Data, insights and statistics











































Information and technology for better health and care

Contents

Foreword	5	Population nealth	40
Data, insights, and statistics	4	Facilities and estates	44
Primary care	9	Workforce	47
Secondary care	13	Indicators	50
Emergency Care	17	National Casemix Office	53
Community services	20	Data standards	55
Maternity services	23	Data Services for Commissioners	59
Mental health	26	Data quality	61
Social care	29	Data dissemination	63
Audits and registries	32	Future work with data	66
Prescribing and medicines	36	Innovative uses of data and data science	72

Foreword

Protecting citizens' rights and managing complexity to improve people's lives

NHS Digital has a privileged remit to lead the standardising, collecting and publishing of data and information from across the health and social care system in England.

It is a responsibility that cuts to the heart of everything we do and one that provides huge opportunity to improve the health and lives of the citizens we serve.

Artificial intelligence, machine learning, predictive analytics and the internet of things are no longer dreams of tomorrow. They are here and evolving at pace to support increasingly personalised care.

The power of data also has huge potential to drive our economy. The NHS has an unrivalled data set covering a single, large population, stretching back two decades and supported by robust governance and the unique identifying NHS number. It is a major national asset and we have a responsibility to continue to build the trust and infrastructure that will allow the UK and the NHS to be global leaders in this space.

This clinical review explores and articulates the benefits of using data and how NHS Digital is putting citizens' rights first and managing complexity to improve people's lives. We can only do this in partnership with health and care professionals, local and regional NHS and care organisations, the research community, the life sciences industry, national bodies, regulators and other government departments, and the public.

Many of these organisations also act as data suppliers and the strength of our products and services is underpinned by the quality of information they supply. We have a responsibility to ensure they receive even more value back.

We have made enormous strides in data, insights and statistics in the first 70 years of the NHS. We can go much further. This review serves as a useful milestone along that journey, and I would like to thank Dr Tom Foley, Dr Neil Lawrence and my data, insights and statistics colleagues for pulling it together.



Tom DenwoodExecutive Director for data, insights and statistics (ai)

Data, insights, and statistics

We have a major role in handling data for health and social care. Our data, insights, and statistics teams work across dozens of topics, providing information that will help improve care for patients.

Here you'll find an overview of the work our data, insights and statistics team do, demonstrating NHS Digital's role in making the NHS a <u>learning health system</u>. You can find out what the teams working with data do, and how you and others can see and work with our data, to help improve the health and care system. The content has been prepared from a clinical perspective by Dr Tom Foley and Dr Neil Lawrence, with extensive input from across the teams.

Our data includes information collected by NHS or social care bodies, and ranges from data about individual patients, through to data about hospital buildings or the people who work in health and social care.

Direct and secondary uses

Data can be used for the direct benefit of a patient. It's easy to see how sharing information between a GP and hospital about a patient's treatment helps them to get the best care. Many of <u>our services</u> help get important data like this to the right place.

Our data, insights, and statistics teams work mainly on what is known as 'secondary uses'. This means using data collected by the NHS to help achieve things like:

- health surveillance watching for trends which could indicate problems, like an outbreak of an infectious disease
- conducting medical research
- planning what type of care is needed, on a national or local level
- developing policy
- determining which treatments are most effective
- creating payment systems which reward best practice

The impact of secondary uses of data can be less immediate, and less obvious to patients, but it forms a vital part of making sure that the NHS continues to learn and improve.

We are trying to create <u>a learning health system</u>, where what we learn from one patient is used to improve care for everyone.

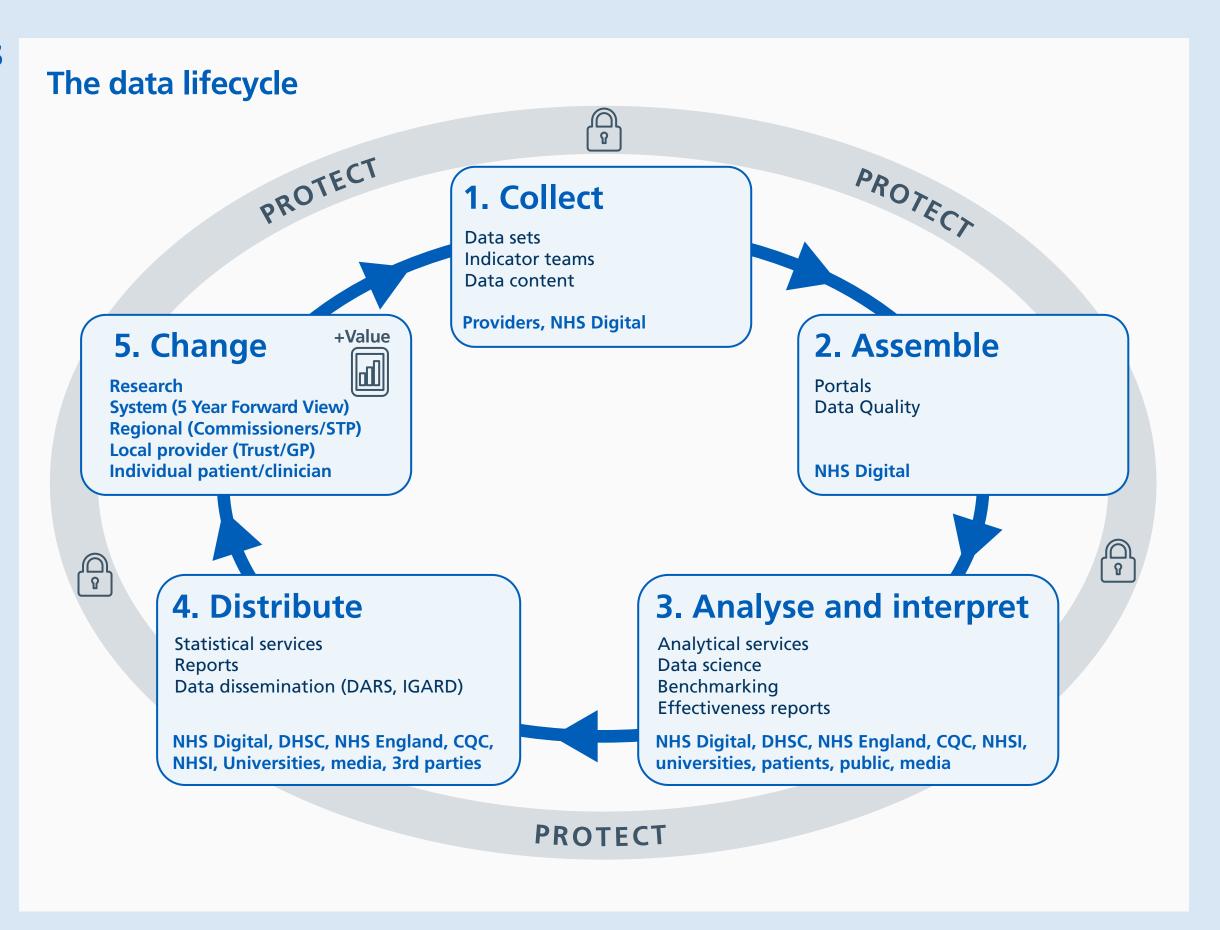
How data makes a difference

Collecting data doesn't, by itself, improve anything. It needs to be part of a system. We've adopted a data lifecycle model, based on work by Freidman et al (2017), to illustrate this. We are at the heart of the system, working with partners to make sure we use data effectively.

