

Data strategy to support delivery of patient centred care

- Records will be shared between systems to allow faster, more specialised treatment
- Plan will help power vital research to discover new treatments and insights to save lives

The way data is used across health and care sectors is set to be transformed, giving patients control of their health data and enabling staff to save more lives through improved care and treatment.

The draft strategy 'Data saves lives: reshaping health and social care with data' published today by NHSX builds on the ground-breaking use of data during the pandemic with privacy and security of data at its core.

Under the proposals, patients will easily be able to access their test results, medication lists, procedures and care plans from across all parts of the health system through patient apps, such as the NHS App, by ensuring data is shared safely and more effectively across the system. By improving their access to data, people will also be able to manage appointments, refill medications and speak with health and care staff when needed.

The strategy aims to break down data barriers and give patients confidence that health and care staff have up-to-date medical information, regardless of the care setting, enabling clinicians to make quicker, more informed decisions to deliver better treatment. Improving data collection and the way NHS systems work together will mean staff spend less time collecting and looking for information they need, so they can spend more time with those they are caring for to focus on looking after them.

Health and Social Care Secretary Matt Hancock, said:

Data saves lives. More effective use of data will deliver better patient focused care. It will free up staff time to focus on patients and allow clinicians to make better, more informed decisions on treatment and support.

The pandemic has taught us we must be bold and the great strides we have made on vaccines and treatments during this time have been made possible by the way we use data.

This strategy seeks to put people in control of their own data, while supporting the NHS in creating a modernised system fit for the 21st century which puts patients and staff in pole position.

So that health and care staff can access the right information when they need it, the strategy proposes a new duty to share anonymous data safely and

appropriately across the entire health system. New legislation will also be introduced to require all adult social care providers to provide information about all the services they fund to ensure service users have the best care and experience. This could transform the care of the most vulnerable by ensuring staff have the information they need as soon as they need it, helping to provide the best possible care to the elderly.

In addition, the strategy proposes better use of personal data to analyse key trends in the health of the nation. This could improve the commissioning and planning of services for local communities and allow better preparation to identify, prepare for and respond to future diseases.

The NHS is committed to using data lawfully, with respect, and holding it securely with the right safeguards in place. These protections reflect the strict parameters for the use of data and security standards set out by the National Data Guardian for Health and Care. Today's new strategy commits the NHS to going even further with a commitment to publish the first transparency statement setting out how health and care data has been used across the sector by 2022.

Minister for Innovation, Lord Bethell said:

The safety of the public will only be improved if the health and care system makes better use of data.

We have already seen how analysing patient data on maternity outcomes has improved care for mothers and babies. Greater sharing of patient information across the health and care system will undoubtedly go on to drive further improvements in patient safety, ultimately saving lives.

The draft strategy proposes:

- putting patients at the heart of their health and care data, with easy access to their own healthcare records
- giving health and care staff easier access to the right information to provide the best possible care through shared records and simplified information governance
- enabling the proportionate sharing of data for the purpose of supporting the health and care system
- giving adult social care high quality, timely and transparent data so they can make individualised choices to personalise care
- modernising data architecture and infrastructure underpinning the health and care system to improve standards, protect data and stay ahead of cyber risk
- supporting innovation for the benefit of patients and staff such as empowering patients to test and monitor changes in their vision remotely using an app, and using AI to assess data from care home worker's reports to predict the likelihood of falls and hospital admissions of patients, enabling appropriate safeguards to be put in place

- building on improvements to speed up access to data during the pandemic, where there is clear benefit for the system as a whole.

The plans have been published in draft ahead of engagement with the sector and the public over the summer.

Patient data has already been vital in enabling quicker, more informed clinical decisions on COVID-19 treatment, saving more lives. Accelerated access to real time data was used to direct resources, such as PPE and ventilators to hospitals and it fuelled life saving research into drugs such as dexamethasone which is estimated to have saved over one million lives.

Matthew Gould, NHSX chief executive, said:

Throughout the pandemic we saw examples of data improving care and saving lives – from the speed of vaccine development to the discovery of treatments for COVID-19. If we want to continue improving care, we need to transform how we use data.

Patients need to own their data, have access to their data, and have confidence on how the NHS is handling it on their behalf.

This strategy takes this agenda firmly forward, and is good news for patients, staff, citizens and anyone who cares about the future of the NHS.

NHS medical director Professor Stephen Powis, said:

For more than a year, NHS staff have been at the forefront of innovations, based on research and development with patients, to help the country deal with the biggest threat in a century, whether it be trialling new treatments like dexamethasone that has saved a million lives around the world from COVID-19, or delivering the biggest and fastest vaccination programme in health service history, and this latest initiative will ensure that many more life-saving treatments can be developed for patients by the NHS thanks to better access to data.

