ensure health disparities are a central consideration in all decision-making, and we will examine and mitigate against any areas of our delivery that may exacerbate health disparities.

Positive steps to shift the system's focus are already underway – including the Core20PLUS5 programme that is the enabler of the vision set out in the NHS Long Term Plan to tackle health disparities.

Our commitments

We will:

- as part of the forthcoming health disparities white paper, set out the role that data – and data improvement initiatives – must play in government's overarching approach to reducing the gap in health outcomes between different places and communities across the country – from June 2022

- ensure that, as we implement this data strategy, all commitments are assessed against their impacts on improving understanding of. and ability to act on tackling health disparities and ill-health – from June 2022

- as part of the forthcoming women's health strategy, explore how data can be used to improve insights for women's health by making better use of data collected from heath and care services – 2022

Keeping children safe and healthy

It is particularly important, and urgent that we improve the way information is accessed between the different services and frontline staff who are responsible for keeping children safe from harm. Beyond safeguarding, the government is committed to support a shift to early intervention, with better access to information-helping services that support babies, children and families to thrive.

All NHS staff have a responsibility to safeguard children who come into contact with NHS services. The NHS also shares a joint and equal responsibility for local child safeguarding arrangements with local authorities and the police. Professionals from across these agencies, and others who work with children and young people, are at the forefront of child safeguarding. Supporting these frontline staff to work better together is one way we can prevent future tragedies in which children come to serious harm.

Currently, staff in different agencies can feel siloed and lacking access to information that would help them see warning signs in a wider context. We are failing them if we do not give them access to the relevant information. Providing professionals with broader, near real-time data will help them support children and families, leading to better outcomes.

There are already systems in place to support information-sharing between health and children's social care professionals, including the Child Protection – Information Sharing service, and shared care records in some local areas.

These are valuable and much-used systems that have already protected a large number of children, but these either do not contain detailed information or are not widely used by all local areas. They are also focused on the children already identified at the very highest levels of risk – children who have been formally assessed as needing to be looked after by a local authority or are already on a child protection plan. They are not designed to prevent families from reaching that level of crisis in the first place by identifying where earlier intervention could help.

Family hubs, which act as a universal front door to services and emphasise the principles of access, connection and a relationship-focused approach to family help, have an important role to play in helping families who are not at that level of crisis get support they need early. Supporting Families is another programme that intervenes earlier, supporting families experiencing multiple disadvantages such as worklessness, domestic abuse and poor mental health. Improved data-sharing between local agencies, centred around the family, is a key enabler for this work. However, we know that local areas are currently at very different levels of readiness – some pursuing innovative and cutting-edge solutions, while others are just getting off the ground. Work is already underway to support local authorities and partnerships in developing their family hubs and their local Supporting Families programme.

Local partnerships face technical barriers to appropriate information-sharing, such as:

- different case management systems for different services that do not all talk to each other

- a lack of a single identifier for children, making it difficult for professionals to be certain that a child in one system is the same child on another system

- different standards and coding systems for data held by different agencies, which result in different criteria for identifying and recording safeguarding concerns

In addition, the failure to routinely link data about other family or household members that might impact the wellbeing of a child (for example, drug and alcohol misuse, domestic violence or chronic disease) to the child's records increases the risk of failure to identify safeguarding risks and undermines the case for justifying information-sharing across organisational boundaries. There are also cultural barriers where frontline staff lack confidence about whether or how they can access information, and with which partners.

These barriers mean a complete picture of a child's health, wellbeing, family and environmental circumstances is sometimes not readily available to professionals at the point of care, making it difficult to assess risk or decide whether support should be offered to prevent a family reaching crisis point. Although information on vulnerabilities is collected by different parts of the system, this is not systematically shared within healthcare, public health or other agencies, either in real time to enable individual care (identifiable data) or for population health purposes (anonymised data).

Some local area partnerships are improving how they appropriately access information across multiple agencies, both for early intervention and safeguarding, but national support is needed to make sure best practice is adopted everywhere, and benefits every family and child. This national support will need to reflect the findings and recommendations of ongoing reviews, including the independent review of children's social care in England and the national review following the murder of Arthur Labinjo-Hughes.

As part of this, the Department for Education (DfE) will publish a report in summer 2023 that will reflect a cross-government position on what actions will be taken to improve information-sharing and cover improved information-sharing between all safeguarding partners, including NHS, local authorities and the police, as well as education. The report will include consideration of issues around applying a consistent child identifier, with DfE leading a multi-disciplinary, cross-government project on this question.

Our commitments

DfE, DHSC, the Department for Levelling Up, Housing and Communities (DLUHC) and the Home Office will:

- work together to identify enablers of appropriate information-sharing by professionals working with children and families, such as consistent identifiers, improved standards and guidance – commenced from April 2022

DfE will:

- publish a report setting out the government's policy on information-sharing to safeguard children, including considerations of issues around applying a consistent child identifier – by July 2023

DHSC will work with DLUHC to:

- provide improved guidance for local partnerships delivering the Supporting Families programme to support appropriate and safe local data-sharing to safeguard and support families, and prevent problems from escalating – from May 2022

Sharing information for children and young people's care

Providing appropriate and safe access to data across health and social care is imperative to deliver the best care to the populations we serve, including children. For example, providing certain information about a child (such as education and social care records) can help health staff make the best decisions possible about their individual care.

However, children and young people's healthcare is provided by the health service and led by DHSC. Children's social care is led by DfE and delivered by local authorities across England. This means that it is important that data is accessed appropriately across organisational boundaries to make sure that they are kept safe.

The Child Protection – Information Sharing service (CP-IS) helps health and social care professionals to access individual care information securely to better protect:

- children with looked-after status

- those who have a child protection plan

- pregnant women who have an unborn child protection plan

It links IT systems used across health and social care to help organisations access information securely. As it covers all local authorities in England, it is the only national register of social care status and the only system to provide information when a child is out of the area. It covers over 1,000 unscheduled healthcare sites.

The Child Protection – Information Sharing service has a roadmap to extend coverage and champion data-sharing between agencies as safeguarding is a key responsibility for every frontline professional. It is a system that saves lives. View a list of case studies from live sites.

Eight local authorities in north-west London developed the Whole Systems Integrated Care (WSIC) data set, which provides data on patients to support their individual care in primary, community and hospital settings. Of over 2.3 million people included in the programme, there was information on appropriately 400,000 children and young people. The data was used to study adverse childhood experiences through a 'rising risk' data dashboard. This information will be used on a pilot project from summer 2021 to link children's educational and social care data held by Westminster, and Kensington and Chelsea local authorities.

Dr Mando Watson, consultant paediatrician at Imperial College Healthcare NHS Trust said:

"As a consultant paediatrician working closely with local GPs, WSIC has already improved the co-ordination and quality of care I can deliver. For example, by flagging those infants who are high users of hospital emergency care – these infants are offered a paediatric review, which usually identifies and addresses underlying concerns, and stops the use of A&E.

"Additional linkage to education and social care records will transform our ability to safeguard vulnerable children by ensuring that clinicians have the information they need to make the right decision for each child."

In addition to clinical care, WSIC provides a unique research and innovation resource as the largest integrated data set of its kind in Europe. Researchers at Imperial College London are using the data to study a wide range of questions. This includes refining Connecting Care for Children, which is a pioneering new model of integrated care for children and young people, and improving care and outcomes of children and young people with asthma.

Early help for families and children

Supporting Families is a programme that benefits families by driving widespread transformation in how family services are delivered in local areas, making them more co-ordinated, family centred and data driven.

The programme has championed whole family and multi-agency working to support vulnerable families (those experiencing multiple disadvantages such as worklessness, domestic abuse and poor mental health) underpinned by strong data-sharing agreements. It proved through a robust impact study that this approach:

- prevents children in vulnerable families from ending up in the care system

- reduces the likelihood of involvement in crime

- supports families back towards work and more fulfilling lives

Further multi-agency collaboration in this area will enable services to identify families needing support early on, and work together to ensure children and young people are back in school and supported to get the best start in life.

Collaborating with devolved administrations

Government has long understood the importance of data to provide effective services for everyone in the UK and the National Data Strategy highlights the importance of using data to deliver complex public sector services that support millions of individuals across the UK every year.

It is important that we have a UK-wide data focus, making sure that the public have confidence that the health and care system will support them, regardless of where they live or work in the UK. This means making sure that health and care data can be accessed safely and effectively across the UK to support individual care, and to improve outcomes for the public.

This will include working with officials across the devolved administrations, noting the devolved nature of health and care policy, and building on the work of units such as the Joint Biosecurity Centre and the newly established UKHSA. This will also help us collaborate to:

- solve public health issues

- improve disease surveillance

- overcome any behavioural or structural obstacles to appropriate data-sharing across our respective health and social care systems

While many of the commitments set out in this strategy extend to England only, there are some areas such as data for genomics and clinical research (see below section 5, 'Empowering researchers with the data they need to develop life-changing treatments,

diagnostics, models of care and insights') where a UK-wide approach is already being taken.

There is also scope for better collaboration within England as we know there are times when appropriate and legal access to health data can deliver better outcomes in other areas, such as education, welfare, housing and social care support. Joining up data across government has the potential to generate better evidence and insight to support the design of more holistic public services. For example, the government's Work and Health Unit works to improve health and employment outcomes for disabled people and those with health conditions.

If we are to shift the health system into a service focused on wellbeing as well as illness, or to effectively respond to emergencies, we need to partner with other public services, and appropriately use all the data we have to deliver the best services and outcomes possible.

We will continue to work with other government departments to improve appropriate data linkage to support the public's health and wellbeing, making sure that any improvements in data access are appropriate, safe and legal, and do not damage public trust in how data is used.

Our commitments

Our public health agencies will draw on multiple data sources to gain new insights into the public's health, with quicker access to high-quality health intelligence to inform improved decision-making and responses to threats to health – from September 2022.

5. Empowering researchers with the data they need to develop life-changing treatments, diagnostics, models of care and insights

Our vision: researchers will be able to safely and easily access data to provide innovative solutions to health and care issues for the benefit of all

As a researcher or analyst, I will have:

- easy ways to find members of the public to join research and innovation studies in areas such as developing new treatments, vaccines or diagnostic tools to support patients and service users

- easy to understand guidance explaining what I need to do to access data

- safe environments to analyse information without needing to receive patient-identifiable data, so that I can explore hypotheses or identify and pursue new areas for research and innovation, through access to wide-ranging studies or clinical data including:

- data from the NHS and social care such as clinical data from diagnoses and outcomes from treatments

- rich genetic and genomic data through Genomics England, UK Biobank and Our Future Health, alongside one of the world's most comprehensive collections of disease registries

- individual-generated data from monitors, wearables and trackers

- data that allows targeting research at those who are most at risk for poorer health – that is, to investigate health inequality

Why this matters

The UK is a leader in clinical and healthcare research, and we have committed to further strengthening our role in the coming years. We have an exceptional health and care research ecosystem including:

- the NHS

- universities and research institutes

- medical research charities

- the NIHR

- a strong life sciences sector with a bold and ambitious Life Sciences Vision

We also have the unparalleled longitudinal health data set held by the NHS, offering the potential for a unique view of a large and diverse population.

We have to close the gap between research and the delivery of care, and encourage research participation and innovation across the system. By increasing the scale and quality of the data sets available to researchers, and enabling more data sets to be linked, while maintaining the necessary safeguards to ensure privacy, we can create even richer data insights. This provides us with huge potential for new clinical options and improved care pathways, as shown using dexamethasone in treating COVID-19.

Research can also inform new care delivery approaches and techniques. Staff will be able to personalise the care they offer, informed by models that help identify the optimal treatment for an individual, learning from the experience of others. We will need to use data-driven models to monitor and study early signs of disease and drive our prevention strategies, supported by the Office for Health Improvement and Disparities (OHID). This is a key driver in reducing health inequalities.

Collaboration is also imperative to ensuring we reach our research goals. NIHR, UKRI, the Department for Business, Energy and Industrial Strategy, and the Office for Life Sciences have provided funding for some of our most successful programmes.

This includes UK Biobank, NHS DigiTrials, the Health Data Research UK Hubs, the Innovate UK digital pathology, imaging and artificial intelligence (AI) centres of excellence, and the Global Alliance for Genomics and Health (GA4GH), and we will continue to collaborate with these organisations and more widely.

As part of the implementation of the government's 10-year strategy for genomic healthcare [Genome UK](#), we will facilitate work to transform our capabilities in genomic data across the UK.

We must make sure that, as we are doing this, we keep public confidence and trust in mind by ensuring the highest standards of privacy and security for the data underpinning this work.

Our mission is for patients to benefit from new therapies, technologies and better, more personalised care, and to strengthen the world-class life sciences sector (including medical research charities), working closely with the NHS. By doing this, we will deliver the data precondition identified in the Life Sciences Vision as critical to fulfilling the ambitions set out in the vision.

Case study: earlier access to medicines

Real-world data is used by the [National Institute for Health and Care Excellence](#) (NICE) to provide earlier access to new cancer medicines.

If a new drug is promising, but not yet fully proven to be cost-effective, NICE can provide initial access to the medicine through the [Cancer Drugs Fund](#), while collecting more data on how well it works to make a final decision on whether to approve. Data collection plays a part in the majority of topics in the Cancer Drugs Fund, helping to enable NHS access to these technologies sooner while developing evidence about their clinical and cost-effectiveness.

NICE has a successful model for using data from the NHS via the [Systemic Anti-Cancer Therapy Dataset](#) (SACT) to gain real-world insights through this approach, which NICE calls 'managed access'. The new [Innovative Medicines Fund](#) is extending the approach beyond cancer.

For this to work, we need to establish access to new, dynamic and linked data sources to make recommendations on promising new treatments, and improve the service we are able to offer.

Progress so far

During the COVID-19 response, we have seen closer co-operation and joint working between national and local organisations.

There has also been unprecedented collaboration across academic and public health services, which has transformed the use of data at national level. COVID-19 has shown us

what can be achieved when the appropriate access frameworks, such as COPI notices, are in place and when we work together across boundaries.

NIHR [BioResource](#) (£37.5 million) draws together over 130,000 genotyped and phenotyped volunteers, with and without health conditions, who have agreed to be approached to participate in research investigating the links between genes, the environment, health and disease.

The NIHR and UKRI Medical Research Council have provided funding (£1 million each) to the [Global Alliance for Genomics and Health](#) to develop standards and policies for sharing genomic and health-related data, and this work is being integrated into the Genome UK Data Working Group delivery plans to accelerate responsible progress in genomic research, ultimately improving health outcomes.

The NIHR has updated its [Open Access Policy](#), which will require, from 1 June 2022, that all taxpayer-funded peer-reviewed research articles must be immediately, freely and openly accessible to all.

We have:

- supported recruitment into 14 vaccine trials through our permission to contact service, with more than 500,000 members of the public who have signed up to be part of the [Vaccines Registry](#)

- launched the first of 4 NHS DigiTrials recruitment pilots, supporting the recruitment of 140,000 participants into the [NHS Galleri trial](#) by identifying and issuing invites for members of the public to take part

Case study: UK Biobank

[UK Biobank](#) is a large-scale biomedical database and research resource containing in-depth genetic and health information from half a million UK participants.

It has led to several scientific breakthroughs to improve human health including:

- a University College London study into factors increasing risk of dementia. Researchers were able to study participant blood samples to identify how genetic makeup affects risk. The diverse participant pool has enabled the research team to [explore ethnic differences in dementia risk](#)

- [research into the hypothesis that 'good' cholesterol may help in the fight against sepsis](#), which causes 11 million deaths worldwide each year. Researchers were able to access genetic data from Biobank to provide critical information for the study

This data has proved especially valuable during the COVID-19 pandemic. The integration of data across a wide range of medical records has enabled researchers to identify individuals diagnosed with COVID-19 across the full spectrum of disease severity.

Coupled with the genetic and lifestyle data already available, this rich data set helps researchers to understand the extent to which genetics, lifestyle and underlying health conditions affect disease severity, and recovery.

Case study: National COVID-19 Chest Imaging Database

The [National COVID-19 Chest Imaging Database](#) (NCCID) is a centralised UK database containing x-ray, computed tomography and magnetic resonance images from hospital patients across the UK to support a clearer understanding of the COVID-19 virus in the long term and develop technology that will enable the best care for patients hospitalised with a severe infection.