The steps of the data lifecycle model are:

- 1. collect
- 2 assemble
- 3. analyse and interpret
- 4. distribute
- 5. change

Where relevant, we've used these steps as headings in the sections of this document, to show where our teams add value to the different stages of the data cycle.



1. Collect

It is important that data we collect is of a high quality. Bad data leads to bad decisions.

We set standards for data, which give clear guidance on:

- what data is required
- what format the data needs to be in
- how to submit the data

We engage with staff in the NHS, especially clinical professionals, to make sure that everyone understands their role in recording and reporting data correctly.

In many cases, we collect data automatically, through systems that the NHS already uses, such as through the electronic health record (EHR) in a GP surgery. This helps staff by keeping the amount of extra work to a minimum.

Data can also be sent to us using tools like **OpenExeter**.

2. Assemble

We assemble data from around the health and care system. We always collect and store information securely and in line with the law.

We check data quality against standards, and provide feedback if it needs to be improved.

3. Analyse and interpret

Once the data is put together and checked, we begin to make use of it. We work to provide insights that can be used to improve the health and care system.

Our analysis includes:

- decision support where we help staff make complex decisions using data we have collected
- predictive modelling where we can predict something is likely to happen, because of data we hold, and the patterns within it
- benchmarking where we can see the high and low performers, and help target support or develop learning opportunities
- health surveillance where we can track the spread of infectious diseases, or see the impact of particular treatments or interventions
- comparative effectiveness research where we can assess the impact of different treatments, to help with clinical studies (randomised control trials or RCTs) or in some cases to remove the need for them.

4. Distribute

Insights won't improve the NHS unless they are shared. We publish our data and insights in several ways, including:

- <u>statistical publications</u>, on dozens of topics each year many of these are accredited National Statistics or Official Statistics, making us the government's official source
- clinical indicators, which track individual measures over time
- interactive web interfaces, like our award-winning General Practice Data Hub

We use anonymised data for all our published outputs, which means that no individual can be identified.

We provide bespoke reports to partners in the NHS, and responses to parliamentary questions and Freedom of Information requests.

There are times where professionals need access to information where individuals can be identified. For instance, our data has saved lives when patients at risk have been identified through research on such data. Our teams are able to match those records back to real individuals and get them the care they need.

Privacy and data protection are at the heart of what we do, and identifiable data can only be accessed through our <u>Data Access Request Service (DARS)</u>, where is assessed by the <u>Independent Group Advising on the Release of Data (IGARD)</u>, and subject to a strict information governance framework.

5. Change

Once insights are released, the health and social care system can start to make improvements. These changes are of all sizes – from an individual to a whole country level.

We work with organisations across health and social care to help them understand our insights, and to make sure that they can deliver effective change.

How our data is used

A range of individuals and organisations use our data to drive change.

Individual patients or members of the public

Individual patients or members of the public can use our data to make decisions about their own health and care, or that of people they care for, including things like choosing a specialist doctor, changing their habits based on new research, or advocating for change.

Health professionals and clinicians

Health professionals and clinicians can use our data to better understand their patient groups, and to identify opportunities to improve their services.

Local provider organisations

Local provider organisations, such as hospitals or GP practices, can use our data to plan their services better and more efficiently, as well as monitoring their performance against other providers like them.

National and regional commissioners

National and regional commissioners can use our data to better understand the changing needs of the population, and to monitor the impact of their policy and work.

Central NHS organisations

Central NHS organisations can use our data to understand population needs and funding requirements, including how these are changing over time. They can also monitor quality of care, using our indicators.

Research organisations

Research organisations, such as universities, charities, think tanks and the life sciences industry, can use our data to research new areas, which helps to better understand a disease or condition, as well as developing new medicines or treatments. They can also assess the efficacy and cost or benefits of individual interventions, or even compare whole health systems.

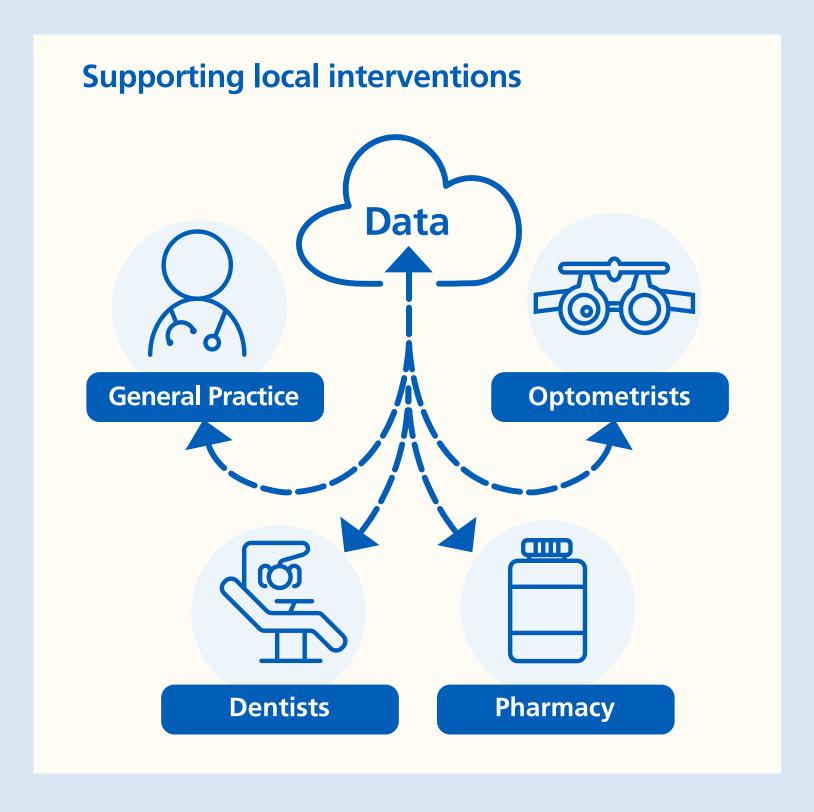
Primary care

Primary care services provide the first point of contact in the health and care system for most patients. They act as the 'front door' of the NHS. GP practices – local doctor's surgeries – provide most primary care in England. Dentists, opticians and community pharmacies are also primary care services.

Our primary care team mainly deals with data from GP practices. We design the technical specifications for data extractions on a range of topics within the <u>General Practice Extraction Service (GPES)</u>, analysing the data and disseminating our findings. We also collect data about dentists, opticians and community pharmacies.

We manage the <u>National Health Application and Infrastructure Services</u> (<u>NHAIS</u>). The NHAIS is a suite of software implemented across primary care that collects workforce data, patient registration and demographic data. It also provides:

- a data centre hosting service
- a prescription pricing divisional data service
- a cytology statistics service for breast and cervical screening
- a print management service



Collect

When a patient visits a GP practice, information about them and their health and care is recorded on the electronic health record (EHR) systems. The systems use codes to define this patient information, which can be collected, analysed and compared. The main coding system is SNOMED CT, although some older systems may still use Read Codes. Our GPES) collects data from EHR systems. Patient data is collected automatically from the system, unless the patient has opted out of this collection by setting a type-1 opt out.