Sir Patrick Vallance, Government Chief Scientific Adviser, said:

The value of timely and comprehensive healthcare data has been brought to light throughout the pandemic. Data handling by the NHS has been instrumental in our response, from monitoring the virus to supporting the vaccine rollout. This refreshed strategy builds on this ground-breaking use of data and protecting privacy, and will ensure that it remains an asset for future research and improvements in healthcare.

Charlotte Augst, Chief Executive of National Voices, said:

The NHSX data strategy addresses many of the issues we need to get right in order to build a health and care system that knows what matters to people and communities and therefore can respond to those needs and priorities.

Refreshingly, it focuses on the work of health and care professionals in the care they provide, rather than on structures, tech or overblown transformation initiatives. It's unpacking of concentric circles around the patient, the team, the system and the wider research and innovation landscape is a good way of conceptualising what will be gained from better data use, whilst staying focused on what matters most: a better experience of care, including better access and outcomes.

Professor Martin Green OBE, Chief Executive, Care England, said:

The role of data in social care is evolving at a very fast rate. Over the course of the COVID-19 pandemic, it has become increasingly apparent that reliable data from social care is a necessity to analyse the health and quality of life of the nation.

The sector is starting to produce data at levels previously unimagined, and data is key to driving decisions which will help improve the quality of life of the people that we care for and support.

Dr Clare Gerarda, a GP and former chair of RCGP said:

Better use of data in health and care will be transformational to our NHS, to research, and is vital in our fight to reduce health inequalities and address unnecessary variations in care.

As a GP, data has long been invaluable in helping us to have complex conversations with patients – from explaining about individual risk of disease or to debunking the myth about a link between MMR and autism.

Thanks to increased use of data and digital technologies, the NHS and general practice will come out of the pandemic better equipped to deliver more responsive services to patients, and this strategy will only help strengthen the care we can provide to the public.

Professor Sir John Bell, Regius Professor of Medicine at the University of Oxford Medical Sciences Division, said:

Like most scientists, I believe use of data has been critical to advances in patient care and has the potential to enable new breakthroughs whilst the opportunity for data-driven technologies to improve our health is already with us.

Managing healthcare data carefully and sensitively is crucial, and this new strategy is a major step forwards putting the citizen in control of their information whilst setting a clear direction to enable scientists and the NHS to use data better to look after patients now and discover the treatments of tomorrow.

Public engagement, to be held in 2021, will be used to inform how people would like to use and access their data. It will include working with the National Data Guardian, patient groups and system leaders.

Supportive quotes

Dr Simon Eccles, NHSX's Deputy Chief Executive and a practising A&E consultant, said:

Everything we know about how to treat and care for people today has been learnt from the data from previous patients. Researchers, and analysts need safe, quick access to high quality data to provide the insights and better answers for us all.

Our draft strategy, published today, sets out our plans to make more, higher quality data securely accessible for life saving research. We will also build on platforms such as NHS DigiTrials to enable and support 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.

Martin Landray, Professor of medicine and epidemiology at the Nuffield Department of Population Health, University of Oxford and the clinical trials lead at Health Data Research UK, said:

Within 100 days, the RECOVERY trial found that a low-dose steroid treatment called dexamethasone reduced the risk of death by a third for patients on ventilators. It was the world's first coronavirus treatment proven to save lives. Estimates are that it may have saved 600,000 or more lives during the course of the subsequent 6 or 12 months.

Pre-COVID, it would have taken 100 days to even get permission to go ahead with the trial. We cannot go back. It is a challenge, but one we have to take on, because the future of all of our care depends on robust knowledge on whether treatments work or do not work.

Margaret Grayson, from patient group useMydata, said:

I made 6 friends during my cancer treatment, within 5 years I'd been to their funerals. I want and expect my data to be used for the benefit of future patients like me, so others in a similar situation can have friendships which endure for longer than 5 years.

Data is precious to people and increasing transparency around how the health and care system protects and uses data, as proposed in this strategy, is important to reassure the public that their data is safe.

Professor the Lord Ara Darzi of Denham, Director of the Institute of Global Health Innovation at Imperial College London, said:

Good data is essential to providing high quality care for patients by guiding decision-making. That is true whether it is for cancer surgeons like me at the frontline or those making crucial choices about how to respond to the pandemic nationally and internationally. By using big datasets and AI, we are now able to detect cancer earlier, improving the chances that people will survive.

Joe Harrison, CEO, Milton Keynes Hospital NHS Foundation Trust, said:

During the COVID-19 pandemic, we have seen the power of partnership and how NHS organisations can work together to deliver the best possible care for patients.

It is vital that we carry this momentum into the way we approach data. Removing unnecessary and unhelpful barriers to sharing between NHS organisations will enable clinicians to safely and securely access the information they need, when they need it, to improve patient care and outcomes.

It is equally important that we give patients access to their own patient record too. We know from our work at Milton Keynes University Hospital that this empowers patients to be active participants in their care and gives them more autonomy over the way their data is used.