It is a unique resource for researchers to analyse the impact of COVID-19 on patients and a way for new AI tools to be trained on a powerful real-world data set. With over 82,000 images from over 28,000 patients in England, Scotland and Wales, researchers will be able to apply machine learning models in a way not previously possible in the UK.

The NCCID will continue to provide a valuable data resource for the development and training of AI technologies. The NHS AI Lab will work with more NHS hospitals and providers to access data and expand the database. This will provide access for other researchers and AI companies to safely train their algorithms.

The NCCID has also demonstrated that, despite the present fragmentation of data collection across different institutions and initiatives, the technology and research communities are ready to work towards a stronger data integration co-ordinated by NHEI.

The NHS AI Lab is now using learnings from NCCID to inform a programme of work supporting the innovation to deployment pathways of AI technologies as part of the development of a new AI medical imaging initiative.

Taking this further

Providing safe and secure data for analysis and research

To provide further reassurance to the public that those entrusted with their data are keeping it safe, we are also looking to the development of new technological advances in how data is collected, stored and analysed. Multiple data sets can be linked within a secure environment in a way that enables appropriate access to an array of data while still protecting the privacy of individuals.

The system will increasingly look to secure data environments where researchers and analysts can access sensitive data without breaching privacy. In-depth analysis can be undertaken on rich data sets without identifiable information ever being seen by researchers and analysts. The term 'secure data environment' captures the safety of the approach, and that they are not only used for research but also for interrogation and analysis for clinical innovation and service planning.

Confidence in these models of data access depends on there being effective safeguards in place to protect data and a transparent process for how data is accessed and used, and the public having the information necessary to ensure accountability – as set out previously in section 1, 'Improving trust in the health and care system's use of data' of this strategy.

Case study: OpenSAFELY

OpenSAFELY is a new secure analytics platform for electronic health records in the NHS, which was established at the beginning of the COVID-19 pandemic.

Initially established on behalf of NHS England and NHSX, it is a collaboration between the DataLab at the University of Oxford, the Electronic Health Records group at London School of Hygiene and Tropical Medicine, the Phoenix Partnership, EMIS and other electronic health record software companies that already manage NHS patient records.

The platform uses a new model for enhanced security and timely access to data: data stays in the secure environment in which it is stored for individual care. It allows the creation and application of models to patient-identifiable data without moving the data.

Trusted analysts run large-scale computation across near real-time pseudonymised patient records, enabling a range of major breakthroughs in COVID-19 research. For example, it identified that key factors related to COVID-19 death included being male, older age, and having uncontrolled diabetes and severe asthma.

A particular characteristic of the OpenSAFELY operation is the use of modern open working methods. This involves sharing all analytic code and development insights, which supports the accelerated development of analyses and other tools by groups with other data sets.

This approach of sharing code has many benefits including:

- increasing reproducibility

- providing an opportunity for quality review

- good practice in terms of transparency and working in the open

By making this code available, the opportunity exists for review and this can help to engender greater public trust in the research findings and analysis derived from the data.

The Goldacre review recommended adopting trusted research environments – a type of secure data environment – to ensure the safety of the public's confidential data, while allowing professionals appropriate and proportionate access for research. It cites their use elsewhere in the public sector, such as the Secure Research Service used by the Office for National Statistics to allow access to UK Census data.

The recommendations of the Goldacre review on the fundamental elements of trusted research environments anticipate work that is already underway. They will inform our engagement as we develop our approach to secure data environments, which will set the direction for how the NHS and social care can benefit from their use. To make the most out of secure environments, we must continue to examine how they operate and are governed to ensure they are fit for the future.

To enable this, we are bringing together our partners across the system to set out the role of secure data environments in the health and care system, the standards they must meet and policies to govern their use. This includes creating partnerships to enhance the exchange of skills and knowledge to enable closer working between groups.

As a starting point, we have developed our 11 draft guidelines for secure data environments, based on the ONS Five Safes Framework:

Secure data environments in the NHS

1. Secure data environments will be the standard way to access NHS health and social care data for research and analysis.

2. Secure data environments providing access to NHS health and social care data must meet, or demonstrate a credible roadmap to meeting, criteria set out within our accreditation framework.

3. Secure data environments must maintain the highest level of cyber security to prevent any unauthorised access to data.

4. Secure data environment owners must be transparent about the data within their environment, who is accessing it and what it is being used for.

5. The secure data environment may only be accessed by appropriate, verified users.

6. Secure data environments must ensure that patients and the public are actively involved in the decision-making processes to build trust in how their data is used.

7. Data made available for analysis in a secure data environment will be de-identified in a proportionate manner to protect patient confidentiality.

8. NHS health and social care data should only be linked with other data sets within an accredited NHS secure data environment.

9. All accredited NHS secure data environments must adhere to a policy of open-working, support code-sharing and facilitate use of technology that supports this, such as RAPs.

10. Secure data environments must be able to support flexible and high-quality analysis for the diverse range of uses they will support.

11. Secure data environments must ensure that nothing is brought in, or removed from, the environment without assessment and approval.

Alongside the 11 draft guidelines above, we will soon be publishing a technical specification and an accreditation framework. We will develop these through engagement with partners across the system, patients and the public as part of creating a comprehensive policy and governance framework that will set out clear expectations on how we want to implement secure data environments.

During the pandemic, the [trusted research environment for COVID-19](#) has given researchers across health and care the ability to review data at speed, streamlining research processes for quicker results while maintaining confidentiality. It demonstrates the value and potential of secure data environments.

Our commitments

We will:

- create partnerships between academic researchers, charities, patient advocacy groups, industry and analytical teams to enhance the exchange of skills and knowledge – commenced from February 2022

- work with expert partners and the public to implement secure data environments as a default across the NHS. We will do this by delivering:

  - a clear public guide to secure data environments and our overarching policy guidelines for the use of secure data environments

  - a robust accreditation regime to ensure our high standards for secure data environments are implemented. This will include not only accreditation requirements for secure data environments but also guidance and oversight on users of the environment, as well as the process to monitor and assess implementation

  - a full technical specification, drawing on industry best practice, including requirements to ensure interoperability, cyber security and the use of privacy-enhancing technologies

  - a comprehensive roadmap to ensure all partners across the system know how to implement our framework, with clear indicative timescales and expectations for those at different readiness levels. This will include not only those delivering the transformation in the NHS but also software providers, academic and industry researchers, as well as funding agencies – December 2022

- create clarity on terminology and legal definitions, working with the research community to alleviate confusion and improve the quality of research access requests – June 2022

Encouraging the use of data for research

Research is crucial to developing the medicines, treatments, technologies and scientific insights of the future, and data is also vital for developing accurate and official statistics. Therefore, we need to make sure researchers can access the data they need for their work, while also adhering to clear and robust legal safeguards, and preserving privacy.

We have seen the positive impact access to data can have during the COVID-19 pandemic with COPI notices giving the health and care system the ability to easily access data to help with the response. We have also seen the benefits of the research community developing vaccines and treatments for and enhancing our understanding of COVID-19.

However, the research community still faces challenges in its efforts to maximise the opportunities of health and care data.

Even though legislation already provides ways to access identifiable data for research, subject to approval, researchers are often seen as operating 'outside' of the system. This

makes it more difficult for researchers to access the information they need. A misunderstanding of information governance can lead to a researcher with justified purposes being denied access to the data they need – an issue that may be compounded by the complexity of the number of organisations providing access to data, each with slightly different access requirements and approvals processes, and interpretations of the law and guidance. This is something we need to change.

We also have strict safeguards that help us keep data risks as low as possible, audit processes to see who is accessing data, and penalties for misuse. However, we must also harness new advances in how data is collected, stored and analysed, such as secure data environments, to help us maintain privacy.

The [Data for Research and Development](#) programme is investing up to £200 million in NHS data infrastructure (subject to HM Treasury approval) to make research-ready data available to researchers in a streamlined, secure and privacy-protected way, through trusted research environments at national and regional level.

They will support a vibrant hub of genomics, imaging, pathology, and citizen generated data, where AI-enabled tools and technologies can be deployed. We will put our policy and governance framework for secure data environments into practice – making life-saving data more securely and quickly accessible and linkable, while offering the highest levels of privacy.

The programme will put the NHS in control and generate public confidence in widespread data-driven innovation while making the UK a world-leading destination for industry to develop cutting-edge life sciences research and development.

This investment in data infrastructure will enable widespread use of NHS data in driving insight to support:

- population health

- resource planning

- clinical research

- health-improving innovations

This will drive significant benefits for patients as well as the NHS, such as earlier access to new innovations that improve patient outcomes and increase efficiency.

Our commitments

We will:

- create at-scale datasets that bring together the different types of health data to develop new tools for prevention, diagnostics and clinical decision-support through the [Data for Research and Development](#) programme – by December 2023

- bring together genomics data, and work with NHSEI to ensure genomic data generated through clinical care is fed back into patients' records – by December 2023

Encouraging clinical research

As set out in the [Future of UK Clinical Research Delivery](#), clinical research is the backbone of healthcare innovation: it is the way we improve the prevention, detection, diagnosis and treatment of disease. Working collaboratively with the devolved administrations to use health data is critical to deliver faster, more effective and innovative clinical research.

Improving the accessibility of high-quality, curated data at national and subnational levels will support clinical research and data-driven innovation, benefitting patients and the NHS as well as generating economic growth. For example, we will deliver more efficient and effective clinical trials by ensuring data is used to support design, recruitment and follow-up. This will reduce unnecessary burdens on the frontline workforce and ensure as many members of the public as possible have access to trials that might benefit them.

Our ambition is to ensure the UK has the most advanced and data-enabled clinical research environment in the world, capitalising on our unique data sets to improve the health and care of patients across the UK. Building on digital platforms such as NHS DigiTrials and other key infrastructure, we will be able to:

- rapidly assess the feasibility for specific clinical studies, using intelligence on patient populations, disease prevalence, and site capacity and capability, and speeding up key research processes to enhance study set-up and bringing patients on to trial sooner

- improve our ability to identify and approach patients who may be eligible for specific studies, increasing access to research for a greater diversity of patients, reducing health inequalities, and ensuring that health research and innovation delivers for everyone

- monitor the progress of patients that agree to take part, reducing the cost and administrative burden of research on frontline, clinical and research teams, giving them more time with patients

- deliver new and innovative research designs to answer questions in new ways and enable studies in cutting edge fields, such as genomics, cell-based therapies and digital therapeutics, opening new potential clinical pathways for patients

Using such digital platforms, we also have new opportunities to connect with and involve the public, patients and service users in shaping research. Join Dementia Research, for example, connects registered volunteers with dementia researchers across the UK who are looking for members of the public to join their studies.

Success at recruitment and retention into trials has declined over recent decades, and now is the time to reverse that trend.

Case Study: NHS DigiTrials supporting the RECOVERY trial

The RECOVERY trial aimed to find treatments for those hospitalised with severe COVID-19. As an urgent public health research study co-funded by the NIHR and the UKRI Medical Research Council, RECOVERY was set up through the University of Oxford in a matter of days. Within weeks, over 10,000 patients from 176 NHS hospital organisations supported by the NIHR Clinical Research Network were enrolled, with data being tracked and analysed. Since then, over 39,000 participants have been involved.

By providing centrally collected and curated data on a weekly basis to track progress and outcomes of participants, NHS DigiTrials made the scale of this trial possible. The data was drawn from extracts from routine electronic health record data and NHS DigiTrials supported rapid access to new COVID-19 specific data. This removed the burden on NHS frontline staff to field additional data requests and enabled the trial team to make rapid decisions.

Within 100 days, the trial identified the world's first coronavirus treatment proven to save lives: dexamethasone. The results were announced on 16 June 2020, adopted into UK practice later the same day and included in new US guidelines within 2 weeks. This treatment has since saved 22,000 lives in the UK and an estimated one million worldwide.

'Platform' and data-enabled trials like this have the potential to be used outside of a pandemic, making it faster and more efficient to find safe and effective treatments for widespread and common illnesses like cardiovascular disease. They also open up the opportunity for trials of different treatments to run simultaneously, all within a common trial framework and using routinely collected NHS data.

Through the NHS DigiTrials programme, we can reduce the cost of bringing new drugs to the NHS and collaborate with clinical trialists to find and recruit the participants they need to make them successful.

We will work closely with the research community to embed these principles further, so we can make research as accessible, streamlined and safe as possible. While doing this, we

must continue to explain to the public how their data is being used to support research through increasing their engagement and involvement.

Our commitments

We will:

- build on platforms such as NHS DigiTrials to support the best use of data and digital tools in study feasibility, identification and monitoring of research participants, to enable faster, more efficient and effective clinical trials – commenced from March 2021

- publish a 2021 to 2022 implementation plan (complete) followed by a 2022 to 2025 implementation plan to progress UK priorities for clinical research as set out in the Future of UK Clinical Research Delivery, including a theme on research enabled by data and digital tools – September 2022

- convene a UK-wide genomic data working group with representation from experts across the UK's genomic healthcare landscape to provide a forum for co-ordination and collaboration, and to ensure that our processes maintain public trust in the safe, appropriate and responsible use of personal data for both clinical care and research – by June 2022

- work with other countries and the World Health Organization (WHO) to facilitate the implementation of the World Health Assembly resolution on strengthening clinical trials to provide high-quality evidence on health interventions and to improve research quality and coordination, and supporting, as appropriate, the development of a WHO progress report by the 76th World Health Assembly – by June 2023

6. Working with partners to develop innovations that improve health and care

Our vision: innovators will be supported to develop and deliver new solutions quickly and safely for the benefit of all citizens, staff and the system

As an innovator creating or deploying new data-driven technology for health and social care, I will have a clear understanding of how to work with the health and care system through:

- clear guidance on data partnerships that maximise benefits to the public and the system

- open standards, code, APIs and systems architecture so that my innovations will easily and effectively work across the system

- adequate documentation of the data and the APIs

- clear understanding of my obligations to respect data privacy and a clear description of any regulatory, data protection, data handling and cyber security obligations, so that I know how to build these in at the beginning of my project

- a speedy and simple approvals process for my application to interact with health and care data, so that I can get it out to users quickly

- clear route maps to deploy technology at scale across the system, so that my solution has the best chance to seamlessly integrate into care pathways and frontline ways of working

Why this matters

The UK has a large and vibrant health and care tech sector. It gives us huge potential both to improve care and power the UK economy.

The Department of Digital, Culture, Media and Sport has estimated that the entire digital sector accounted for 7.7% of the UK economy as a whole and contributed £149 billion to it in 2018. Growth in the sector is nearly 6 times larger than growth across the rest of the economy.

As data is the cornerstone of the health and care tech sector, we must make sure innovators are given clarity over what, how and where it can be accessed and used.

Clear frameworks, standards and guidance on data use, ensuring the highest levels of data protection and privacy, will allow us to bring all the benefits of innovation back into the system, while maintaining public confidence in how we handle people's information. Data partnerships are central to accelerating opportunities for innovation.

Over recent years, the UK has seen the growth of multidisciplinary innovation, with collaboration between health and care partners, academia and industry occurring at increasing scale and pace. In addition to running our own analysis and buying data-driven tools, local health and care organisations also have opportunities to work with innovators directly to create new algorithms and digital services that can improve health outcomes.

So that we can continue to provide the best care for the citizens we serve, we must safely grasp the opportunities for data-driven innovation, ensuring that they:

- provide benefits and improve outcomes for all citizens

- maintain respect for data privacy

- do not widen existing health and care disparities

Innovation also supports staff, carers and colleagues to do their jobs, and to continually improve how our health and care system works for the benefit of everyone.

Progress so far

We have:

- created the NHS AI Lab to promote the effective, ethical, sustainable and safe use of AI technologies within health and adult social care

- completed 2 rounds of the AI in Health and Care Award and supported 80 promising AI projects that align with the aims of the NHS Long Term Plan

- made the case for international co-operation, producing an original policy white paper and recommendations AI for healthcare: creating an international approach together on behalf of the Global Digital Health Partnership

- published code for the NHS COVID-19 App and NCCID, and our analysis in OpenSAFELY through the NHSX GitHub

Taking this further

Driving interoperability for innovation

Open and reusable code also helps data-driven innovators build systems that can easily work with the health and care system.