We collect certain information from GP records, including:

- quality outcomes framework measures on the management of conditions, public health concerns and preventative services
- vaccinations
- dementia diagnoses
- care of patients with learning disabilities
- unplanned admissions to hospital
- diabetic retinopathy screening
- <u>patient online management information</u> for <u>NHS England</u> who monitor how well GPs are doing in providing online services to their patients.

NHAIS also extracts data at the end of each quarter about GP workforce, to form a census of GPs that are on the General Medical Services (GMS) contract.

Assemble

Our <u>General Practice Extraction Service</u> (<u>GPES</u>) collects information for a wide range of purposes, including providing GP payments. It works with our <u>Calculating Quality Reporting Service</u> (<u>CQRS</u>), Data Management Service and GP clinical systems as part of the <u>GP Collections service</u>. The CQRS system, run by us, is an approval, reporting and payments calculation system for quality outcome-related achievement in GP practices.

Analyse and interpret

We analyse and interpret data in various ways, including:

- GP Contract Services data is analysed for payment these are additional services GPs can offer their patients
- the <u>Quality and Outcomes Framework</u> is used to distribute over £1.2 billion of payments to GPs, based on achievement of performance measures and size of practice
- dementia diagnosis data is analysed to monitor the national dementia diagnosis rate and target and address the problem of under-diagnosis
- Learning Disability Observatory data, the first national primary care data collection of people with learning disabilities, is analysed to help understand inequalities between people with and without a learning disability
- individual GP metrics, commissioned by the Secretary of State, are extracted and linked to other data to enable benchmarking
- diabetic retinopathy screening data is extracted for direct patient care and is used by <u>Public Health England (PHE)</u> to invite people for eye screening appointments
- the <u>Clinical Practice Research Datalink (CPRD)</u> helps researchers analyse primary care data and link data sets to other sources from NHS Digital and beyond

Primary care

The primary care team makes sure the data we extract and analyse is reliable and can confidently be used to improve health and care. The clinical expertise of our team is crucial, particularly in making sure the two medical terminologies currently in use, SNOMED and Read codes, are matched appropriately and associated properly with new QOF metrics.

Distribution

We make analysis of extracted data available to practices and commissioners through CQRS reports. Other aggregate information is available on our <u>primary care webpages</u>.

Ophthalmic and Dentistry activity data and GMS census data is produced for use by NHS England and the <u>Department of Health and Social Care (DHSC)</u> in policy and planning.

We also produce answers to parliamentary questions, Freedom of Information requests and other ad hoc data requirements.

We perform an advisory role for Secretary of State, DHSC and NHS England senior colleagues on potential uses of primary care data to inform key policies and the 5-year general practice forward view. We also produce and support answers to parliamentary questions, Freedom of Information requests and other ad hoc requirements.

Patient Online Management Information (POMI) can be found on our website, and in our <u>interactive power BI</u>. Users can see how a GP or CCG is performing in providing online services to their patients, and how the country as a whole is performing in providing online services.

Change

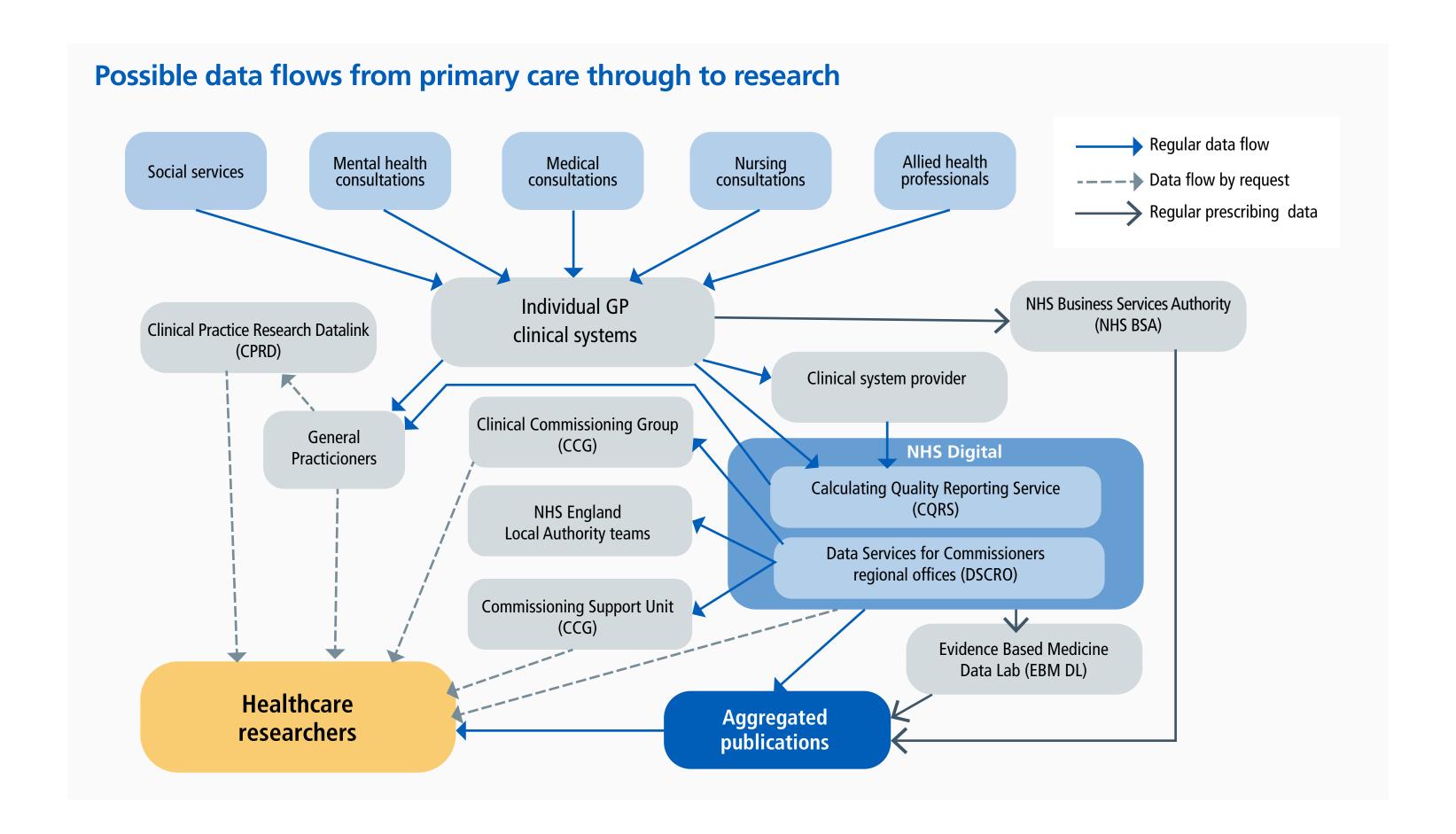
We work closely with analysts in NHS England, DHSC, Care Quality Commission and Public Health England, among others, to provide the data needed to monitor policy initiatives to improve care for patients.