The type of transformation that this data strategy sets out is essential if the NHS is to work together to meet growing demand while improving outcomes.

Data sharing helps to increase patient safety, improve patient experience and ultimately saves lives.

Neil Tester, Director of The Richmond Group of national health and care charities, said:

The draft data strategy marks a big step forward on many of the issues people using health and care services, and the professionals who deliver them, have cared about for a long time.

We need a joined-up approach to data to deliver joined-up care. This strategy brings that much closer. It's good to see this draft strategy is built upon what people have said they want to see happen with their data.

The Richmond Group is also pleased to see the strategy focusing on putting people in control of both their data and the care and support they need. I hope people will engage with this to make sure that the final strategy gets this right, and makes data-driven care a reality for everyone, not just those with the best access to and understanding of technology.

Julian Hartley, Chief Executive at Leeds Teaching Hospitals, said:

Improving the quality and use of data is crucial to meet our challenges in the NHS. I welcome the aims of the strategy and it's particularly good to see emphasis on using data to improve patient safety and integrating care.

Adam Steventon, Director of Data Analytics at the Health Foundation, said:

We very much welcome the data strategy. Health data has played a critical role in the last year – from tracking COVID-19 outbreaks and developing treatments, to getting people booked in for their vaccines. It is particularly positive that the government has committed to building analytical and data science capability in the NHS and to improving data on social care. The next steps are to build public trust and demonstrate how their data is improving the NHS and saving more lives.

Professor Sir Rory Collins, Principal Investigator and Chief Executive of UK Biobank said:

For more than a decade, UK Biobank has been able to access data on its 500,000 participants, with their consent, from the NHS. This data – which include hospitalisations, cancers and deaths – have made it possible for researchers to make discoveries that are benefiting patients suffering from life-threatening and disabling diseases. During the pandemic, access to data has saved many lives.

Indeed, UK Biobank's recent access to primary care records enabled researchers to identify who is most at risk from COVID-19 and how best to protect them, and demonstrated just how much more could be done to improve patient and public health. By making data the foundation of our health system, we can accelerate medical research and find better ways to prevent and treat common diseases.

Background information

[Read the draft data strategy](#)

Since autumn 2020 NHSX have run workshops and roundtables with representatives from across the health and social care system.

We are publishing the strategy in draft so the public can comment and offer views before we publish a final version. The public will be able to engage through a range of channels including a survey and/or by attending events. Up to date opportunities will be published on the NHSX website. This survey will close at 5pm on Thursday 22 July.

Data saves lives – case studies

Maternal deaths

Data is central to patient safety and to continually improving the health and care system. [MBRRACE-UK's](#) recent audits of maternal deaths identified an increase in deaths amongst women with epilepsy from a condition known as 'Sudden Unexpected Death in Epilepsy'. By using the data collected about the circumstances of these tragic deaths, the NHS has been able to make sure that pregnant women with epilepsy are better supported, helping keep pregnant women and their children safe.

Marian Knight, Lead for Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries (MBRRACE) said:

Around 200 new mothers and 5,000 babies die each year. Sharing data and information about these deaths helps us to identify problems, see patterns and make changes that keep mothers and children safe.

MBRRACE-UK provides the evidence that is needed to shape the delivery of safe, equitable, high quality, patient-centred maternal, newborn and infant health services. We cannot do this important work unless the law supports our continued access to timely and accurate confidential patient information relating to all maternal and infant deaths.

Shielding patients

During the pandemic, data has been crucial to developing the Shielded

Patients List. Working together, organisations such as NHS England, NHS Digital, local government, adult social care, and the Ministry for Housing, Communities and Local Government used data to advise the people most at risk from COVID-19 on how to stay safe early in the pandemic, and this year the list allowed them to be prioritised for vaccination. Access to real time data during the pandemic has triggered a transformation in the way our hospitals are run and enabled communities to, for the first time, work better together to tackle issues such as inequalities at a population level.

NHS COVID-19 Data Store – improving NHS services

The NHS COVID-19 Data Store was set up during the pandemic and uses cutting edge technology to integrate data into a single platform where it can support decision-making and improve outcomes for patients at a time of immense pressure. Dashboards and tools have been developed within this data platform to help senior leaders to make strategic decisions and NHS leaders and local government officials with the information they need to make informed decisions.

NHS teams have also been given access to predictive technology to help them save lives by forecasting COVID-19 hospitalisations. Using these forecasts, NHS trusts are able to plan how to use their available capacity for both COVID-19 patients and routine care and operations, with the benefit of advance knowledge of how the need to care for more or fewer patients with the virus might change over the coming one to two weeks.

Data for research – 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 (UCL) study into factors increasing risk of dementia. Researchers were able to study participant blood samples to elucidate 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.

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 dataset helps researchers to understand the extent to which genetics, lifestyle and underlying health conditions affect

disease severity, and recovery.