Our new standards registry will be open source and documented on our GitHub page to enable and encourage feedback, suggestions and collaboration. We will explore ways in which we can signpost or host reference implementations, guidance and best practice around interoperability interfaces (in particular Fast Healthcare Interoperability Resources, APIs, guides and profiles) to share learning among digital health communities and accelerate standards adoption. Our forthcoming open-source strategy and playbook will help deliver similar outcomes for open source adoption.

The Goldacre review envisages a future of greater openness in data analysis through the use of open code and sharing, reinforced throughout the system by working practices and governance. With partners across the health and care sectors, and the analysts who support them, we will implement best practice for open coding, and other methods of open and transparent working. Some of this openness will also be achieved through the use of secure data environments.

We will lead by example, as well as pushing the case across the system to modernise and strengthen the use of data and analytics.

Case study: identifying the most at risk of COVID-19

Early on in the COVID-19 pandemic, the Chief Medical Officer commissioned a research consortium to create a model to predict which combination of factors could increase risk of serious outcomes from COVID-19.

The consortium, led by the University of Oxford, used linked anonymised GP records to develop a model, QCovid®, that used various factors to calculate risk of hospitalisation and death from COVID-19.

This information became invaluable in February 2021 when the model was used to identify 1.5 million high-risk individuals who needed to be placed on the shielded patient list so they could be prioritised for the vaccine.

The research was published in the British Medical Journal and Oxford University Innovation provided a reference implementation to demonstrate how the model works.

Oxford also made the QCovid® Calculation Engine source code available at GitHub in the interests of transparency, flexibility and accountability, and in line with government guidance on the use of open source code. This enabled the model to be used by interested researchers for academic purposes, enabling further potential societal benefits.

This ability to identify and protect those at high risk from COVID-19 demonstrates the power of data-driven population health management and proactive care.

Our commitments

We will publish a digital playbook on how to open source your code for health and care organisations. Guidance on where to put the code, how to license and maintain it, and best practice for working with suppliers will be published in addition to case studies of teams who have done this – completed May 2022.

Encouraging AI innovation

AI technologies have real potential to improve the delivery of health and care services by analysing large quantities of complex information.

The AI in Health and Care Award, run by the NHS AI Lab, the Accelerated Access Collaborative and the NIHR, made funds available to support innovators and technologies across the full spectrum of development, from initial feasibility to NHS adoption and testing within clinical pathways.

The first round of the AI in Health and Care Award concluded in September 2020, taking forward 42 promising AI technologies that align with the aims of the NHS Long Term Plan. Details of some previous winners can be found in the case study below.

Case study: AI in Health and Care Award winners

The 42 winners in the first round include:

- Brainomix for E-Stroke, a set of tools that uses AI methods to interpret acute stroke brain scans, and helps doctors make the right choices about treatment and the need for specialist transfer of patients with confidence. It also provides a platform for doctors to access real-time information between hospitals, avoiding delays

- Kheiron Medical Technologies for Mia Mammography Intelligent Assessment deep learning software. It has been developed to solve critical challenges in the NHS Breast Screening Programme, including reducing missed cancers, helping manage staffing pressures and tackling delays that put women's lives at risk

- [Mirada Medical Ltd](#) for DLCExpert, which uses AI software to automate the time-consuming and skill-intensive task of contouring organs on medical images for radiotherapy planning, so that the healthy tissue is spared from irradiation

- [Ibex Medical Analytics](#) to study the effectiveness of their AI system for detecting cancer and other clinically important histological features in biopsy slides. The study uses data from 600 men across 6 NHS hospitals, and compares the results of their system with conclusions from trained pathologists

- [Ultromics Ltd](#) for the EchoGo Pro, a fully automated application for quantification and interpretation of stress echocardiograms that autonomously processes echocardiographic images to predict cardiac disease

For innovations to be successfully deployed, staff and patients must have confidence that they are safe. We are developing approaches to using the technical validation and testing of models. This will provide buyers and clinicians with the assurance that a product's technical performance is appropriate for clinical use. Once the validity of the software is proven through a robust regulatory approach, these technologies can support clinicians' workflow.

The NHS AI Lab has been working with the UKHSA and OHID to test a validation approach for AI models for future screening programmes. We have focused on mammography initially and are working towards publishing a peer-reviewed paper with our methodology in 2022.

There are currently no standardised methods for the real-world evaluation of AI products. However this is crucial to understand how effective the technologies are when deployed in the health and care setting.

The NHS AI Lab is rising to challenge through its [AI in Health and Care Award](#) by developing an evaluation methodology for market-authorised products. We will iterate and improve this as we test it in practice. The evaluation of the AI awardees is being undertaken throughout the lifespan of the NHS AI Lab.

The NHS AI Lab has also launched the [AI Ethics Initiative](#) to ensure that we have a rigorous approach to using AI products in health and care settings, including:

- working with the Health Foundation to improve the health and care outcomes of minority ethnic groups through understanding opportunities to use AI to address health inequalities, optimising data sets, and improving AI development, testing and deployment

- working with the [Ada Lovelace Institute to design and trial algorithmic impact assessments](#)

- empowering healthcare professionals to make the most of AI through providing learning and development opportunities

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AI, and racial and ethnic health inequalities

The NHS AI Lab and the Health Foundation have awarded £1.4 million in funding to 4 projects to:

- understand and enable opportunities to use AI to ensure innovation happens in response to the health needs of ethnic minority groups

- contribute to improving the quality, availability and appropriate use of data sets to account for ethnic diversity in the development of AI models

- improve the development, testing and deployment of AI models across patient populations to reduce bias, and improve the performance and accuracy of emerging and existing tools for different subpopulations

The chosen projects are:

- University of Westminster aims to raise the uptake of screening for STIs and HIV among ethnic minority communities through an automated AI-driven chatbot that provides advice about sexually transmitted infections. The research will also inform the development and implementation of chatbots designed for minority ethnic populations in public health more widely and within the NHS

- Loughborough University aims to use AI to improve the investigation of factors contributing to adverse maternity incidents among mothers from different ethnic groups. This research will provide a way of understanding how a range of causal factors combine, interact and lead to maternal harm, and make it easier to design interventions that are targeted and more effective for these groups

- St George's, University of London and Moorfields Eye Hospital aim to ensure that AI technologies that detect diabetic retinopathy work for all by validating the performance of AI retinal image analysis systems that will be used in the NHS Diabetic Eye Screening Programme (DESP) in different subgroups of the population. In parallel, the perceptions, acceptability and expectations of healthcare professionals and people with diabetes will be evaluated in relation to the application of AI systems within the North East London NHS DESP. This study will provide evidence of effectiveness and safety

prior to potential commissioning and deployment within the NHS. (Co-investigators: Homerton University Hospital, Kingston University and University of Washington, USA)

- University Hospitals Birmingham NHS Foundation Trust and partners will lead STANDING Together, an international consensus process to develop standards for data sets underpinning AI systems to ensure they are diverse, inclusive and can support development of AI systems that work across all demographic groups. The resulting standards will help inform regulators, commissioners, policymakers and health data institutions on whether AI systems are underpinned by data sets that represent everyone, and don't risk leaving underrepresented and minority groups behind

Case study: empowering healthcare professionals to make the most of AI

The Topol Review set out the important contribution that digital healthcare technologies can make in improving patient care, and made recommendations for the education and training of the current and future workforce. Health Education England has established an overarching Digital, Artificial Intelligence and Robotics Technologies in Education (DART-Ed) programme bringing together a number of projects to further explore and build on these findings.

One of these projects is delivered with the NHS AI Lab, with the aim of better understanding levels of trust and engagement with AI solutions in health and care. The research explores how to develop 'appropriate confidence' in the procurement, implementation and clinical use of these technologies.

The findings will inform the health and care skills and capabilities framework, which could, for example, include a module for local decision-makers on key considerations when procuring AI products. This framework will ultimately help empower healthcare professionals to make the most of AI, and realise its benefits for both patients and themselves.

Our commitments

We will undertake further work on using data to improve health outcomes and reduce health disparities, including through the AI Ethics Initiative. The initiative will report in 2023 to 2024 on its joint research call with the Health Foundation, exploring how to use AI-driven technologies to improve health outcomes for ethnic minority populations in the UK – by March 2024.

Clear and understandable AI regulation

Following our departure from the EU, we also have an opportunity to make the UK the leader in proportionate, innovation-friendly regulation of AI technologies.

The government's [Office for Artificial Intelligence](#) is currently considering the UK's pro-innovation approach to governing AI with support from stakeholders, and will set out in a white paper later this year how the government intends to address the opportunities and risks arising from AI.

The NHS AI Lab is supporting the advancement of a robust regulatory framework for AI in health and care that supports innovation, and gives patients and clinicians confidence that AI products are safe and effective.

The NHS AI Lab is doing this in partnership with the UK's regulatory bodies and other key health organisations including the Medicines and Healthcare products Regulatory Authority (MHRA), NICE, CQC, Health Research Authority and NHS Resolution. For example, their work will sit alongside NICE's [evidence standard framework for digital health technologies](#), ensuring new technologies are effective and offer economic value.

Our commitments

We will:

- develop unified standards for the efficacy and safety testing of AI solutions, working with MHRA and NICE – by December 2023

- optimise the regulatory process through the creation of a [Multi Agency Advisory Service](#) – by August 2022

Supporting partners to work with health and care organisations

Some of the most exciting areas of tech innovation that can have a positive impact on patients and the workforce in health and social care come from data-driven technologies, such as AI and other types of algorithms.

We are taking steps to help local NHS organisations become stronger buyers and more informed consumers of data-driven tools and services. Similar work has already been undertaken for the [government guidelines on AI procurement](#).

The size and structure of the health and care system also means that, to scale solutions, you would have to work with multiple organisations. To help make this as simple as possible, our work across information governance and standards (as mentioned in previous sections and in alignment with the [Life Sciences Vision](#)) includes:

- issuing clear guidance through our [information governance portal](#) for data protection rules for data-driven technologies that access personal data

- providing open standards for interoperability so that developers know how to build for the health and social care system

- working with vendors, suppliers, developers and the open-source community to ensure that standards are realistic, do not favour specific suppliers, and do not overburden small suppliers

Case study: University Hospitals Birmingham

University Hospitals Birmingham NHS Foundation Trust (UHB) has partnered with a number of technology companies to deliver improvements in 3 key areas:

1. Smart access.

2. Smart diagnostics.

3. Smart support.

This has led to the adoption of digital technologies that have transformed models of care for the population of Birmingham and Solihull, as well as supporting the restoration and recovery of services impacted by the COVID-19 pandemic. Projects include:

- an AI-powered skin cancer pathway, which has helped 40% of patients avoid the need for a hospital appointment

- an ophthalmology pathway where scans and diagnostics are carried out in the community without the need for a hospital appointment, with all individual care information being reviewed by UHB consultant ophthalmologists remotely. This care model and technology is now being applied to a broad range of specialties across the trust

- a 5G connection between community intermediate care and acute hospital teams, including digital stethoscopes, electrocardiogram and high-resolution video, to allow comprehensive assessments to be carried out without the need to convey patients to hospital

- 'ask A&E' symptom checker, where 64% of 19,000 users were appropriately sign-posted to non-hospital settings to receive care

UHB has established contractual relationships that recognise the expertise and intellectual property that UHB brings through their clinical staff and pathway-mapping, as well as through their data.

Case study: automation at Kettering Hospital

The [NHS AI Lab Skunkworks](#) commissioned [Foundry4](#) to undertake a discovery to understand the problem, and to determine the suitability of intelligent automation within NHS hospitals and trusts across England.

To support the COVID-19 pandemic response, [Kettering General Hospital](#) decided to work with Foundry4 to automate some of their processes to free up staff time to focus more on patient care. Each hospital had to provide a daily COVID-19 situational report with information provided by multiple departments in order to support planning and oversight. The team was able to build the automation in just 9 weeks, and it is estimated that over 4,400 hours of staff time will be saved every year, which can be used on patient care.

Following this successful project, Kettering identified 2 further processes ideally suited for automation. The first was automating appointment bookings for GP referrals, speeding up the process so patients are contacted sooner and saving nearly 1,500 hours of staff time.

The second is the 'unappointed patients' process where outpatient referrals that are no longer relevant (for legitimate health reasons) are removed from the system. This created a lot of 'noise' in internal systems and took up valuable appointment spaces from members of the public who needed to book as quickly as possible, having been referred from primary care such as their GP. This process had a negative impact on staff motivation with the existence of the year-long backlog due to COVID-19. The automation helped Kettering gain an estimated staff time saving of 550 hours a year.

We will be taking learning from these projects to help other NHS trusts use technology to free up staff time so it can be spent on higher-value tasks.

Our commitments

We will:

- make up to £100 million of funding available through the AI in Health and Care Award to accelerate the testing and evaluation of AI technologies – by December 2024

- help regulators develop fit-for-purpose regulations that are easy for the market to navigate, including approaches for the health and care sector to

validate AI technologies and recommendations on the use of synthetic data sets –
June 2022

7. Developing the right technical infrastructure

Our vision: we will ensure the data architecture underpinning the health and care system can easily work together to make more effective and efficient use of data

As a chief information officer, data architect, data analyst, cloud engineer, commissioner, provider or standards lead, I will:

- have quick access to high-quality and validated information that I need to plan, oversee, improve and run my systems effectively

- drive interoperability across the health and care system by:

  - having clear and open standards, making it easier to access data safely and efficiently, whilst maintaining respect for data privacy

  - understanding the wider data architecture so I can build and buy the right systems

- have clear cyber security guidance to make sure that my systems and the data held within them is as safe as possible

- understand, and undertake to reduce, the environmental impact of systems and data storage, while also leveraging the power of data to reduce wider environmental impacts of health and social care

- be able to build more efficient and resilient data solution – for example, by choosing the cloud for storage

Why this matters

Data-driven technologies have so much potential for our health and care system, but we can only unlock this potential if we have the right technical infrastructure in place. As we break down the organisational silos that hold data, we must rebuild them on the foundations of a unified architecture, open standards and better interoperability to enable the best use of data.

We must also give those who work in health and adult social care the clear cyber standards they need to keep that data as safe and secure as possible in order to respect

people's data privacy, as those risks change over time. This will help underpin all of our work to enhance privacy and safe use of data across the system.

We want to reshape our legacy systems and platforms into smaller discrete services by creating platforms that can talk to each other and work together, and so can easily be used to access data.

This will avoid delays in diagnosis, prevent tests from being repeated unnecessarily, and get members of the public the treatment and care that they need. These changes will be challenging to deliver, requiring collaborative working across the health and care system, but they are essential for the population to fully realise the benefits from the data available.

Progress so far

We have put in place the following measures to facilitate the linking of information:

- requiring use of the NHS number for transfers of information, which has allowed us to link information to individuals in a consistent way

- to support this work, we have developed a number of services to support access to the NHS number across health and care, including the personal demographic service API using HL7 Fast Healthcare Interoperability Resources (FHIR) standard, which has 30 services connected and over 500 million requests to date

- creating the CareConnect profiles, a set of FHIR-based models and API specifications, which facilitate the exchange of data about patient allergies, procedures, problems, observations, encounters, medications and immunisations data

- programmes such as GP Connect have implemented CareConnect profiles by developing APIs to open up information held within GP practice IT systems. These APIs have allowed authorised clinical staff to access GP practice clinical information and manage appointments between IT systems. IT system suppliers have gained full roll-out approval for inpatient discharge messages, meaning 98% of GP practices will have the ability to receive inpatient discharge FHIR messages

- creating new standards as part of the Transfer of Care Initiative, resulting in over 350,000 primary care notifications of events such as discharge

- continuing to increase the number of APIs available on the national healthcare gateway and NHS developer site

We already have a number of widely used national components and services that provide us with learning to build on. Some examples include:

- [Summary Care Record Application](): a national portal enabling access to a view of core information from the GP record, such as medications and allergies

- 2 information services that give clinicians a way of notifying children's services and identifying children and young people at risk: for child protection ([CP-IS]()) and female genital mutilation (FGM) ([FGM-IS]())

- [Personal Demographics Service](): a national master demographics service used across the NHS to access information such as the NHS number

- [Electronic Prescription Service](): a national service to support efficient and secure sending of prescription data from general practice to pharmacies

Progress on data standards across government, with learning shared across health and social care, includes:

- the [Data Standards Authority](), which establishes standards to make it easier and more effective to access and use data across government

- the [Government Data Quality Framework](), which provides a consistent approach to managing data quality across government

Examples of how we have maximised the environmental benefit of our data services include:

- the COVID-19 vaccinations programme issued reminders by SMS rather than letter, saving an estimated 173 tonnes of carbon dioxide, equivalent to taking 34 passenger vehicles off the roads for a year

- the NHS App enables patients to manage appointments and complete consultations online, resulting in fewer visits by car or taxi to GP practices. In the financial year 2020 to 2021, the app facilitated management of 247,000 GP appointments and 365,000 online consultations, resulting in a reduction of approximately 386 tonnes of carbon dioxide

Case study: improving data quality in support of COVID-19 testing

In just over a year, the UK's testing capacity increased from a few thousand to hundreds of thousands of tests a day. This achievement has been crucial to the fight against the virus – with digital technology and data at the heart of it.