The current annual GP Census provides ministers, the DHSC, outside bodies and the wider public with information on GPs, the services they provide and the staff they employ. This information is used to monitor and develop policies in primary care, in GP workforce planning and GP payments. Data from the census is also used to inform negotiations with the British Medical Association and other health associated bodies, for GMS expenditure forecasting and by the Doctors and Dentists Review Body in recommending pay awards.

The data extracted by us directly impacts the payments received by individual GPs and can be a powerful lever to influence their practice.

Researchers can access primary care data through us but also directly from providers and commissioners. The <u>Clinical Practice Research</u> <u>Datalink (CPRD)</u> support has led to over 2,000 publications including, for example, the proof of safety of the MMR vaccination. The <u>Evidence Based Medicine Datalab</u> allows providers and commissioners to more easily identify unwarranted variation. Despite successes and the enormous potential of such research, the data has been underused.

Possible data flows from primary care through to research are summarised on the next page.



Secondary care

Our secondary care team is responsible for producing official and national statistics about hospital activity.

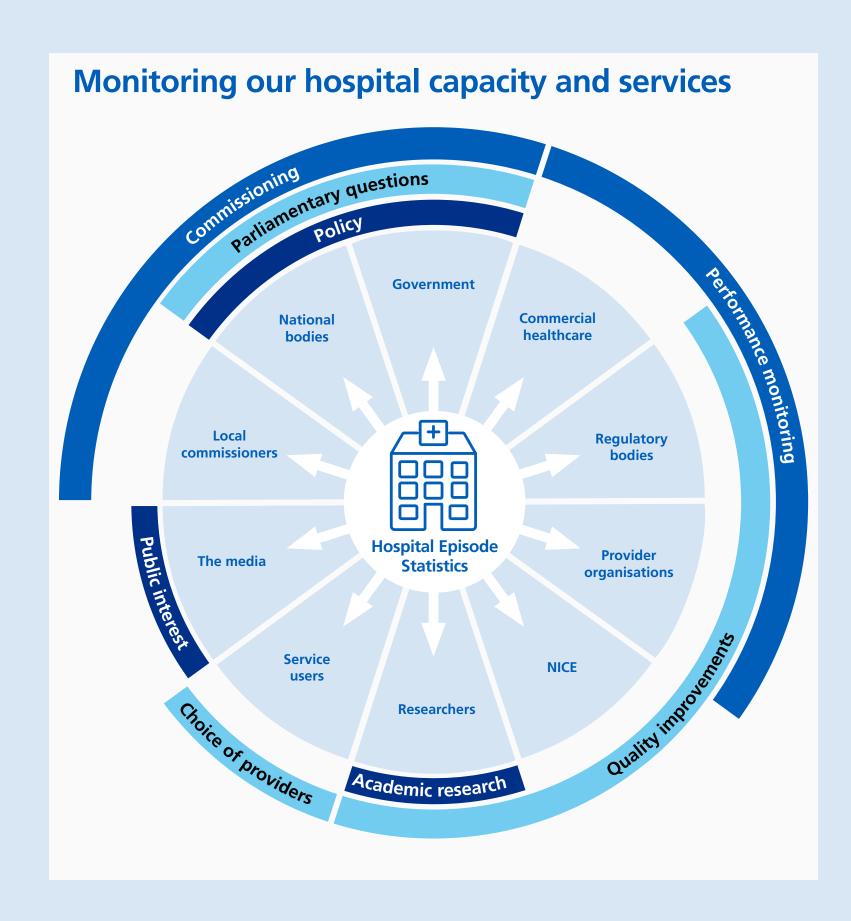
Patient level secondary care data is submitted to us by providers of NHS care. The process is incentivised by payments linked to diagnostic codes.

The data is widely used by:

- policy makers
- commissioners
- providers
- researchers
- charities
- the public.

Uses can include:

- comparative effectiveness research
- benchmarking
- policymaking
- monitoring the implementation and impact of interventions.



13

Collect

Patient level secondary care data is submitted to our organisation by providers of NHS care. Admitted patient care data in maternity, outpatients and accident and emergency (A&E) is submitted by hospital trusts. This information includes:

- clinical information
- reason for attendance or cause
- organisational data
- geographical data
- patient demographics
- administrative data (such as length of stay).

It's collected from:

- Patient Administration Systems (PAS) and Radiology Information Systems
- patient health records
- Patient Reported Outcome Measures (PROMS) questionnaires
- Patient Level Information Costing Systems (PLICS)
- supplementary collections.

Patient Administration Systems (PAS)

Hospitals obtain data from their own Patient Administration Systems (PAS). Radiology data is from the Radiology Information System (RIS) and from the Picture Archiving and Communication System (PACS), in support of the <u>National Cancer Waiting Times</u> measures and the Diagnostic Imaging Data Set (DIDS).

Patient health records

For providers without an Electronic Health Record (EHR), clinical codes are taken from paper records by clinical coders.

Patient Recorded Outcome Measures (PROMS)

Patient Recorded Outcome Measures (PROMS) are collected through health status questionnaires given to patients before and after knee and hip surgery. These questionnaires are carried out by accredited suppliers (such as Capita), who submit data to us.

Patient Level Information Costing Systems (PLICS)

Patient Level Information Costing Systems (PLICS) collects patient level financial data around admitted patient care, non-admitted patient care and accident and emergency activity in secondary care. The PLICS data set is being expanded through 2018/19 to collect mental health, Improving Access to Psychological Therapies data (IAPT), and ambulance data. A final expansion of the collection will include social care data.

Supplementary collections

Data submission rates and quality vary between care settings and some data items are poorly recorded, so supplementary collections of data have been developed in response to this.

Hospital and Community Health Services Complaints data (KO41a) and Admissions, Changes in Status and Detentions under the Mental Health Act data (KP90) are submitted to the <u>Strategic Data Collections Service</u> at NHS Digital.

Assemble

Hospital activity data is submitted to the <u>Secondary Uses Service (SUS)</u>, where it's stored. Functionality is being added over time.

The following data is not submitted to SUS+:

- <u>Diagnostic Imaging Data Set (DIDS)</u>
- Patient Reported Outcome Measures (PROMS)
- Patient level information and costing systems (PLICS)
- National Cancer Waiting Times
- Emergency Care Data Sets (ECDS).

Data can be modified by providers up to 12 months after submission.

Analyse and interpret

Initial validation of data submitted takes place within SUS+ before two extracts are taken. The first extract is used for developing Healthcare Resource Groups (HRGs) and the second (the National Extract) serves all other uses.

Our Secondary Care team carry out validation and data quality checks on all the datasets.

Distribute

Statistical publications, extracts and linkages are created for Hospital Episode Statistics (HES), DIDS, and PROMS, and new publications will be launched in 2018/19 for PLICS and Emergency Care Data Set (ECDS).

See our statistical publications and other data on hospital care.

We also produce answers to parliamentary questions, Freedom of Information requests and other ad hoc data requirements.

The National Extract can also be packaged into reports back to providers, and released to customers through the <u>Data Access Request Service (DARS)</u> or in response to specific queries (such as parliamentary and media questions).

DIDS data and linkages is available via monthly extract and is available to customers via the DARS service and an iView facility.

The national data submission is judged for data quality on a monthly basis, and can be viewed through an <u>interactive Power BI report</u>. Organisation performance can be viewed by each provider, which enables submitters to correct data quality issues within the flex and freeze period.

Change

The uses of secondary care data include:

- benchmarking
- policymaking
- monitoring the progress of interventions
- comparative effectiveness research on interventions to enhance the evidence base.

HRG4+ has increased the collection of multi-morbidities, where patients have more than one medical condition, enriching the data that is submitted through HES. This will lead to better insight into the health needs of the multi-morbid, which is increasingly important in an ageing population. The changes to SNOMED-CT will also lead to improved data quality and utility.

Other data sets have been linked to HES data to gain additional insights and follow up the progress of patients. The data enables benchmarking between departments, providers and regions.

There are specific examples of this data bringing benefits to patients. The outbreak of a slow growing bacteria (M. Chimaera) was identified as a potential infection risk to any patient that had undergone cardiothoracic surgery between 2013 and 2017. Public Health England, in partnership with NHS Digital and NHS England, used HES data to identify all at risk patients, allowing them to be contacted for potentially life-saving screening tests.

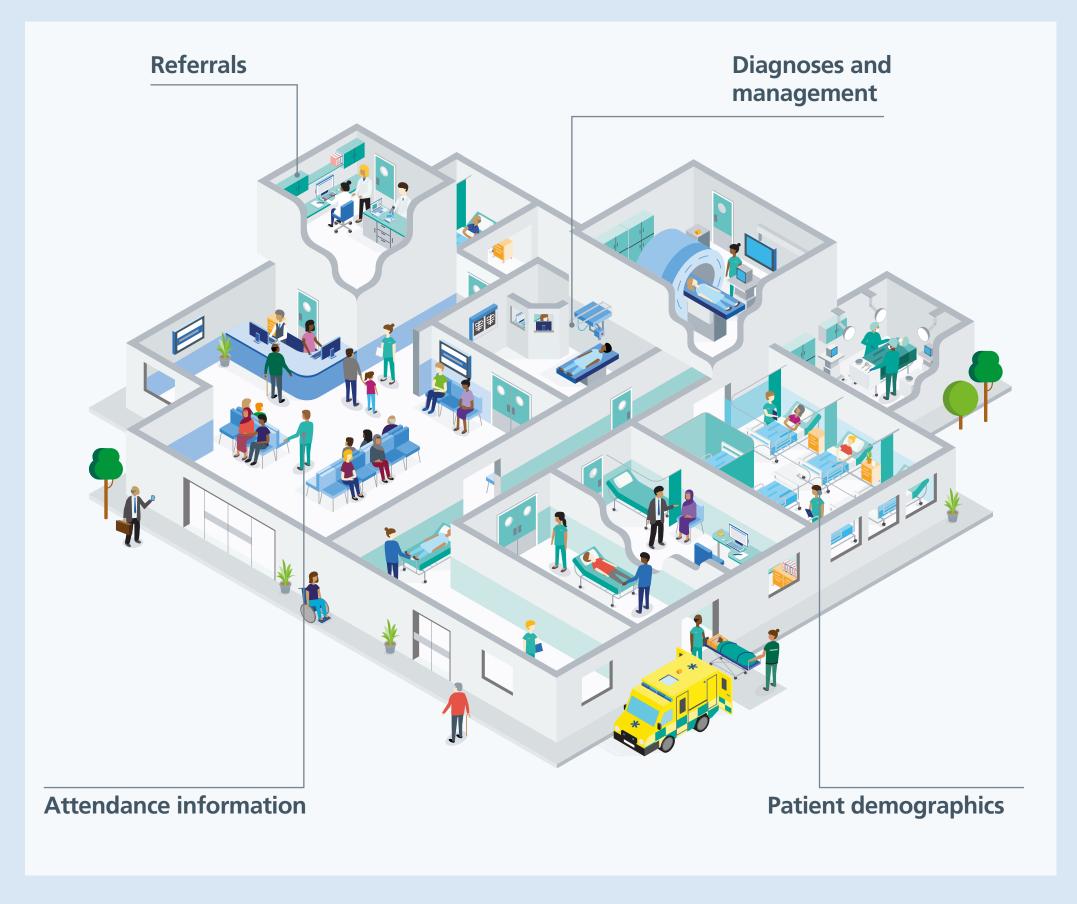
Emergency Care

The Emergency Care Data Set is a recently created national data set for urgent and emergency care. The data set has been designed in partnership with the Royal College of Emergency Medicine (RCEM), following consultation and piloting in hospitals.

It replaces the previous Accident and Emergency Commissioning Data Set which was not reflecting changes in health care practice or collecting enough data to understand how and why people attend Accident and Emergency (A&E) departments.

The new, more detailed data set will:

- improve patient care through better and more consistent information
- allow better planning of healthcare services, particularly over the winter
- improve communication between health professionals
- improve coverage across all A&E departments.



Emergency Care

The better the data we capture, the more we can understand and commission services that improve care for patients and reduce pressure for staff. Hospital trusts are being actively encouraged to improve the quality of data submissions.

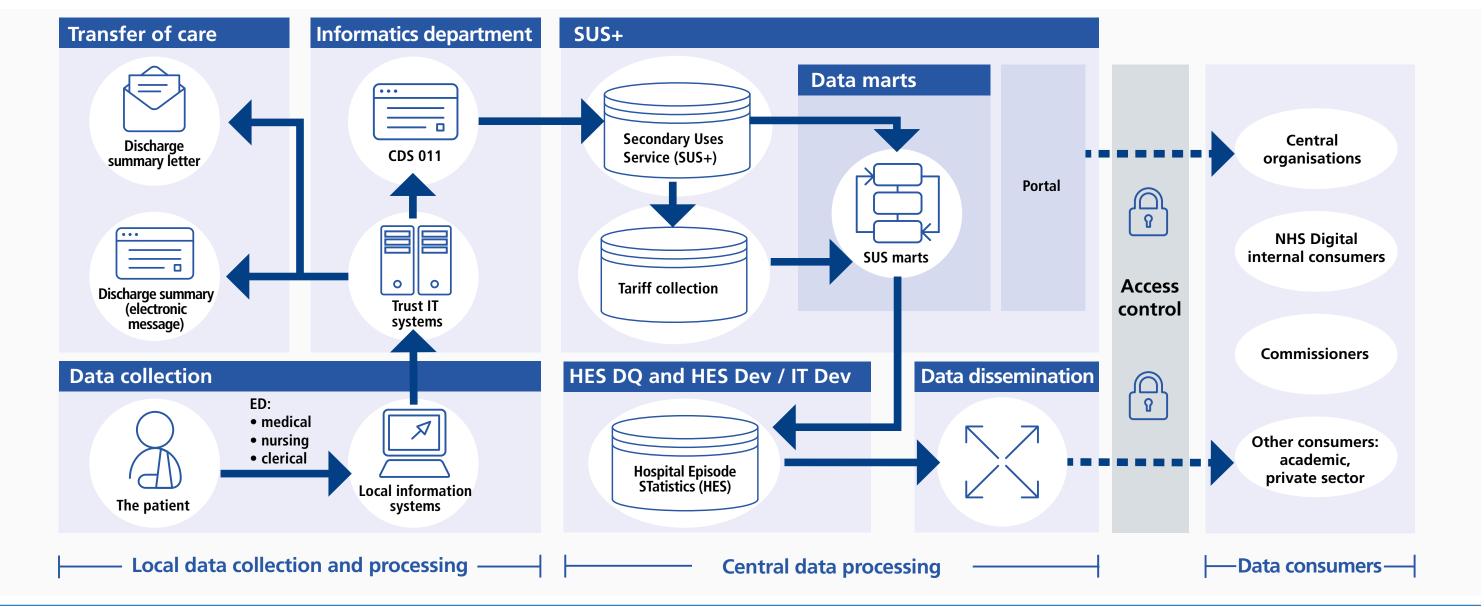
Collect

The ECDS is collected from records made by clerical and clinical staff within A&E departments and is fed directly into the <u>Hospital Episode</u> Statistics data collection.