When COVID-19 first arrived in the UK in early 2020, the testing infrastructure necessary to understand the spread of the disease at scale and at pace did not exist. Since then, the

capability has been transformed: more than a quarter of a billion tests have been done in England alone. There is a lab capacity of up to 800,000 PCR tests a day as well as a digital infrastructure capable of processing and returning more than 10 million test results a day.

But the usefulness of this activity relies on getting the key information to the right members of the public. Establishing data flows to organisations and systems has been a major part of the COVID-19 testing programme.

These data flows included sending test results to NHS Test and Trace so close contacts could be identified and provided with the latest guidance to help stop the spread of the disease.

Direct data feeds into GP systems were also established to give clinicians information about whether their patients test positive for COVID-19. To do this, there needed to be 100% confidence that data is matched to the right patient and the difficulties were considerable.

For example, when the solution to send results automatically to GP systems was first delivered in July 2020, 45% of new results could not be automatically sent because of data quality issues, such as misspelt names. As a result, an additional matching process was established and up-front verification to maximise data quality was introduced. The system was able to match 1.7 million historic results with missing or incorrect demographic data because of these measures.

Analysis and evaluation from an operational perspective is done to understand where there are data quality issues and where there is a need to make improvements to the digital journey. The more that is done to improve the quality of the data and how it is captured upfront, the better chance there is of matching data into GP records the first time.

Making sure high-quality data is flowing securely has been crucial in controlling the virus, supporting population health and getting back to the things that matter to us.

Taking this further

Modernising our data architecture

Currently, there are many legacy systems and platforms used by health and care staff.

The Topol Review found that between 15% and 70% of a clinician's working time can be spent on administrative tasks, which outdated systems can exacerbate. As well as this, 27% of doctors who responded to a survey by the British Medical Association in its vision

for NHS IT [Technology, infrastructure and data supporting NHS staff report](#) said they lost more than 4 hours a week because of inefficient hardware or systems.

We must use the best technologies to support our staff with their work as well as using the data by clinicians for making effective decisions using AI, machine learning and advanced analytics.

We will do this by providing more support and direction to IT systems providers on the appropriate platforms and systems they should use to access data most effectively. We will also build capability to effectively integrate AI and machine learning innovations into service delivery, in areas such as clinical imaging and workflow automation. This will provide additional capacity for clinicians to spend more time with patients.

By moving towards smaller discrete services built to work with national systems, we can improve interoperability, reuse and agility across health and social care to access data, improving efficiency and reducing costs. This requires us to think of the health and care system as a platform.

A key enabler of this will be the establishment of a mature offering for data infrastructure services, promoting collaboratively designed standards to enable the flow of consistent, coherent and interoperable data across the system. This will provide a foundation for accurate and up-to-date patient information regardless of healthcare setting.

Our goal is a modern architecture in which data can be accessed real-time through APIs. This goal cannot be achieved when the data is held in silos across disparate systems. Modernising the data architecture represents a significant task, and we will work with providers and integrated care systems to understand any impact this may have on current systems and commissioning plans.

We are determined to reduce the amount of working time clinicians spend on administrative tasks. To do this we have outlined below our new data architecture principles, which set the rules and guidelines that must be followed when we create or adopt new services that work with health and care data. Our principles answer the key questions:

- how will we use data?

- what data do we have and what data do we need?

- where do we store data?

- how do we manage data?

- how do we integrate data across the system?

Data architecture principles

1. All data will be validated at the point of entry to improve data quality.

Poor-quality data leads to many downstream problems. It can have serious impacts on the quality of care a person receives, and create extra work for our colleagues in health and care. All of our national platforms will automatically validate data at the point of entry to improve data quality and prevent poor-quality data being used within our health and care system. Where necessary, we will provide validation services, such as address look-up, using APIs to allow systems to improve the quality of data at point of entry.

2. All data will be made discoverable.

In conjunction with data standards that mandate the use of the NHS number for patient-identifiable data and records in many care settings, we also need to use well-defined APIs and metadata. This will help create a catalogue of the data that is easily discovered and reused across all appropriate settings and for appropriate analysis, where information governance allows. Every team that creates new data sets must adhere to this principle.

3. Data will be kept consistent.

Data being used should be of high quality and consistency. Too often data is copied from one application or system to another without considering how the data will be kept consistent. This approach also creates multiple copies of data, which can cause confusion about which version of the data is authoritative and reduce traceability of data for the citizen. Duplication of data also has an environmental impact. Where it must be duplicated, suitable data management plans must be in place to ensure consistency with primary sources and the origin of non-authoritative data must be made clear.

4. Consistent data vocabulary and data models.

We need to use a common vocabulary for our data architecture, and manage data based upon common building blocks of data models to reduce confusion and data set divergence. This is fundamental in building a single version of the truth, which will create data models that correctly define entities and translate them into executable code, and which are not based upon the specific care setting.

5. All clinical data stored will be made accessible using APIs published on the API gateway.

Patients, their carers and clinicians should be able to access the data relevant to them using systems and applications that are retrieving their data using a standard suite of APIs, reducing the complexity of using multiple systems. The NHSEI COVID-19

vaccinations programme has started on this journey with how it presents flu and COVID vaccination data. Patients and carers will be able to access all appropriate clinical records, transactional data and events like booking an appointment, where clinically safe to do so, using APIs.

6. The public will be able to self-manage any data relating to their contact details and personal preferences.

They will have the ability to manage their own data to make sure it is up to date, and reflects their circumstances and preferences.

7. Organisations should be able to self-manage any data relating to them – for example locations and types of services offered.

Organisations working with and on behalf of the NHS and adult social care will have the power to manage the data relating to them in one place.

8. Data should be digitally signed to an appropriate level.

Data about certain activities should have unique digital identifiers attached to them to show who made a decision. Prescription services already are digitally signed in this way, but there are other activities that also require assurance to manage issues such as fraud.

9. The environmental costs of data storage should be taken into account. This means:

- using cloud-based storage offerings or energy-efficient colocation and resilient on-premise data-hosting as appropriate

- storing only what is necessary, including considering whether information could be stored as text or audio rather than video

- ensuring the resolution of images is proportionate

- ensuring data compression, archiving and deletion is appropriate and timely

10. Green software engineering principles should be utilised in how we configure, optimise and re-architect using cloud technologies.

The NHS is committed to tackling climate change and reaching net zero by 2040 for the emissions it controls directly, and by 2045 for the emissions it can influence. These principles will support this agenda, for example using cloud storage or the use of serverless technologies.

We have already been working hard to put these principles into action through our data initiatives, where we followed a number of simple steps as shown below:

1. Consistent use of the NHS number across COVID-19 services: this is the primary identifier for anyone who uses the NHS. We want it to be used consistently across all our digital services. By accurately identifying individuals at the start of their journey, we can make sure all data generated about them is associated with their NHS number, and that there is a more complete record of their data.

2. Structured data store for clinical events: national NHS services aggregate a variety of clinical data for different purposes. We will bring these different data sets together and make them accessible to both clinicians and patients, where appropriate. We will use standard data formats to enable data-driven outcomes and more responsive, real-time analytical capabilities.

3. NHS login: we need to make sure all our digital services provide the option for citizens to register and login using their NHS login, which provides verification of their identity when using NHS services.

4. NHS Account: we will also develop an NHS Account that will bring patient details from different services across the system into a collective individual account, including information found in appointment bookings, vaccination status, health records and personalised wellness services. An account API will be made available nationally for strategic partners to integrate with.

5. Update patient details electronically: we need to make sure that we have up-to-date and accurate contact information for members of the public, including their contact preferences.

6. Consistent staff identity: we need to be able to confirm staff identity consistently across all services through a single staff identity used consistently across our systems. This will make it easier for them to be able to verify themselves at a workplace and allow them to move more freely across areas that need them.

7. Agreed approach on data architecture: the COVID-19 pandemic has highlighted the need for a change in how data is structured and accessed throughout the health and social care sector. Changes to the data architecture had to be made at pace to help clinicians make decisions. Those changes must now be secured and scaled across the wider system, using the goals outlined above as early priority areas.

These principles will support us to fix any technical debt (legacy technical issues or systems) that no longer work for the health and care system. This debt is often in the form

of a narrow solution that was selected because it could be implemented quickly, but can no longer meet the changing needs of the system with staff having to find workarounds.

Systems need to be designed against clearly defined business needs and around the user, whether that is someone receiving care, a member of staff or a researcher. By developing our data architecture with this user-focused vision, underpinned by the principles set out above, we can deliver the best structure for innovation to thrive, with benefits for staff and service users.

Our commitments

We will:

- agree a target data architecture for health and social care, outlining how and where data will be stored and accessed, starting with health (by July 2022) and then followed by social care – by September 2022

- publish the NHS Cloud Strategy, Principles and Policies to establish a more standardised and optimised approach to cloud adoption throughout the NHS – by June 2022

- deliver a target state that considers environmental impact through our cloud migration, and use of strategic cloud suppliers who have credible sustainability targets and roadmaps – by September 2022

- map the technical debt for national systems, and prioritise what must be addressed and completed through relevant programmes of work – by September 2022

- provide services to find and retrieve records from wherever they are created across health and social care – from June 2022

- improve our integration approach to scale APIs already being used by the market, starting with elective care – from May 2022

- improve the process of onboarding to national systems to increase uptake of national services and products such as the NHS number – from March 2022

- develop the roadmap for core NHS services using cloud technologies where appropriate – by March 2023

- build centres of excellence in the area of data architecture that focus on promoting best practices, support and training – by December 2022

- enhance the [NHS service standard](#) to provide more information on the right tools and technology that can be used to develop products and services – by December 2022

Promoting and developing data and technical standards

Instead of data flowing seamlessly between digital systems in different health and social care organisations, too often staff face 'information jams'. Their time is wasted logging into disparate systems or searching for information in outdated formats. The availability of high quality systems can be uneven both between and within organisations. Staff may have to rely on individuals repeating their information, forcing them to remember difficult histories and running the risk that care is provided on partial or inaccurate information. This can impact the relationship between the patients and service users receiving and the staff providing care.

Standards and interoperability help to overcome this by providing benefits to the system and citizens such as:

- improving patient safety by reducing errors from re-entering information across systems and care settings, and by ensuring clinicians and carers have the data they need on patients in transfers, discharges and referrals

- enabling better care by making relevant data available when clinicians need it, providing context and saving time for staff, patients and the public who draw on care and support

- avoiding lock-in and supporting innovation by enabling providers to choose from a diverse set of supplier products and systems, knowing they won't lose access to information and that the technology will work with other parts of the health and care system. This allows them to be driven by quality and value, as open standards drive down costs, not fear of things breaking and losing data

- enabling better policy and decision-making through frictionless reporting and analysis based on accurate, real-time and granular data, and audit trails. Standards would allow federated delivery at the pace that suits – for example, through an integrated care system – while ensuring that what is built can be used nationally and at a local level. This allows the flexibility for systems to be designed around local needs to a common design

- supporting individuals to access their health and care data so they can access information and make informed decisions about their own care

- improving data quality by enabling a shared responsibility for maintaining high standards, from staff seeing the benefits of correctly inputting information, suppliers

providing a system that is easy to use, data controllers storing and supplying data appropriately, and commissioners using and avoiding duplication of it

- creating energy efficiencies and reducing carbon by allowing a move from paper-based communication to digital communications, reducing hardware infrastructure for service delivery, and enabling web-based services that allow flexibility between end-user devices for lower-energy choices

In order to make sure that our standards are fit for the health and care system, and for suppliers working with it, we must promote ready-to-use standards that are:

- open, maintained, usable and accessible: standards are powerful when everyone can use and find them. This means they are free and openly licensed, maintained and well documented. We will be inspecting standard contract terms to identify opportunities to mandate interoperable and open ways of working. Wherever possible our terms should be fit for the future, encouraging a wide range of suppliers to offer innovative solutions that meet NHS benchmarks for best practice by default

- tested in reality and based on actual behaviours and needs: we understand that staff may not have the time and skills to correctly code up all their observations, diagnoses and procedures, and will develop our standards accordingly

- designed to meet the public's needs: standards must benefit staff and the public, not just make it easier for products to interoperate. Standards development should be purpose and person-centric, considering the context and needs of those who draw on care and support as well as health and care professionals, from clinicians to carers to administrative staff

- developed collaboratively with vendors, suppliers, digital technologists, app developers and the open source community: we will be looking to digital health, innovator and vendor communities to ensure standards are realistic, and help health technologies interoperate consistently. Part of this means balancing a variety of different perspectives and preferences, making sure standards do not favour specific suppliers and we do not overburden small suppliers

Our commitments

We will:

- develop and publish the draft standards and interoperability strategy to get fit-for-purpose standards widely adopted across health and adult social care, reusing and building on international standards where relevant – completed April 2022

- introduce a power for the Secretary of State for Health and Social Care to mandate standards for how information is collected and stored, so that information flows through the system in a usable way. This will make sure that when information is accessed or provided (for whatever purpose), it is in a standard form, both readable by and consistently meaningful to the user or recipient – delivery date subject to Parliamentary processes

- publish and maintain a standards roadmap, working with vendors and procurement frameworks to ensure effective implementation – completed April 2022

- develop a focused core of UK-wide FHIR profiles profiles to be a stable foundation for new standards – completed September 2021

- develop a portal to improve the visibility, clarity and accessibility of existing and future interoperability standards, enabling us to monitor adoption and support compliance, and promote collaboration and co-design, making it easier to find and contribute to standards development – by August 2022

Staying ahead of the evolving cyber and fraud risk

As the digital transformation of the health and social care system accelerates, so does the volume of data collected and the number of devices used to collect it. We must maintain public trust in the cyber security of the health and adult social care sector, providing safe and secure access to data with confidence, and enabling innovative data-driven technologies that can improve the quality and outcomes of care.

Cyber security incidents can impact services and the delivery of care. Incidents can have a large financial impact, both for costs incurred by recovering systems or financial penalties if any of the incidents ended in a regulatory breach.

Furthermore, if public confidence in the health and care system as a safe haven is reduced, it can have a negative impact on how we can use data for the benefit of patients and service users.

Case Study: the Data Security and Protection Toolkit

The Data Security and Protection Toolkit is an online self-assessment tool that helps NHS and social care organisations measure their performance against the National Data Guardian's 10 data security standards.

It is mandatory for all arm's length bodies, NHS trusts, commissioning support units, clinical commissioning groups and GP practices to complete the toolkit each year. The

content is updated every year, and is tailored to different types and sizes of organisations to understand their specific cyber security risks.

Analysis of the toolkit's data provides us with an overall picture of progress made by NHS organisations and adult social care, and importantly highlights areas where challenges remain. It also provides an in-depth picture of cyber resilience and maturity at individual trust level, so we can provide a more tailored approach to helping them improve.

Adult social care is significantly behind the cyber compliance levels of healthcare when measured against the Data Security and Protection Toolkit, and we recognise the sector's needs are differentiated. Through the Better Security Better Care programme, in partnership with representative organisations, we provide sector-specific support to raise cyber awareness and standards.

Good cyber hygiene and compliance with basic cyber standards goes a long way towards mitigating cyber threats to system data, for example, making sure that security patches are implemented quickly and systems do not become unsupported.