How the Emergency Care Dataset (ECDS) will flow from the point of care to the data consumers.

The ECDS contains 108 data items, including:

- patient demographics (gender, ethnicity, age at activity date)
- episode information (including arrival and conclusion dates, source of referral and attendance category type)
- clinical information (such as chief complaint, acuity, diagnosis, investigations and treatments)
- injury information (such as date and time of injury, place, type, activity and mechanism)
- referred services and discharge information (onward referral for treatment, treatment complete, streaming, follow-up treatment and safeguarding concerns).



Assemble

Data Is submitted to us via <u>MESH (Message exchange for Social Care and Health)</u> onto the <u>Secondary Uses Services SUS+ platform</u>.

Information will flow from ECDS to SUS+ as 'Commissioning data set type' messages. This flow will be daily or weekly (as opposed to the previous monthly submissions).

Analyse and interpret

This data is analysed by us to:

- produce publications
- support the payment by results (PbR) process (which provides funds to hospital trusts)
- support NHS comparators.

Researchers, policy makers, commissioners, local organisations and members of the public will be able to analyse and interpret this data for their own purposes. These might include:

- health services research
- monitoring and managing NHS service agreements
- developing commissioning plans
- monitoring Health Improvement Programmes
- underpinning clinical governance
- understanding the health needs of the population.

Distribute

<u>Hospital Accident and Emergency Activity</u> is published yearly by our organisation and NHS England in joint reports.

Data on attendances, emergency admissions and four-hour waits are also collected, which are published monthly by NHS England (MSitAE).

It will be possible to publish aggregate level ECDS data daily, to support local planning. When appropriate, patient level data will be available to researchers through the Data Access Request Service. ECDS will provide opportunities for linkage with other data sets to provide valuable data about associations and pathways of care across different settings.

We also produce answers to parliamentary questions, Freedom of Information requests and other ad hoc data requirements.

Change

Although it is impossible to confirm all the benefits of the new data at this stage, it is anticipated that:

improved quality of data collected in emergency departments relating to patient presentation, diagnosis, discharge and follow up will support improved commissioning, planning of staffing and other resources. It will also lead to a better understanding of the benefits from new models of care, helping patients to receive care in the most appropriate care setting

feeding data back to the departments that have submitted it will help to ensure local improvements to patient care

better information will underpin future healthcare policy and strategy to ensure an improved quality of patient care

researchers will benefit from more accurate and comprehensive data on emergency healthcare to support research, audit and service improvement based on an extended evidence base

the information generated will allow commissioners to accurately fund, demand and implement strategic changes.

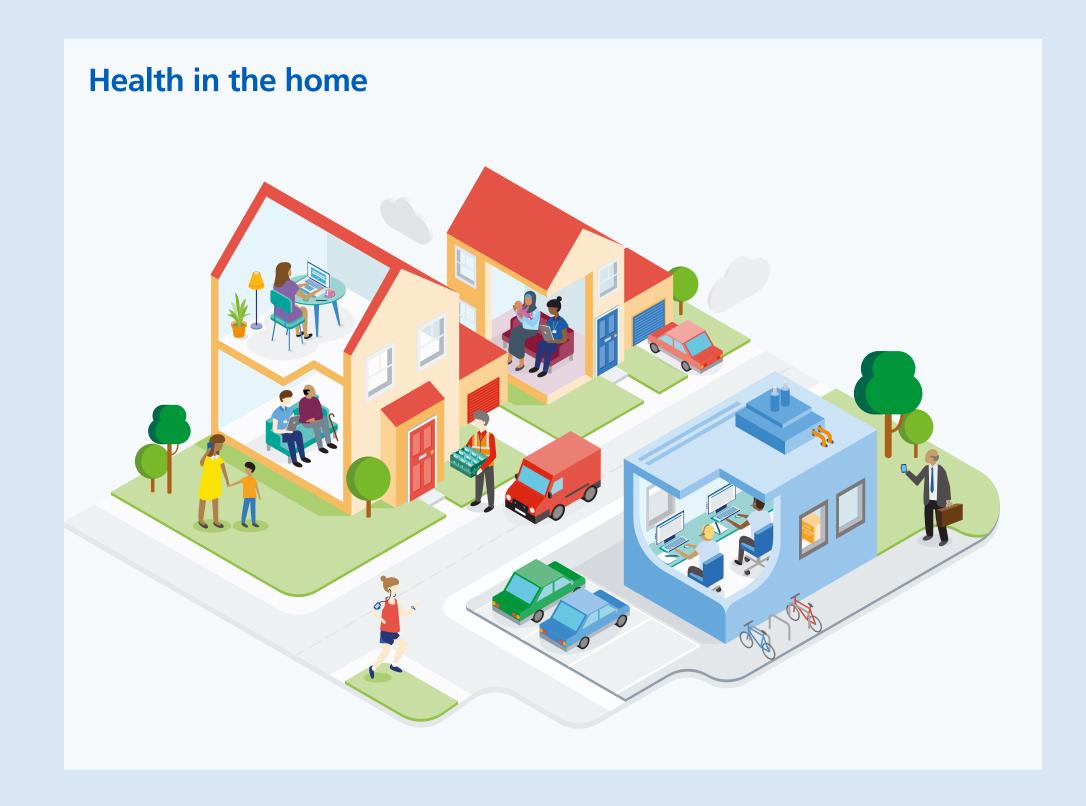
Community services

The <u>Community Services Data</u> <u>Set (CSDS)</u> is a patient level, output based, secondary uses data set. It is designed to deliver patient level data about every episode of care delivered by publicly-funded community services.

In late 2017, the <u>CYPHS (Children and</u> <u>Young Persons Health Services) data set</u> was widened to become the CSDS by removing the age restriction.

This collection has been developed in consultation with the <u>Department of Health</u> and <u>Social Care</u>, <u>NHS England</u>, <u>Public Health England</u>, service providers and commissioners.

With a total yearly expenditure of more than £10 billion, community services make up 10% of the NHS budget.



Community services

Community services include:

- health centres
- Sure Start centres
- day care facilities
- schools
- community centres
- mobile facilities
- services provided in a patient's own home.

Collect

All providers of publicly funded community services must submit to the data set, including:

- acute trusts
- mental health trusts
- community healthcare trusts
- care trusts
- social enterprises
- integrated care organisations
- any qualified providers
- independent sector providers (including third sector)
- local authorities.

Data collected includes the following information:

- personal and demographic
- social and personal circumstances

- breastfeeding and nutrition
- care event and screening activity
- diagnoses, including long-term conditions and disabilities
- scored assessments.

All data items collected in the CSDS can be found in the <u>technical</u> outcomes specification under the tab 'Master Data Item List'.

Assemble

Data is submitted through the **Bureau Service Portal**.

Currently, a small proportion of providers are submitting data. Work is ongoing to increase both the registration for data submission and the quality of the submissions.

Analyse and interpret

The data and statistics are currently analysed for the:

- number of providers who submitted, and the quality of that data submitted
- number of referrals to community services, separated by gender and age
- proportion of visits that were health visitors
- nature of the purpose of each home visit
- number of immunisation encounters
- number of care contacts
- number of appointments attended, not attended and cancelled
- source and reason for referrals.

Distribute

We publish statistical reports on community services.

Data is also fed into the <u>Data Services for Commissioners</u> regional offices to inform <u>commissioning support units</u> that advise <u>clinical</u> <u>commissioning groups</u> around the commissioning of services.

The data may also be published by Public Health England and other bodies, providing the appropriate information governance approvals are in place. Requests from any external bodies, for patient level data, are processed through the <u>Data Access Request Service (DARS)</u>.

We also produce answers to parliamentary questions, <u>Freedom of Information requests</u> and other ad hoc data requirements.

Change

Reliable local and national comparative data is vital to improving community services. It is used to underpin policy, inform commissioning decisions and manage services. It can also be used to predict demand on services and can be linked to other data sets to provide further insights.

Maternity services

The <u>Maternity Services Data Set (MSDS)</u> collects, analyses and reports data to achieve better outcomes for babies, children and mothers.

Information collected from the data set supports payments for maternity services and commissioning. The data set supports NHS England's <u>national maternity transformation programme</u>.



Collect

Data is collected throughout pregnancy, from routine booking appointment activities to screening results during labour and after birth. This includes data from GP surgeries and hospitals.

Data collected in the MSDS includes:

- routine booking appointment activities
- maternity care plans
- dating scans
- antenatal screening tests
- structural foetal anomaly screenings
- labour and delivery
- newborn screenings
- maternal or neonatal death.

Assemble

Maternity data is submitted using XML format, through the submission portal on the NHS Digital Bureau Service Portal web pages.

Data is fed from MSDS into the Data Services for Commissioners Regional Offices to inform commissioning support units that advise clinical commissioning groups around the commissioning of services.

Analyse and interpret

We publish statistical reports on maternity services.

MSDS is grouped by hospital trust.

Maternity data is analysed by:

- demographics age, ethnic group
- number of previous births
- gestational age at booking
- the presence of 'complex social factors'
- smoking status at booking
- smoking status at delivery
- breastfeeding initiation by trust
- BMI at booking.

Birth data is analysed by:

- percentage born before or after 37 weeks
- method of delivery
- percentage of vaginal births who suffered a traumatic lesion and the sub-type of lesions
- percentage who had skin to skin contact within 1 hour of birth
- first feed breast milk status.

The range of analysis of data within MSDS will continue to increase.

Distribute

The MSDS team is responsible for the production of official and national statistics to support and lead in planning, delivery and monitoring services, including monthly statistics.

We also produce answers to parliamentary questions, <u>Freedom of Information requests</u> and other ad hoc data requirements.

Patient level data can be requested through the <u>Data Access Request Service (DARS)</u>.

A new <u>maternity services dashboard</u> for quality improvement has been developed. These changes are targeted at making the data more user friendly, particularly for clinicians.

Change

The MSDS provides reliable information for:

- payment of maternity services
- local and national monitoring
- reporting for effective commissioning
- monitoring outcomes
- addressing health inequalities.

This data set supports the NHS England <u>national maternity</u> <u>transformation programme</u>. Our MSDS team report directly to the maternity transformation programme at NHS England. <u>Better births</u> is the associated national maternity review paper, the 5 year forward view for maternity, and sets out the direction of change.

We have created an expert reference group to help develop an improved MSDS version 2. This will go live in 2019.

We continue to work to develop quality improvement metrics that help drive clinical quality improvement in services and patient outcomes. In doing this, we aim for better outcomes for babies, children and mothers

Mental health

Data on adults and children referred into NHS services for severe or enduring mental health problems and those referred into Improving Access to Psychological Therapies (IAPT) services is captured within the Mental Health Services Data Set (MHSDS) and the IAPT data set. This data has been captured on clinical systems as part of patient care.

These data sets contain information about patients and the services that they received, which is used to improve care and monitor policy initiatives.

The MHSDS covers not only services provided in hospitals, but also in outpatient clinics and in the community, where most of the people in contact with these services are treated.

MHSDS statistics are for anyone wanting a comprehensive national picture of the use of specialist mental health, learning disabilities or autism spectrum disorder services in England, including:

- policy makers
- commissioners
- mental health service users
- members of the public.



Mental health

The Improving Access to Psychological Therapies (IAPT) programme began in 2008 and has transformed treatment of anxiety disorders and depression in England. Over 900,000 people now access adult IAPT services each year. They are provided with a range of talking therapies and outcomes are measured at each appointment. The IAPT data set captures details about patients, services, therapies and outcome measures.

The mental health team also collects the <u>Assuring Transformation (AT)</u> collection. This collects data about people with learning disabilities or autism who are admitted to hospital. It was set up in reaction to the <u>Winterbourne View scandal</u>. Data is collected to make sure people are not in hospital if they would be better looked after in the community.

It is expected that the AT collection will stop in March 2019, as MHSDS now includes people in contact with learning disability services.

Collect

The <u>MHSDS</u> collects information from service providers and organisations that provide specialist secondary mental health, learning disabilities and autism spectrum disorder services.

The <u>IAPT data set</u> collects information about patients with depression and anxiety disorders that are offered <u>NICE</u> approved evidence-based psychological therapies.

Assuring Transformation (AT) collects information about people with a learning disability, autism or both who are being cared for or treated in a hospital. Data is collected on how many people are in hospital, how long they have been in hospital for, when their care and treatment is checked and what hospital they are in.

Assemble

Submissions for MHSDS and IAPT are monthly. Data is submitted through the Open Exeter service portal. Providers have three weeks following the end of the monthly reporting period to submit data for the MHSDS and it then takes us a further three weeks to prepare it for publication.

Data for the Assuring Transformation data is collected and assembled in the live data collection system <u>Clinical Audit Platform (CAP)</u> from CCGs and commissioning hubs. A cut of the data is taken on the last day of every month. An extra cut is taken every Sunday at midnight.

Analyse and interpret

Mental health data can be analysed and interpreted by our teams and others to generate actionable insights. This analysis can take the form of predictive modelling, benchmarking, surveillance and comparative effectiveness research

Distribute

We publish monthly data sets and annual publications for <u>MHSDS</u> and <u>IAPT</u>, and monthly and quarterly reports for the <u>Assuring</u> Transformation data set.

We also produce answers to parliamentary questions, <u>Freedom of Information</u> requests and other ad hoc data requirements.