However, our best defence in staying ahead of the cyber threat is ensuring that we have security baked into the design of everything we do. Ensuring that all digital transformation in the sector is 'secure by design' from the outset is a key pillar of our emerging Cyber Security Strategy, being published in 2022.

Since the WannaCry ransomware attack in 2017, our centralised defences have been systematically upscaled. The Cyber Security Operations Centre now provides local and national network monitoring, incident response and threat intelligence. It blocks around 21 million items of malicious activity every month and has, since 2018, prevented at least 5 WannaCry-style attacks.

Government's cyber security lead, the National Cyber Security Centre (NCSC), also provides regular threat assessments to help the health and social care system stay up to date in our understanding of cyber risks so that we can plan our defences accordingly.

Case study: cyber incident exercising

Since the start of the COVID-19 response, we have moved to new exercise delivery models, and delivered several cyber incident response exercises remotely. This has allowed us to continue to make improvements to our incident response capability despite work-from-home restrictions, and has resulted in delivering exercises that are more true to real-life incidents where a multi-organisational response takes place from multiple different locations.

During this time, we have also increased the reach of our exercising programme into new parts of the sector. Exercise Cashmere expanded our reach into primary care and gave South Central and West Commissioning Support Unit an opportunity to take us through its incident management plans in the event of an IT incident affecting its client organisations.

Exercise Taffeta strengthened our high severity alert process, which has been invaluable during responses to many high severity alerts, including 6 individual alerts during the response to the logging tool Log4j's critical vulnerability.

Most recently, Exercise Denim gave senior leadership from DHSC, NHS Digital and NHS England the opportunity to step through a national-level incident, and will be followed up later this year with a further national-level exercise.

Skills are also important for any cyber security defence. Training and guidance are available for everyone working in health and social care on the importance of cyber security and basic cyber hygiene.

We are promoting the development of the cyber workforce through professional training, which will extend to the general health and care workforce, offering cyber basics and an annual training scheme. Board and Senior Information Risk Owner-level training is also being delivered to ensure that all levels of the workforce develop strong cyber skills.

According to the latest NHS Counter Fraud Authority estimate, fraud costs the NHS £1.14 billion a year – enough to pay for 7,900 ambulances. NHS fraud is linked to NHS activity and there are times when this requires the use of data that concerns NHS patients, their treatment or those that support it. There is a clear and strong public interest to access and use the appropriate records to remove this loss, and mitigate the risk, wherever possible, through robust detection and prevention methods. However, this must take place against our commitment to the public, who have a right to know how their personal data is being used and be assured it is being properly handled.

In 2021, the NHS Counter Fraud Authority produced their own data strategy, which set out their commitments to the robust application of data to support these goals while emphasising standards of good practice, and recognising their obligations and duties to the public.

Our commitments

We will:

- provide leaders with the data they need to understand their organisation's cyber risk status – from March 2022

- work with the MHRA, NHS Digital and NCSC through the Connected Medical Device Security Steering Group to proactively identify the risks around connected medical devices across the health and care system – from March 2022

- ensure backup reviews are completed for target organisations and, where needed, remediation plans are in place – by December 2022

- engage with the health and care system to develop the cyber security strategy for health and care, which we will publish later this year, to help drive collective effort from all the parts of the system – by December 2022

- triple the number of adult social care providers completing the Data Security and Protection Toolkit to at least 'approaching standards' status, an increase from 14.3% to 43% – by June 2022

- set clear cyber standards for health and care organisations and suppliers, annually reviewing and publishing standards in the mandatory Data Security and Protection Toolkit – next standards refresh in July 2022 and then continuing annually

- deliver at least 3 incident response exercises with national and local bodies – completed March 2022

As we move towards integrated care systems, we will continue to embed effective cyber security across the health and care system, including adult social care.

Creating the target data architecture

The target data architecture will be created to support 4 actions:

1. Effective data infrastructure using cloud technologies.

2. Improving access to data via APIs and open standards.

3. Improving uses of the data including AI, machine learning and advanced analytics.

4. Providing individuals with access and control over their data.

This data architecture will:

- ensure data is available in time and of the right quality to make better clinical decisions

- improve operational services

- improve population health

- power new research

This data architecture will support integrated care systems to meet health and care needs across an area, to co-ordinate services, and to plan in a way that improves population health and reduces inequalities between different groups, as well as meet data needs for secondary uses without creating bespoke data collections.

By providing national support to create cloud-and-edge infrastructure and services, the data architecture promises to make data more accessible and promotes high-performance computing to support health and social care use cases such as AI and machine learning.

The data architecture will provide:

- data at the right time and of the right quality to the right user

- the scalable data architecture to allow real-time data availability for certain use cases with decoupling between data storage and applications

- clinical and public-facing applications that are able to access authoritative data directly

- the ability for data to be captured once and used for multiple use cases, including improving operational services, secondary uses, population health and research

We have begun this approach for COVID-19 vaccination records and this will expand for other critical parts of a patient record, including diagnostic test results in pathology and radiology.

We will work with patients, vendors and tech leaders in health and care to gather views, so we can construct the most effective route map to get to our intended goal.

Our commitments

We will:

- establish 4 cloud exemplar sites across health and social care to store and utilise the data in the cloud – by December 2022

- build upon the work done in integrated care system target architecture to provide the reference architecture to support the integrated care systems – by December 2022

- develop the data orchestration layer and metadata catalogue, which allows the data discovery and data flows supported by APIs across the data sources in the health and social care system – by December 2022

- establish the exemplar data flows, allowing multiple patterns including query or response, publish or subscribe, and automated alerting to support real-time data usage in the health and social care system – by March 2023

- develop data standards and supporting processes based upon the reusable clinical models rather than based upon the care settings type – by September 2022

How you can get involved

Publishing this strategy is only one more step towards harnessing data to help all the populations we serve, and to help our health and care system run at its best.

As we work to deliver against the commitments we have made in the strategy, we will do so in the open. We will involve the public through our engagement programmes and report on our progress.

To keep in touch or find out more, [visit our online hub](#)

Annex A: legislative changes

The imperative for change

We acted quickly using existing legislation to enable the safe and effective use of data to support the response to the pandemic, and the country has benefitted from it. Government has ensured that health and care professionals, those managing the national response, and researchers have had access to the right information: quickly, easily and when they need it.

From the rapid establishment of the shielded patient list to the development of new research platforms such as the NHS COVID-19 Data Store, the changes we made were key both to our immediate response to the pandemic, and our longer-term understanding of the disease and its impacts.

We want to ensure that these benefits can be felt by patients and service users across the health and care system. We are working to identify and tackle existing barriers including through changes to legislation (set out below) that will enable more effective use of data.

This includes implementing the recommendation of [Putting data, digital and tech at the heart of transforming the NHS](#) that there should be a joined-up centre driving digital and data transformation, by merging NHS Digital into the transformation directorate of NHS England, using legislation to transfer statutory responsibilities.

These changes will improve the delivery of care by supporting the health and care system to:

- develop effective policies

- plan and commission services

- target care where it is most needed

- identify poor performance

None of the changes we are making will remove the duties of organisations to meet the requirements of data protection legislation. This means that all uses of an individual's data will need to be necessary, proportionate, transparent, and subject to that individual's rights to access, correction and information on use.

Primary legislation

We will use powers in the [Health and Care Act 2022](#) to:

- allow health and adult social care public bodies to require anonymous information (information that is in a form that does not identify any individual or enable the identity of any individual to be ascertained) from other health and adult social care public bodies, and from providers who are commissioned by such public bodies to provide health and adult social care services

- allow the Secretary of State for Health and Social Care to require data from all regulated adult social care providers about services they provide, whether funded by local authorities or privately by individuals

- make changes to NHS Digital's legal framework to:

  - introduce a new general duty on NHS Digital to have regard to the need to promote the effective and efficient planning, development and provision of health services and of adult social care in England

  - place a requirement on NHS Digital to have regard to the need to balance its general duties where they compete

  - clarify that the purposes for which NHS Digital can access data include purposes 'connected with' the provision of health care or adult social care (alongside the promotion of health)

- enable NHS Digital to require data from private health care providers when it considers it necessary or expedient for it to have such data to comply with a direction from the Secretary of State to establish an information system. Our expectation is that any transfer of NHS Digital's functions as part of the future merger with NHS England will include the transfer of these new statutory responsibilities

- allow the Secretary of State for Health and Social Care to mandate standards for processing of information to both private and public bodies that deliver health and adult social care, so that data flows through the system in a usable way, and that when it is accessed or provided (for whatever purpose) it is in a standard form, both readable by and consistently meaningful to the user or recipient. NHS England is also being given new powers to publish mandatory information standards to a wider range of organisations, including private health and adult social care providers, where the standards relate to the provision of NHS services

[Part 3 of the Health and Care Act](#) also includes provisions that allow the Secretary of State to make regulations to transfer functions of certain arm's length bodies (ALBs), including NHS Digital, to certain other ALBs, and the intention is to use this power to transfer the functions of NHS Digital, as far as possible, to NHS England.

It remains important that the right legal framework and protections for the use of health and care data are in place, whichever organisation carries out those functions, and we remain committed to taking forward the changes to NHS Digital's functions and powers.

Secondary legislation

We will amend the [Health Service (Control of Patient Information) Regulations 2002](#) in due course to facilitate timely and proportionate sharing of data – including, where necessary and appropriate, personal information – for the purposes of supporting the health and care system.

We will engage with stakeholders and the public to make sure that changes to the regulations are implemented transparently and that appropriate safeguards are in place.

Annex B: list of commitments

1. Improving trust in the health and care system's use of data

Commitment 101 – to be completed by December 2022

We will work with expert partners and the public to implement secure data environments as a default across the NHS. We will do this by delivering:

- a clear public guide to secure data environments and our overarching policy guidelines for the use of secure data environments

- a robust accreditation regime to ensure our high standards for secure data environments are implemented. This will include not only accreditation requirements for secure data environments but also guidance and oversight on users of the environment, as well as the process to monitor and assess implementation

- a full technical specification, drawing on industry best practice, including requirements to ensure interoperability, cyber security and the use of privacy-enhancing technologies

- a comprehensive roadmap to ensure all partners across the system know how to implement our framework, with clear indicative timescales and expectations for those at different readiness levels. This will include not only those delivering the transformation in the NHS, but also software providers, academic and industry researchers, as well as funding agencies

Commitment 102 – to be completed by December 2022

We will work with the public to establish, for the first time, a data pact that will set out how we will use health and care data, and what the public has the right to expect.

Commitment 103 – to be completed by December 2022

We will co-design a transparency statement, as part of a regularly updated online hub, setting out how publicly held health and care data is used across the sector.

Commitment 104 – completed December 2021

We will lead the work of the Health and Care Information Governance Panel to develop additional information governance guidance, including the first part of the information

governance frameworks for integrated care covering individual care and standards (such as data-sharing and transparency), so the public can be confident in our handling of their data, to be published on the [information governance portal](#).

Commitment 105 – completed May 2022

We will establish an expert advisory group drawn from a wide range of stakeholders from across health and adult social care with whom we will co-design a robust and detailed plan for rebuilding public trust, including commitments set out here, and provide a check and challenge function to make sure we never fall below the ambition and standard set out in this strategy.

Commitment 106 – to be completed by December 2022

We will agree, with the expert group, how we will transparently measure and monitor levels and drivers of public trust so that all organisations using health and care data have up-to-date information about the public's attitudes to data use.

Commitment 107 – in testing from January 2022

We will develop a central portal for data partnerships guidance for healthcare leaders and seek feedback ahead of a wider roll-out.

Commitment 108 – to be completed by March 2023

We will publish the value sharing framework, which will support the health system to deliver good data partnerships.

Commitment 109 – to be completed by March 2023

We will update the 5 principles to include the adult social care sector.

Commitment 110 – to be completed by December 2023

We will develop commercial principles to ensure that partnerships for access to data for research and development have appropriate safeguards, and benefit the public, and the NHS and NHS Digital's template contracts for access to data will be reviewed to ensure they are consistent with these principles.

Commitment 111 – to be completed by December 2022

We will develop a standard for public engagement, setting out best practice for health and care organisations, and any other body using NHS data, to engage appropriate with the public and staff across the system on data programmes and issues.

Commitment 112 – to be completed from July 2022

We will undertake in-depth engagement with the public and professionals through forums such as focus groups with seldom-heard groups, and large-scale public engagement on topics and questions that are high priority or particularly complex, including how we deliver secure data environments and the future of the national data opt-out, and working closely with regions to understand local needs.

Commitment 113 – to be completed from April 2022

We will work with local health and care systems and partners including integrated care systems, including co-designing regional engagement, to make sure that we understand the needs, concerns and opportunities for different communities across England.

Commitment 114 – to be completed by July 2022

We will work with the public, the expert advisory group, the National Data Guardian and other stakeholders to ensure that we have a simple opt-out system in place that provides clarity and choice, giving patients confidence, and ensuring data continues to support the functioning of the health and care system.

Commitment 115 – to be completed by December 2023

We will improve access to GP records in the NHS App by giving patients access to their latest health information (November 2022) and provide patients with the ability to digitally request historic coded information, including diagnosis, blood test results and immunisations.

Commitment 116 – to be completed by March 2024

We will continue to develop the NHS App so that 75% of the adult population will be registered to use the NHS App and NHS website, and content and services produced on these national channels will be tailored to a person's needs and choices, making it easy to self-serve and provide choice in the ways they interact with us.

Commitment 117 – to be completed by December 2025

We will continue to support local systems to roll out shared care records across England (subject to HM Treasury approval), providing the necessary data and API infrastructure to enable the public to access their records through national and local solutions.

2. Giving health and care professionals the information they need to provide the best possible care

Commitment 201 – completed December 2021

We will improve information governance guidance so staff are confident in sharing individuals' data for their care, including publishing the Information Governance Framework for Integrated Health and Care: Shared Care Records.

Commitment 202 – to be completed from April 2022

We will action the findings of the user research to embed the information governance portal as the one-stop shop for help and guidance, as evidenced by an increase in the number of visits to the online portal.

Commitment 203 – to be completed by July 2022

Working with the Health and Care Information Governance Panel, we will create fit-for-purpose rules around different types of data (such as pseudonymised), so that staff can clearly understand them, addressing concerns around pseudonymised data as raised by the Goldacre review.

Commitment 204 – to be completed by December 2022

We will develop a national information governance transformation plan, focusing on practical data-sharing situations, creating professional standards and addressing training for frontline staff.

Commitment 205 – to be completed from April 2022

We will establish a head of profession to ensure the development of competency frameworks, standards, job families and appropriate professional accreditation for information governance staff working in health and care.

Commitment 206 – to be completed by December 2022

We will lead the development and implementation of information governance as part of a multi-disciplinary function for informatics and champion the work of information governance professionals.

Commitment 207 – to be completed by July 2022

We will review the [Data Security and Protection Toolkit](#) and its language to bring it into line with our work to simplify information governance.

Commitment 208 – delivery date subject to Parliamentary processes

We will introduce a statutory power to enable health and adult social care public bodies to require anonymous information that relates to the provision of health and adult social care services in England.

Commitment 209 – completed March 2022

We will ensure that each integrated care system has a basic shared care record in place to enable sharing of key information between GP practices and NHS trusts.

Commitment 210 – to be completed by December 2024

We will support every integrated care system to ensure that all organisations are able to access a shared care record that meets the requirements set out in the standards roadmap, enabling individuals, their approved caregivers and their care team to view and contribute to the record.

Commitment 211 – to be completed by end of 2022 and reviewed annually

We will have in place a system-wide target for the rationalisation of data collections to reduce the time spent by health and care staff inputting and processing data for national use.

Commitment 212 – to be completed by September 2022

UKHSA will put FAIR (findability, accessibility, interoperability and reusability) principles at the heart of its data strategy, designing institutional capabilities and processes that reduce burdens on public health system stakeholders while responding to user needs.

Commitment 213 – completed February 2022

We will scale up our digital home care projects to support 600,000 members of the public with care at home, including those resident in care homes, improving their health outcomes.

3. Improving data for adult social care

Commitment 301 – to be completed from April 2023

We will continue to pursue the collection of pseudonymised client-level data rather than aggregate data from local authorities as set out in the [adult social care reform white paper](). This will ensure we have regular and comprehensive data to enable person-centred, sustainable innovation for adult social care.

We will use the NHS number to ensure data can be appropriately linked and plan to make client-level data collection mandatory with all local authorities expected to commence data flows by 2023 to 2024.

Commitment 302 – to be completed from June 2022

We will develop an easily accessible data-sharing solution with local authorities and providers over the next 3 years that supports real-time decision-making at local, regional and national levels, building on the learning from the pandemic, and seek to ensure different actors in the system have access to the same rich data sets.

Commitment 303 – commenced from April 2022

We will develop, in collaboration with Skills for Care, a digital skills framework that will support the improvement of the digital capabilities of everyone working in the adult social care sector (phase one completed March 2022), supported by the delivery of an inclusive approach to training opportunities to improve the data and digital literacy of the adult social care workforce from April 2022.

Commitment 304 – to be completed by March 2024

We will ensure that at least 80% of social care providers have a digitised care record in place that can be connected to a shared care record and we will reinforce the use of the NHS number universally across adult social care to support this.

Commitment 305 – delivery date subject to Parliamentary processes

We will introduce a power to require information from all adult social care providers (both public and private), so that we can build a better picture of the delivery of adult social care services across England.

Commitment 306 – to be completed by December 2022

We will establish a data framework for adult social care setting out:

- what data the sector needs to collect

- the purpose of those collections

- the standards it is collected to

We will engage with the sector, including local authorities and providers, to develop the framework, which will set out how we will improve the quality of data and rationalise collections so that we minimise the collection burden.

We will:

- share our proposed approach with the Data Alliance Partnership – June 2022

- work with the sector on its detailed design – July to November 2022

- publish the framework – December 2022

Commitment 307 – to be completed by March 2023

We will continue to promote NHSmail – or other appropriate services that meet the government's secure email policy requirements – to all providers to enable secure information-sharing, and will work with the sector to identify a long-term and sustainable approach.

Commitment 308 – to be completed by March 2023

We will work with our partners to evaluate the impact of the solutions currently in place for access to primary care data – for example, the recent expansion of a restricted view of GP Connect to specific community and social care staff. Over the next year, we will explore further options for appropriate access to information to deliver high-quality care.

Commitment 309 – to be completed by March 2023

We will publish a standards and capabilities roadmap for digital social care record solutions (completed May 2022), which assured suppliers providing digital social care records are required to comply with. Its development will be co-designed with the adult social care sector, and will include data and reporting standards that will allow providers and commissioners across the NHS and adult social care sector to access information. This will begin by developing a process to consolidate existing social care terminology standards.

Commitment 310 – to be completed by July 2022

We will work with the telecare sector ahead of the telecoms industry-led transition from analogue to digital phone lines by 2025, and issue an action plan to support those who commission, deliver and supply telecare services and equipment.

Commitment 311 – to be completed from April 2022

We will support care providers in adopting proven technologies that can transform quality of care and safety, and fund implementation support within each integrated care system to rapidly digitise social care as set out in the white paper People at the Heart of Care.

4. Supporting local and national decision-makers with data

Commitment 401 – to be completed by September 2024

Social care records will be integrated into local shared care records within 6 months of a provider's digital system going live – based on current forecasts for digital roll-out, this will mean 80% of providers will be integrated.

Commitment 402 – completed March 2022

We will develop a workforce observatory, including an annual census, to inform how to better harness the professional skills of analysts and data managers, engineers and scientists, and support their professional learning and development.

Commitment 403 – completed December 2021

We will develop an online Analytics Hub, working with AnalystX, to share, promote and endorse training, events and other resources aimed at analysts and non-analysts across all career levels.

Commitment 404 – completed March 2022

We will grow the AnalystX community and build the team of future analytical leaders through a champions programme.

Commitment 405 – to be completed by September 2022

We will continue to encourage innovation and collaborative working through a data and analytics accelerator by promoting the use of open data, and working with a plurality of solutions and teams. The principles of the accelerator will be tested through hackathons and real business cases.

Commitment 406 – to be completed by December 2022

We will develop and roll out a unified set of competency frameworks aligned to the government analysis function skills, and the digital, data and technology profession.

Commitment 407 – to be completed by March 2024

Through the Developing Data and Analysis as a Profession Board, we will:

- agree frameworks, guidelines and policies to support the analytical community and address the concerns raised in the Goldacre review

- build the ecosystem of the profession through communities of practice (local, regional, national and virtual)

- signpost and provide development opportunities for analysts in both health and social care

Commitment 408 – completed March 2022

We will initiate a national pilot on improving care co-ordination via the Improving Care Coordination for Patients programme.

Commitment 409 – completed March 2022

We will be able to showcase replicable archetypes of national data and analytics technology infrastructure based on the maturity of integrated care systems.

Commitment 410 – to be completed by April 2023

We will have a federated data platform that will provide the connectivity needed to transform care and improve outcomes for patients.

Commitment 411 – commenced from December 2021

We will begin to make new source code that we produce or commission open and reusable by default (with clear exceptions) and publish it under appropriate licences to encourage further innovation (such as MIT and OGLv3, alongside suitable open data sets or dummy data). Subject to consultation, the relevant policies will also aim to be open and reusable.

Commitment 412 – to be completed from March 2022

We will consult with the UKRI and NIHR to consider how outputs from research they fund involving health and care data can follow open and reusable code principles.

Commitment 413 – delivery date subject to Parliamentary processes

We will amend the 2002 COPI regulations to ensure that they facilitate timely and proportionate sharing of data, engaging with stakeholders and the public by the end of 2022 to make sure that changes are implemented transparently.

Commitment 414 – to be completed from June 2022

We will, as part of the forthcoming health disparities white paper, set out the role that data – and data improvement initiatives – must play in government's overarching approach to reducing the gap in health outcomes between different places and communities across the country.

Commitment 415 – to be completed from June 2022

We will ensure that, as we implement this data strategy, all commitments are assessed against their impacts on improving understanding of and ability to act on tackling health disparities and ill-health.

Commitment 416 – to be completed by 2022

We will, as part of the forthcoming Women's Health Strategy, explore how data can be used to improve insights for women's health by making better use of data collected from heath and care services.

Commitment 417 – to be completed from April 2022

DfE, DHSC, DLUHC and the Home Office will work together to identify enablers of appropriate information-sharing by professionals working with children and families, such as consistent identifiers, improved standards and guidance.

Commitment 418 – to be completed by July 2023

DfE will publish a report setting out the government's policy on information-sharing to safeguard children, including considerations of issues around applying a consistent child identifier.

Commitment 419 – to be completed from May 2022

DHSC will work with the DLUHC deliver improved guidance for local partnerships delivering the Supporting Families programme that will support appropriate and safe local data-sharing to safeguard and support families, and prevent problems from escalating.

Commitment 420 – to be completed from September 2022

Our public health agencies will draw on multiple data sources to gain new insights into the public's health, with quicker access to high-quality health intelligence to inform improved decision-making and responses to threats to health.

5. Empowering researchers with the data they need to develop life-changing treatments, diagnostics, models of care and insights

Commitment 501 – completed February 2022

We will create partnerships between academic researchers, charities, patient advocacy groups, industry and analytical teams to enhance the exchange of skills and knowledge.

Commitment 502 – to be completed by December 2022

We will work with expert partners and the public to implement secure data environments as a default across the NHS. We will do this by delivering:

- a clear public guide to secure data environments and our overarching policy guidelines for the use of secure data environments

- a robust accreditation regime to ensure our high standards for secure data environments are implemented. This will include not only accreditation requirements for secure data environments, but also guidance and oversight on users of the environment, as well as the process to monitor and assess implementation

- a full technical specification, drawing on industry best practice, including requirements to ensure interoperability, cyber security and the use of privacy-enhancing technologies

- a comprehensive roadmap to ensure all partners across the system know how to implement our framework, with clear indicative timescales and expectations for those at different readiness levels. This will include not only those delivering the transformation in the NHS, but also software providers, academic and industry researchers, as well as funding agencies

Commitment 503 – to be completed by June 2022

We will create clarity on terminology and legal definitions, working with the research community to alleviate confusion and improve the quality of research access requests.

Commitment 504 – to be completed by December 2023

We will create at-scale data sets that bring together the different types of health data to develop new tools for prevention, diagnostics and clinical decision support through the Data for Research and Development programme.

Commitment 505 – to be completed by December 2023

We will bring together genomics data, and work with NHSEI to ensure genomic data generated through clinical care is fed back into patients' records.

Commitment 506 – commenced from March 2021

We will build on platforms such as NHS DigiTrials to support the best use of data and digital tools in study feasibility, identification and monitoring of research participants to enable faster, more efficient and effective clinical trials.

Commitment 507 – to be completed by September 2022

We will publish a 2021 to 2022 implementation plan (complete) followed by a 2022 to 2025 implementation plan to progress UK priorities for clinical research as set out in the Future

[of Clinical Research Delivery](#), including a theme on research enabled by data and digital tools.

Commitment 508 – to be completed by June 2022

We will convene a UK-wide genomic data working group with representation from experts across the UK's genomic healthcare landscape to provide a forum for co-ordination and collaboration, and to ensure that our processes maintain public trust in the safe, appropriate and responsible use of personal data for both clinical care and research.

Commitment 509 – to be completed by June 2023

We will work with other countries and the World Health Organization (WHO) to facilitate the implementation of the World Health Assembly resolution on strengthening clinical trials to provide high-quality evidence on health interventions and to improve research quality and coordination, and supporting, as appropriate, the development of a WHO progress report by the 76th World Health Assembly.

6. Working with partners to develop innovations that improve health and care

Commitment 601 – completed May 2022

We will publish a digital playbook on how to open source your code for health and care organisations. Guidance on where to put the code, how to license and maintain it, and best practice for working with suppliers will be published in addition to case studies of teams who have done this.

Commitment 604 – to be completed by March 2024

We will undertake further work on using data to improve health outcomes and reduce health disparities, including through the AI Ethics Initiative. The initiative will report in 2023 to 2024 on its joint research call with the Health Foundation exploring how to use AI-driven technologies to improve health outcomes for ethnic minority populations in the UK.

Commitment 605 – to be completed by December 2023

We will develop unified standards for the efficacy and safety testing of AI solutions, working with MHRA and NICE.

Commitment 606 – to be completed by August 2022

We will optimise the regulatory process through the creation of a [Multi Agency Advisory Service](#).

Commitment 607 – to be completed by December 2024

We will make up to £100 million of funding available through the AI in Health and Care Award to accelerate the testing and evaluation of AI technologies.

Commitment 608 – to be completed by June 2022

We will help regulators develop fit-for-purpose regulations that are easy for the market to navigate, including approaches for the health and care sector to validate AI technologies, and recommendations on the use of synthetic data sets.

7. Developing the right technical infrastructure

Commitment 701 – to be completed by September 2022

We will agree a target data architecture for health and social care outlining how and where data will be stored and accessed, starting with health (July 2022) and then followed by social care (September 2022).

Commitment 702 – to be completed by June 2022

We will publish the NHS Cloud Strategy, Principles and Policies to establish a more standardised and optimised approach to cloud adoption throughout the NHS.

Commitment 703 – to be completed by September 2022

We will deliver a target state that considers environmental impact through our cloud migration, and use of strategic cloud suppliers who have credible sustainability targets and roadmaps.

Commitment 704 – to be completed by September 2022

We will map the technical debt for national systems, and prioritise what must be addressed and completed through relevant programmes of work.

Commitment 705 – to be completed from June 2022

We will provide services to find and retrieve records from wherever they are created across health and social care.

Commitment 706 – to be completed from May 2022

We will improve our integration approach to scale APIs already being used by the market starting with elective care.

Commitment 707 – to be completed from March 2022

We will improve the process of onboarding to national systems to increase uptake of national services and products such as the NHS number.

Commitment 708 – to be completed by March 2023

We will develop the roadmap for core NHS services using cloud technologies where appropriate.

Commitment 709 – to be completed by December 2022

We will build centres of excellence in the area of data architecture that focus on promoting best practice, support and training.

Commitment 710 – to be completed by December 2022

We will enhance the NHS service standard to provide more information on the right tools and technology that can be used to develop products and services.

Commitment 711 – completed April 2022

We will develop and publish the draft standards and interoperability strategy to get fit-for-purpose standards widely adopted across health and adult social care, reusing and building on international standards where relevant.

Commitment 712 – delivery date subject to Parliamentary processes

We will introduce a power for the Secretary of State for Health and Social Care to mandate standards for how information is collected and stored, so that information flows through the system in a useable way. This will make sure that when information is accessed or

provided (for whatever purpose), it is in a standard form, both readable by and consistently meaningful to the user or recipient.

Commitment 713 – completed April 2022

We will publish and maintain a standards roadmap, working with vendors and procurement frameworks to ensure effective implementation.

Commitment 714 – completed September 2021

We will develop a focused core of UK-wide [FHIR profiles](#) to be a stable foundation for new standards.

Commitment 715 – to be completed by August 2022

We will develop a portal to improve the visibility, clarity and accessibility of existing and future interoperability standards, enabling us to monitor adoption and support compliance, and promote collaboration and co-design, making it easier to find and contribute to standards development.

Commitment 716 – to be completed from March 2022

We will provide leaders with the data they need to understand their organisation's cyber risk status.

Commitment 717 – to be completed from March 2022

We will work with the MHRA, NHS Digital and NCSC through the Connected Medical Device Security Steering Group to proactively identify the risks around connected medical devices across the health and care system.

Commitment 718 – to be completed by December 2022

We will ensure backup reviews are completed for target organisations and, where needed, remediation plans are in place.

Commitment 719 – to be completed by December 2022

We will engage with the system to develop the cyber security strategy for health and care, which we will publish later this year to help drive collective effort from all parts of the health and social care system.

Commitment 720 – to be completed by June 2022

We will triple the number of adult social care providers completing the Data Security and Protection Toolkit to at least 'approaching standards' status, an increase from 14.3% to 43%.

Commitment 721 – next standards refresh in July 2022 and then continuing annually

We will set clear cyber standards for health and care organisations and suppliers, annually reviewing and publishing standards in the mandatory Data Security and Protection Toolkit.

Commitment 722 – completed March 2022

We will deliver at least 3 incident response exercises with national and local bodies.

Commitment 723 – to be completed by December 2022

We will establish 4 cloud exemplar sites across health and social care to store and utilise the data in the cloud.

Commitment 724 – to be completed by December 2022

We will build upon the work done in integrated care system target architecture to provide the reference architecture to support the integrated care systems.

Commitment 725 – to be completed by December 2022

We will develop the data orchestration layer and metadata catalogue that allows the data discovery and data flows supported by the APIs across the data sources in the health and social care system.

Commitment 726 – to be completed by March 2023

We will establish the exemplar data flows allowing multiple patterns including query or response, publish or subscribe, and automated alerting to support real-time data usage in the health and social care system.

Commitment 727 – to be completed by September 2022

We will develop data standards and supporting processes based upon the reusable clinical models rather than based upon the care settings type.

Annex C: organisations who provided feedback on the draft strategy

Academy of Medical Sciences
Ada Lovelace Institute
Age UK
Alzheimer's Society
Association of British HealthTech Industries
Association of Medical Research Charities
Association of Mental Health Providers
Association of the British Pharmaceutical Industry
Asthma UK
Breast Cancer Now
British Medical Association
Cancer Research UK
Care England
Care Providers Alliance
Care Trust
Chartered Society of Physiotherapy
Crohn's and Colitis UK
Cystic Fibrosis Trust
Diabetes UK
Digital Social Care
Faculty of Public Health
Future Care Capital
General Medical Council
General Pharmaceutical Council
Genomics England
Health Data Research UK
Health Statistics User Group
Health and Care Professions Council
Health and Social Care Alliance Scotland
Healthcare Watch
Healthwatch
Homecare Association (formerly UKHCA)
IBM
Imperial College London
Information Commissioner's Office
Local Government Association
Macmillan Cancer Support
Med Confidential
Medical Research Council
Mind
NHS Counter Fraud Authority
NHS Resolution
NIHR Biomedical Research Centre (NIHR)
National Academy for Social Prescribing
National Autistic Society

National Care Forum
National Care Forum
National Data Guardian
National Institute for Health and Care Excellence
Nuffield Council
Nursing and Midwifery Council
Office for Statistics Regulation
One London
Open Data Institute
Our Future Health
Parkinsons UK
Patients Association
Pharmaceutical Services Negotiating Committee
Professional Record Standards Body
Professional Record and Standards Body
Registered Nursing Home Association
Royal College Speech Language Therapists
Royal College of General Practitioners
Royal College of Music
Royal College of Nursing
Royal College of Occupational Therapists
Sense
Shelford Group
Skills for Care
Society and College of Radiographers
Stroke Association
TechUK
The Academy of Medical Sciences
The Association of Directors for Adult Social Services
Think Local Act Personal
UK Pandemic Ethics Accelerator's Data use workstream
UK Research and Innovation
Understanding Patient Data
University of Nottingham
University of Oxford
Versus Arthritis
Voluntary Organisations Disability Group
Which?

Annex D: recommendations of the Goldacre review

Summary

Professor Ben Goldacre was [commissioned by the Secretary of State for Health and Social Care in February 2021](#) to review how to improve safety and security in the use of health data for research and analysis.

The final report of the Goldacre review [Better, broader, safer: using health data for research and analysis](#) was published on 7 April 2022. Learning lessons from the pandemic, the report provides wide-ranging and well-evidenced recommendations with the potential for positive improvements in how health data is used. The report is informed by interviews, open sessions and deep dives with more than 100 stakeholders throughout academia and healthcare.

This annex outlines how the summary recommendations of the Goldacre review are being taken forward under the strategy's commitments. We expect to further engage partners to consider the implementation of these recommendations as part of the wider conversation on this strategy.

Given the broad nature of the recommendations made by the review, there are some specific elements that are not directly addressed by the data strategy commitments. The relevant recommendations, indicated in this annex, will require further consideration, with some being addressed through ongoing programmes of work and others sitting outside of the remit of DHSC.

[A summary of the review's findings (titled 'Better, broader, safer: using health data for research and analysis – summary')](#) sets out how the 30 recommendations presented below are linked to the more detailed recommendations made.

Platforms and security

Recommendation 1: build trust by taking concrete action on privacy and transparency: trust cannot be earned through communications and public engagement alone

How this is being addressed through the strategy commitments:

Commitment 102 – to be completed by December 2022

We will work with the public to establish, for the first time, a data pact that will set out how we will use health and care data, and what the public has the right to expect.

Commitment 103 – to be completed by December 2022

We will co-design a transparency statement, as part of a regularly updated online hub, setting out how publicly held health and care data is used across the sector.

Commitment 105 – completed May 2022

We will establish an expert advisory group drawn from a wide range of stakeholders from across health and adult social care with whom we will co-design a robust and detailed plan for rebuilding public trust, including commitments set out here, and provide a check and challenge function to make sure we never fall below the ambition and standard set out in this strategy.

Commitment 111 – to be completed by December 2022

We will develop a standard for public engagement, setting out best practice for health and care organisations, and any other body using NHS data, to engage appropriate with the public and staff across the system on data programmes and issues.

Recommendation 2: ensure all NHS data policies actively acknowledge the shortcomings of 'pseudonymisation' and 'trust' as techniques to manage patient privacy: these outdated techniques cannot scale to support more users (academics, NHS analysts, and innovators) using ever more comprehensive patient data to save lives.

How this is being addressed through the strategy commitments:

Commitment 203 – to be completed by July 2022

Working with the Health and Care Information Governance Panel, we will create fit-for-purpose rules around different types of data (such as pseudonymised), so that staff can clearly understand them, addressing concerns around pseudonymised data as raised by the Goldacre review.

Recommendation 3: build a small number of secure analytics platforms – shared trusted research environments (TREs) – then make these the norm for all analysis of NHS patient

records data by academics, NHS analysts and innovators, wherever there is any privacy risk to patients, unless those patients have consented to their data flowing elsewhere.

Every new TRE brings a risk of duplicated effort, duplicated information governance, duplicated privacy risks, monopolies on access or task, and obstructive divergence around data curation and similar activity: there should be as few TREs as possible, with a strong culture of openness and re-use around all code and platforms.

How this is being addressed through the strategy commitments:

Commitment 502 – to be completed by December 2022

We will work with expert partners and the public to implement secure data environments as a default across the NHS. We will do this by delivering:

- a clear public guide to secure data environments and our overarching policy guidelines for the use of secure data environments

- a comprehensive roadmap to ensure all partners across the system know how to implement our framework, with clear indicative timescales and expectations for those at different readiness levels. This will include not only those delivering the transformation in the NHS but also software providers, academic and industry researchers, as well as funding agencies

As set out in the strategy, we have already developed 11 guidelines as a starting point for a comprehensive policy and governance framework for secure data environments (see section 5, 'Empowering researchers with the data they need to develop life-changing treatments, diagnostics, models of care and insights').

Recommendation 4: use the enhanced privacy protections of TREs to create new, faster access rules and processes for safe users of NHS data; ensure all TREs publish logs of all activity, to build public trust.

How this is being addressed through the strategy commitments:

Commitment 502 – to be completed by December 2022

We will work with expert partners and the public to implement secure data environments as a default across the NHS. We will do this by delivering:

- a robust accreditation regime to ensure our high standards for secure data environments are implemented. This will include not only accreditation requirements

for secure data environments but also guidance and oversight on users of the environment, as well as the process to monitor and assess implementation

- a full technical specification, drawing on industry best practice, including requirements to ensure interoperability, cyber security and the use of privacy-enhancing technologies

Recommendation 5: map all current bulk flows of pseudonymised NHS GP data, and then shut these down, wherever possible, as soon as TREs for GP data meet all reasonable user needs.

While this recommendation is not addressed in the strategy commitments, it may be considered as part of the wider conversation on secure data environments.

Recommendation 6: use TREs – where all analysts work in a standard environment – as a strategic opportunity to drive modern, efficient, open, collaborative approaches to data science.

How this is being addressed through the strategy commitments:

Commitment 502 – to be completed by December 2022

We will work with expert partners and the public to implement secure data environments as a default across the NHS. We will do this by delivering:

- a clear public guide to secure data environments and our overarching policy guidelines for the use of secure data environments

- a robust accreditation regime to ensure our high standards for secure data environments are implemented. This will include not only accreditation requirements for secure data environments but also guidance and oversight on users of the environment, as well as the process to monitor and assess implementation

- a full technical specification, drawing on industry best practice, including requirements to ensure interoperability, cyber security and the use of privacy-enhancing technologies

- a comprehensive roadmap to ensure all partners across the system know how to implement our framework, with clear indicative timescales and expectations for those at different readiness levels. This will include not only those delivering the transformation in the NHS but also software providers, academic and industry researchers, as well as funding agencies

Modern, open working methods for NHS data

Recommendation 7: promote and resource 'Reproducible Analytical Pathways' (RAP, a set of best practices and training created in ONS) as the minimum standard for academic and NHS data analysis: this will:

- produce high-quality, shared, reviewable, re-usable and well-documented code for data curation and analysis

- minimise inefficient duplication

- avoid unverifiable 'black box' analyses

- make each new analysis faster

Recommendation 8: ensure all code for data curation and analysis paid for by the state through academic funders and NHS procurement is shared openly, with appropriate technical documentation, to all data users.

Data preparation, analysis and visualisation is complex technical work, requiring collaboration by many individuals, who may never meet, in a range of organisations, across the NHS and other sectors. The only way to manage this shared complexity is by sharing information, as in other technical fields.

How these are being addressed through the strategy commitments:

Commitment 411 – commenced from December 2021

We will begin to make new source code that we produce or commission open and reusable by default (with clear exceptions) and publish it under appropriate licences to encourage further innovation (such as MIT and OGLv3, alongside suitable open data sets or dummy data). Subject to consultation, the relevant policies will also aim to be open and reusable.

Commitment 601 – completed May 2022

We will publish a digital playbook on how to open source your code for health and care organisations. Guidance on where to put the code, how to license and maintain it, and best practice for working with suppliers will be published in addition to case studies of teams who have done this.

Recommendation 9: recognise software development as a central feature of all good work with data. UKRI and NIHR should provide open, competitive, high-status, standalone funding for software projects and developers working on health data.

Universities should embrace research software engineering (RSE) as an intellectually and academically creative collaborative discipline, especially in health, with realistic salaries and recognition.

How this is being addressed through the strategy commitments:

Commitment 412 – to be completed from March 2022

We will consult with the UKRI and NIHR to consider how outputs from research they fund involving health and care data can follow open and reusable code principles.

Elements of the recommendation are not addressed in the strategy commitments as they are directed towards universities and their operation.

Recommendation 10: bridge the gap between health research and software development:

- train academic researchers and NHS analysts in contemporary computational data science techniques, using RAP where appropriate

- offer 'onboarding' training for software developers and data scientists who are entering health services research and epidemiology

- use in-person and online training

- make online resources openly available where possible

How this is being addressed through the strategy:

We will build the profile of data and analysis as a profession. This will include consistent and appropriate competency frameworks, networks, training, career opportunities and status. This approach to building data and analysis as a profession is identified as a priority in the Goldacre review and its recommendations will be used to help inform the development of the data and analytical community. Our work with the Association of Professional Healthcare Analysts (AphA) has led to a report to give structure and support to uplift the analytical workforce. We will work with AphA, stakeholders in higher education and training, as well as research and NHS environments, to ensure these skills are being developed effectively.

Commitment 403 – completed December 2021

We will develop an online Analytics Hub, working with AnalystX, to share, promote and endorse training, events and other resources aimed at analysts and non-analysts across all career levels.

Recommendation 11: note that 'open code' is different to 'open data': it is reasonable for the NHS and government to do some analyses discreetly without sharing all results in real time.

While this recommendation is not addressed in the strategy commitments, the recommendation may be considered as part of wider work on open code policy.

Data curation and knowledge management

Recommendation 12: stop doing data curation differently, to variable and unseen standards, duplicatively in every team, data centre, and project: recognise NHS data curation as a complex, standalone, high-status technical challenge of its own.

While this recommendation is not addressed in the strategy commitments, the recommendation may be considered as part of wider work on open code policy.

Recommendation 13: meet this challenge with systematic curation work, devoted teams, shared working practices, shared code, shared tools and shared documentation – driven by open competitive funding to develop new shared curation methods and tools – and to manually curate data for individual datasets and fields.

How this is being addressed through the strategy commitments:

Commitment 411 – commenced from December 2021

We will begin to make new source code that we produce or commission open and reusable by default (with clear exceptions) and publish it under appropriate licences to encourage further innovation (such as MIT and OGLv3, alongside suitable open data sets or dummy data). Subject to consultation, the relevant policies will also aim to be open and reusable.

Commitment 412 – to be completed from March 2022

We will consult with the UKRI and NIHR to consider how outputs from research they fund involving health and care data can follow open and reusable code principles.

Recommendation 14: use TREs as an opportunity to impose standards on how commonly used datasets are stored, and curated into analysis-ready tables.

How this is being addressed through the strategy commitments:

Commitment 502 – to be completed by December 2022

We will work with expert partners and the public to implement secure data environments as a default across the NHS. We will do this by delivering:

- a clear public guide to secure data environments and our overarching policy guidelines for the use of secure data environments

- a robust accreditation regime to ensure our high standards for secure data environments are implemented. This will include not only accreditation requirements for secure data environments, but also guidance and oversight on users of the environment, as well as the process to monitor and assess implementation

- a full technical specification, drawing on industry best practice, including requirements to ensure interoperability, cyber security and the use of privacy-enhancing technologies

- a comprehensive roadmap to ensure all partners across the system know how to implement our framework, with clear indicative timescales and expectations for those at different readiness levels. This will include not only those delivering the transformation in the NHS, but also software providers, academic and industry researchers, as well as funding agencies

Recommendation 15: create an open online library for NHS data curation code, validity tests and technical documentation with dedicated staff who have appropriate skills in data science, curation, and technical documentation, so that new analysts, academics and innovators can arrive to find platforms with well curated data and accessible technical documentation.

While this recommendation is not addressed in the strategy commitments, it may be considered as part of a wider conversation on secure data environments and how we support local and national decision makers with data.

NHS data analysts

Recommendation 16: create an NHS Analyst Service modelled on the Government Economic Service and Statistical Service, with:

- a head of profession

- clear job descriptions tied to technical skills

- progression opportunities to become a senior analyst rather than a manager

- realistic salaries where expensive specific skills are needed

How this is being addressed through the strategy commitments:

Commitment 406 – to be completed by December 2022

We will develop and roll out a unified set of competency frameworks aligned to the government analysis function skills, and the digital, data and technology profession.

Commitment 407 – to be completed by March 2024

Through the Developing Data and Analysis as a Profession Board, we will:

- agree frameworks, guidelines and policies to support the analytical community and address the concerns raised in the Goldacre review

- build the ecosystem of the profession through communities of practice (local, regional, national and virtual)

- signpost and provide development opportunities for analysts in both health and social care

Recommendation 17: embrace modern, open working methods for NHS data analysis by committing to Reproducible Analytical Pipelines (RAP) as the core working practice that must be supported by all platforms and teams; make this a core focus of NHS analyst training.

While this recommendation is not addressed in the strategy commitments, the recommendation may be considered as part of wider work on the analytical profession.

Recommendation 18: create an Open College for NHS analysts: this should devise (and coordinate delivery of) a curriculum for initial training and continuing professional development, tied to job descriptions; all training content should be shared openly online to all, and cover a range of skills and roles from deep data science to data communication.

How this is being addressed through the strategy commitments:

Commitment 402 – completed March 2022

We will develop a workforce observatory, including an annual census, to inform how to better harness the professional skills of analysts and data managers, engineers and scientists, and support their professional learning and development.

Commitment 404 – completed March 2022

We will grow the AnalystX community and build the team of future analytical leaders through a champions programme.

Recommendation 19: recognise the value of knowledge management:

- create and maintain a curated national open library of NHS analyst code and methods, with adequate technical documentation, for common and rare analytic tasks, to help spread knowledge and examples of best practice across the community

- use this in training

How this is being addressed through the strategy commitments:

Commitment 403 – completed December 2021

We will develop an online [Analytics Hub](#), working with AnalystX, to share, promote and endorse training, events and other resources aimed at analysts and non-analysts across all career levels.

Commitment 405 – to be completed by September 2022

We will continue to encourage innovation and collaborative working through a data and analytics accelerator by promoting the use of open data, and working with a plurality of solutions and teams. The principles of the accelerator will be tested through hackathons and real business cases.

Recommendation 20: seek expert help from academia and industry, but ensure all code and technical documentation is openly available to all, procuring newly created 'intellectual property' on a 'buy out' basis. Commission best practice guidance on outsourcing data analytics to cover:

- where external collaborations can be most helpful

- the role of skilled analysts in guiding procurement

- common red flags for delivery

- why RAP builds capacity, quality and continuity of service

How this is being addressed through the strategy commitments:

Commitment 411 – commenced from December 2021

We will begin to make new source code that we produce or commission open and reusable by default (with clear exceptions) and publish it under appropriate licences to encourage further innovation (such as MIT and OGLv3, alongside suitable open data sets or dummy data). Subject to consultation, the relevant policies will also aim to be open and reusable.

Commitment 412 – to be completed from March 2022

We will consult with the UKRI and NIHR to consider how outputs from research they fund involving health and care data can follow open and reusable code principles.

Commitment 715 – to be completed by August 2022

We will develop a portal to improve the visibility, clarity and accessibility of existing and future interoperability standards, enabling us to monitor adoption and support compliance, and promote collaboration and co-design, making it easier to find and contribute to standards development.

Recommendation 21: train senior non-analysts and leaders in how to be good customers of data teams.

How this is being addressed through the strategy commitments:

Data skills are not just important for data professionals. These skills are necessary in all roles and at all levels, and so we need to promote these skills across our health and care system. Just as we are encouraging digital skills across organisations, we need to encourage data skills in national and local government and across the whole health and care workforce, and make sure data and analytics expertise is represented at board level. The Goldacre review highlights the need to support leaders to be data literate, 'to help them make better use of data in their day-to-day jobs', and we will work to ensure there are readily available resources for leaders to use.

Commitment 403 – completed December 2021

We will develop an online Analytics Hub, working with AnalystX, to share, promote and endorse training, events and other resources aimed at analysts and non-analysts across all career levels.

Governance

Recommendation 22: rationalise approvals:

- create one map of all approval processes

- require all relevant organisations to amend it until all agree it is accurate

- de-duplicate work by creating a single common application form (or standard components) for all ethics, information governance and other access permissions

- co-ordinate shared meetings when approval requires multiple organisations

- have researchers available to address misunderstandings of their project

- build institutions to help users who are blocked

- recognise and address the risk of data controllers asserting access monopolies to obstruct competitors

- publish data on delays annually

- ensure high-quality patient and public involvement and engagement (PPIE) is done

How this is being addressed through the strategy commitments:

Commitment 111 – to be completed by December 2022

We will develop a standard for public engagement, setting out best practice for health and care organisations, and any other body using NHS data, to engage appropriate with the public and staff across the system on data programmes and issues.

Commitment 112 – to be completed from July 2022

We will undertake in-depth engagement with the public and professionals through forums such as focus groups with seldom-heard groups, and large-scale public engagement on topics and questions that are high priority or particularly complex, including how we deliver secure data environments and the future of the national data opt-out, and working closely with regions to understand local needs.

Commitment 113 – to be completed from April 2022

We will work with local health and care systems and partners including integrated care systems, including co-designing regional engagement, to make sure that we understand the needs, concerns and opportunities for different communities across England.

Commitment 114 – to be completed by July 2022

We will work with the public, the expert advisory group, the National Data Guardian and other stakeholders to ensure that we have a simple opt-out system in place that provides clarity and choice, giving patients confidence, and ensuring data continues to support the functioning of the health and care system.

Commitment 202 – to be completed from April 2022

We will action the findings of the user research to embed the information governance portal as the one-stop shop for help and guidance, as evidenced by an increase in the number of visits to the online portal.

Commitment 207 – to be completed by July 2022

We will review the Data Security and Protection Toolkit and its language to bring it into line with our work to simplify information governance.

Recommendation 23:

- have a frank public conversation about commercial use of NHS data for innovation, but only after privacy issues have been addressed through adoption of TREs

- ensure the NHS gets appropriate financial return where marketable innovations are driven by NHS data, which has been collected at great cost over many decades

- avoid exclusive commercial arrangements

How this is being addressed through the strategy commitments:

Commitment 110 – to be completed by December 2023

We will develop commercial principles to ensure that partnerships for access to data for research and development have appropriate safeguards, and benefit the public, and the NHS and NHS Digital's template contracts for access to data will be reviewed to ensure they are consistent with these principles.

Commitment 111 – to be completed by December 2022

We will develop a standard for public engagement, setting out best practice for health and care organisations, and any other body using NHS data, to engage appropriate with the public and staff across the system on data programmes and issues.

Commitment 112 – to be completed from July 2022

We will undertake in-depth engagement with the public and professionals through forums such as focus groups with seldom-heard groups, and large-scale public engagement on topics and questions that are high priority or particularly complex, including how we deliver secure data environments and the future of the national data opt-out, and working closely with regions to understand local needs.

Commitment 113 – to be completed from April 2022

We will work with local health and care systems and partners including integrated care systems, including co-designing regional engagement, to make sure that we understand the needs, concerns and opportunities for different communities across England.

Recommendation 24: develop clear rules around the use of NHS patient records in performance management of NHS organisations, aiming to:

- ensure reasonable use in improving services

- avoid distracting NHS organisations with unhelpful performance measures

How this is being addressed through the strategy commitments:

Commitment 201 – completed December 2021

We will improve information governance guidance so staff are confident in sharing individuals' data for their care, including publishing the [Information Governance Framework for Integrated Health and Care: Shared Care Records](#).

Commitment 204 – to be completed by December 2022

We will develop a national information governance transformation plan, focusing on practical data-sharing situations, creating professional standards and addressing training for frontline staff.

Commitment 205 – to be completed from April 2022

We will establish a head of profession to ensure the development of competency frameworks, standards, job families and appropriate professional accreditation for information governance staff working in health and care.

Commitment 206 – to be completed by December 2022

We will lead the development and implementation of information governance as part of a multi-disciplinary function for informatics and champion the work of information governance professionals.

Recommendation 25: address the problem of 160 trusts and 6,500 GPs all acting as separate data controllers. Do this either through one national organisation acting as Data Controller for a copy of all NHS patients' records in a TRE, or an 'approvals pool' where trusts and GPs can nominate a single entity to review and approve requests on their behalf.

While this recommendation is not addressed in the data strategy commitments, the recommendation may be considered as part of wider work on the development of secure data environments. We will work with expert partners across the system to consider any required changes in information governance as we implement secure data environments as a default across the NHS.

Approaches and strategy

Recommendation 26: use people with technical skills to manage complex technical problems – create very senior strategic leadership roles for developers, data architects and data scientists; offer leadership training to those in existing technical roles. (Also train senior leaders in the basics of data analysis, software development, and clinical informatics; but recognise the limitations of that approach.)

How this is being addressed through the strategy commitments:

Commitment 403 – completed December 2021

We will develop an online Analytics Hub, working with AnalystX, to share, promote and endorse training, events and other resources aimed at analysts and non-analysts across all career levels.

Commitment 404 – completed March 2022

We will grow the AnalystX community and build the team of future analytical leaders through a champions programme.

Commitment 709 – to be completed by December 2022

We will build centres of excellence in the area of data architecture that focus on promoting best practice, support and training.

Recommendation 27: build impatiently, but incrementally, accepting that new ways of working are overdue, but cannot replace old methods overnight. We must build skills and prove the value of modern approaches to data in parallel to maintaining old services and teams.

How this is being addressed through the strategy commitments:

Commitment 402 – completed March 2022

We will develop a workforce observatory, including an annual census, to inform how to better harness the professional skills of analysts and data managers, engineers and scientists, and support their professional learning and development.

Commitment 405 – to be completed by September 2022

We will continue to encourage innovation and collaborative working through a data and analytics accelerator by promoting the use of open data, and working with a plurality of solutions and teams. The principles of the accelerator will be tested through hackathons and real business cases.

Recommendation 28: identify a range of 'data pioneer' groups from each key sector:

- 3 ICS analyst teams

- 3 national quality improvement registry or audit teams

- 3 academic birth cohort or electronic health record analysis teams

- 1 to 3 national NHS analytic teams

These should be selected competitively as those with the best current technical skills. Resource them to adopt modern working practices (Reproducible Analytic Pipeline working methods in a TRE alongside research software engineer support) and to develop shared re-usable methods, code, technical documentation and tools. This can be in parallel to 'business as usual' in their organisation, but should incrementally subsume it.

How this is being addressed through the strategy commitments:

Commitment 411 – commenced from December 2021

We will begin to make new source code that we produce or commission open and reusable by default (with clear exceptions) and publish it under appropriate licences to encourage further innovation (such as MIT and OGLv3, alongside suitable open data sets or dummy data). Subject to consultation, the relevant policies will also aim to be open and reusable.

Recommendation 29: build TRE capacity by taking a hands-on approach to the components of work common to all TREs. Avoid commissioning multiple closed, black box data projects from which little can be learned, or framing these as 'experiments'. Experimentation is only powerful where it delivers openly shared working methods, code, outputs and technical documentation from which all can learn.

Develop a common 'service wrapper' for TRE access, with civil servants.

Develop common working practices for the 'generic compute and database layer' of TREs with generic skilled technical teams from private and public sectors.

Develop 'code and methods for working with health data in a TRE' through open competitive funding on key challenges such as data curation, secure analytics, automated disclosure checks and data minimisation, recognising this as a creative academic and technical challenge requiring deep knowledge of medicine, health data, data science and software development. Ensure all funded work is focused on insights, methods and code that are transferable between TREs and settings.

Ensure funding for TRE work is competitive, open to all, and overseen by those with data architecture skills – not closed, or prioritised for single organisations who may not have the best ideas and teams. Ensure all TRE teams work in the open, sharing and documenting all code and working methods as they go, to support adaptive innovation.

All academic or commercial funding for TREs and code should be openly disclosed, including, for each investment:

- the source of funding

- the amount

- the recipient

- the headline objectives

- a link to the GitHub repository or website where outputs and work in progress can be seen (including code, technical documentation or live services)

How this is being addressed through the strategy commitments:

Commitment 502 – to be completed by December 2022

We will work with expert partners and the public to implement secure data environments as a default across the NHS. We will do this by delivering:

- a clear public guide to secure data environments and our overarching policy guidelines for the use of secure data environments

- a robust accreditation regime to ensure our high standards for secure data environments are implemented. This will include not only accreditation requirements for secure data environments, but also guidance and oversight on users of the environment, as well as the process to monitor and assess implementation

- a full technical specification, drawing on industry best practice, including requirements to ensure interoperability, cyber security and the use of privacy-enhancing technologies

- a comprehensive roadmap to ensure all partners across the system know how to implement our framework, with clear indicative timescales and expectations for those at different readiness levels. This will include not only those delivering the transformation in the NHS, but also software providers, academic and industry researchers, as well as funding agencies

Elements of the recommendation set out in the report are not addressed in the strategy commitments as they are directed towards academic trusted research environments and their funding.

Recommendation 30: focus on platforms by resourcing teams, services and institutions who are focused solely on facilitating great analytic work by other people, working closely with users. Data curation, secure analytics, TREs, libraries, RAP training, and platforms are the key missing link: they will only be delivered if they become high status, independent activities.

How this is being addressed through the strategy commitments:

Commitment 410 – to be completed by April 2023

We will have a federated data platform that will provide the connectivity needed to transform care and improve outcomes for patients.

Commitment 501 – completed February 2022

We will create partnerships between academic researchers, charities, patient advocacy groups, industry and analytical teams to enhance the exchange of skills and knowledge.

Commitment 506 – commenced from March 2021

We will build on platforms such as NHS DigiTrials to support the best use of data and digital tools in study feasibility, identification and monitoring of research participants to enable faster, more efficient and effective clinical trials.

Commitment 507 – to be completed by September 2022

We will publish a 2021 to 2022 implementation plan (complete) followed by a 2022 to 2025 implementation plan to progress UK priorities for clinical research as set out in the Future

of Clinical Research Delivery, including a theme on research enabled by data and digital tools.

Annex E: glossary

Anonymisation

The process of rendering data into a form which does not identify individuals either directly or indirectly and where identification is not likely to take place by any means reasonably likely. Data is effectively anonymised when it:

- does not relate to an identified or identifiable individual, or

- is rendered anonymous in such a way that individuals are not (or are no longer) identifiable

Source: Information Commissioner's Office (ICO)

Anonymous data

Anonymous data is data that does not relate to an identified or identifiable individual. This could include data that never included anything identifiable – for example, an anonymously filled in opinion survey. Anonymous data may be presented as general trends or statistics. Information about small groups or people with rare conditions could potentially allow someone to be identified and so would not be considered anonymous.

Sources: ICO and Understanding Patient Data

APIs

An application programming interface (API) is a set of programming code that queries data, parses responses, and sends instructions between one software platform and another. APIs are used extensively in providing data services across a range of fields and contexts.

Source: Investopedia

Caldicott guardian

A senior person in an organisation responsible for protecting the confidentiality of patient and service user information and enabling appropriate information sharing by providing advice to professionals and staff.

Care provider

An organisation or individual providing a range of services, from some extra help around the house and assistance with washing and dressing, through to help with building positive relationships, access to specialist equipment, or full-time residential care.

Source: HFT

Carer

An individual who provides unpaid care to a patient or service user, most commonly a member of their family or friend.

Care worker

A person employed to support and supervise vulnerable, infirm or disadvantaged people, or those under the care of the state.

Source: NHS Data Model and Dictionary

Chief clinical information officer (CCIO)

The CCIO provides clinical focus on how to best implement and benefit from digital technologies in a hospital setting and acts as a link between the chief information officer (CIO) and ICT team, and the clinical teams in delivering technology into clinical areas. The CIO and CCIO jointly develop optimal ways of implementing any technology within the organisation in a way that enhances clinical activities and patient care. The CCIO's main role is to improve the healthcare of patients, as well as patient experience, using information, data and digital technologies.

Source: British Medical Journal of Health and Care Informatics

Chief information officer

The CIO has oversight of how IT professionals and non-IT professionals should interact in the healthcare organisation and has a senior strategic role, usually at executive level, regarding things such as purchase of IT equipment, decisions on systems and delivery of the overall information and communications technology strategy.

Source: British Medical Journal of Health and Care Informatics

De-identified data

A high-level definition covering pseudonymised, anonymised and aggregated data. Identifiers are either removed or hidden so that users cannot reidentify data subjects. The 3 states referred to are different states of de-identified data.

Differentially private algorithms

Enabling useful population-level insights about a data set to be gained, while limiting what can be learned about any individual in the data set.

ECG (electrocardiogram)

An ECG is a simple test that can be used to check your heart's rhythm and electrical activity.

Source: NHS

Electronic health record (also electronic patient record)

Any digital document or system that contains information on an individual's health and care. This could be online, on an internal network, or on a device.

Source: Chartered Society of Physiotherapy

Federated analytics

Applying data science techniques by moving code to the data, rather than the traditional approach of collecting data centrally.

Health and adult social care organisations

(in the section 'Sharing anonymous health and social care information')

As defined in the Health and Care Bill for the purposes of that clause of the bill as:

> "a public body which exercises functions in connection with the provision of health services or of adult social care in England".

Health and care system

A system consisting of all organisations, people and actions whose primary intent is to promote, restore or maintain health. This includes efforts to influence wider determinants of health, as well as more direct health-improving activities.

Source: [The King's Fund](#)

Health and social care providers

As defined in the Health and Care Bill for the purposes of that clause of the bill:

> "'health or social care body' means a public body which exercises functions in connection with the provision of health services or of adult social care in England".

Health data

Any information which relates to the physical or mental health of an individual, or to the provision of health services to the individual.

Source: [IGI Global](#)

Homomorphic encryption

Allowing computations to be performed on encrypted data.

Integrated care system

Partnerships between health and care organisations that meet needs and requirements across an area, to coordinate services and to plan in a way that improves population health and reduces inequalities between different groups.

Source: [NHS England](#))

Private providers

As defined in the Health and Care Bill for the purposes of that clause of the bill:

"'private health or social care provider' means a person (other than a public body) who provides health services, or adult social care in England, pursuant to arrangements made with a health or social care body".

Pseudonymisation

Processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information, provided that such additional information is kept separately, and is subject to technical and organisational measures to ensure that the personal data are not attributed to an identified or identifiable natural person.

Source: [ICO](#)

Pseudonymous

A form of data that uses a unique identifier, which does not reveal the 'real world' identity of the data subject. The pseudonymisation process reduces the links between individuals and the data that relates to them, but does not remove them entirely. While individuals may not be identifiable from the pseudonymous data itself, they can be identified by referring to other information held separately. Both the data set and the additional information are therefore still personal data.

Source: [ICO](#)

Reproducible analytical pipelines (RAPs)

Automated statistical and analytical processes. They incorporate elements of software engineering best practice to ensure that the pipelines are reproducible, auditable, efficient, and high quality.

Source: [Government Statistical Service](#)

Robotic process automation

A type of business process technology allowing organisations to integrate human interactions within digital systems for more efficient business processes, for example moving and copying files, or responding to an email.

Source: [HealthTech magazine](#)

Secure data environment

Controlled digital environments used to store or analyse sensitive data securely.

Shared care record

Previously called 'local health and care records', these allow people involved in your care to access your health and care records safely and securely so that they can provide better joined-up care as you move between different parts of the health and social care system.

Source: [NHSX](#)

Social care data

Used to track client journeys through the social care system so they can be assessed locally and nationally across England.

Source: [NHS Digital](#)

Summary care record

An electronic record of important patient information, created from GP medical records. They can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care.

Source: [NHS Digital](#)

Synthetic data

Generating data that is statistically consistent with a real data set and can replace or augment sensitive data.

Trusted research environment (TRE)

A form of secure data environment, TREs allow analysts and researchers to undertake in-depth analysis on rich, joined-up datasets without them seeing any identifiable information.