The Mental Health Data Hub makes it easier to look at mental health statistics through the use of visualisations and Microsoft Power BI.

Data about <u>out of area placements</u> is collected and published monthly by our Audits and Registries team.

Providers and commissioners can download record level MHSDS and IAPT extracts for their own populations, by logging into the <u>Bureau Service Portal</u>. Providers can access data quality reports about their submissions directly after they have submitted.

Patient level data can be requested through the <u>Data Access Request Service (DARS)</u>.

Change

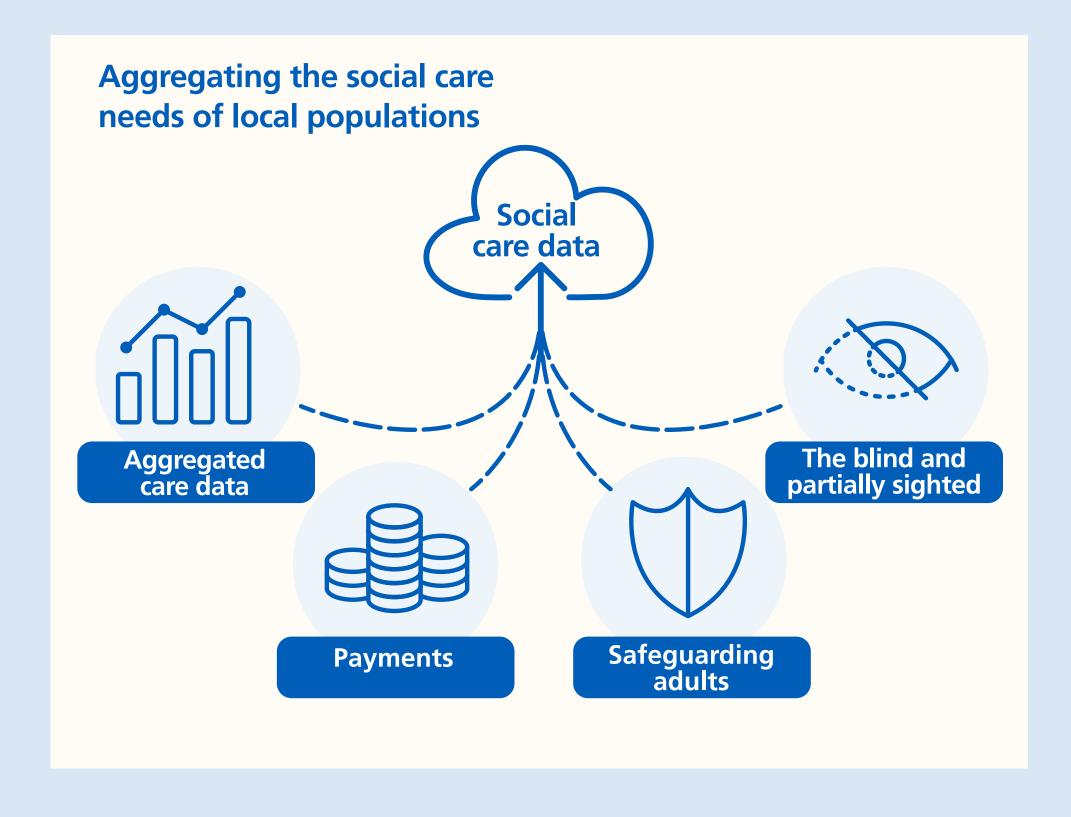
Data is used for a variety of functions, including commissioning, clinical audit, research, service planning, inspection and regulation, as well as local and national performance management and benchmarking, national reporting and underpinning government policies.

We have started linking MHSDS and IAPT data to other data sets to gain additional insights and follow up the progress of patients. The data allows benchmarking between teams, providers and regions, allowing peers to learn from good practice. For example, through the linkage of MHSDS and the <u>Maternity Services Data Set (MSDS)</u> we have published <u>exploratory analysis of women in contact with mental health services</u> who were new or expectant mothers.

Social care

Social care provides care for those who need it by providing a system of services and support to help people to retain their independence and dignity.

We collect and publish a wide range of information on social care activity. This data gives us an insight into how much money is spent on social care and what it is spent on. The data we collect is used to help plan, deliver and monitor services.



Collect

Social care data is collected by councils responsible for adult social care through council administration systems. This data is submitted to us by the 152 councils with adult social services responsibilities in England. It is used to track client journeys through the social care system so it can be assessed locally and nationally across England.

Social care data collections cover:

- social services activity
- safeguarding adults
- the Mental Health Act
- the Mental Capacity Act
- surveys of those in receipt of care and their carers
- an adult social care finance return
- summaries of the registers of people who are blind and partially sighted
- a social care minimum data set.

Most of the national social care data collections are aggregate (counts of service users, carers, and events), not individual records. The social care data we collect populates the <u>Adult Social Care Outcomes</u>

<u>Framework (ASCOF)</u>. This measures how well the care and support services achieve the outcomes that matter most to people.

Assemble

Councils submit data through the our Strategic Data Collection Service

Analyse and interpret

ASCOF is used both locally and nationally to set priorities for care and support, measure progress and strengthen transparency and accountability. ASCOF measures care and support services through four domains:

- 1. enhancing quality of life for people with care and support needs
- 2. delaying and reducing the need for care and support
- 3. ensuring that people have a positive experience of care and support
- 4. safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm.

Distribute

We publish this data through our <u>social care publications</u> including the Adult Social Care Outcomes Framework (ASCOF), which measures how well services are performing.

You can also see the data in our social care data hub.

Change

The data we collect is used by local authorities to:

- support service planning and improvement
- benchmark against peers
- monitor performance (including against their legal requirements)
- provide local accountability.

It is also used by the <u>Department of Health and Social Care</u> for performance benchmarking, research and policy making.

We produce and support answers to parliamentary questions, Freedom of Information requests and other ad hoc requirements.

Our social care data is used by other public bodies like <u>Public Health</u> <u>England</u> and the <u>Care Quality Commission (CQC)</u> as well as charities and researchers.

The ASCOF report is of interest to central government (for policy development and monitoring, and for parliamentary questions and Prime Minister's questions), councils, charities, academics and the general public. It allows performance to be monitored and improved. The other publications allow monitoring of critical legal obligations and can focus attention on areas for improvement.

An example of change driven by social care datasets is the <u>Transfer of Care Initiative</u>. This was set up in reaction to patient safety information highlighted by social care reporting. 33 per cent of the 10,000 patient safety incidents reported to the <u>National Reporting and Learning System (NRLS)</u> between October 2012 and September 2013 related directly to poor communication when a patient leaves hospital. The initiative was developed to improve communication between professionals as the patient's care is transferred from hospital to social care providers. This has led to a near universal uptake of electronic discharge summaries, making sure that important information is passed on and patients can be looked after properly.

Audits and registries

A clinical audit is a systematic review of care against explicit criteria. It is a way to find out if healthcare is being provided in line with standards, and it lets care providers, commissioners and patients know where their service is doing well, and where there could be improvements.

The aim is to allow quality improvement to take place where it will be most helpful and will improve outcomes for patients. Registries collect data about the health status of patients and the health care they receive over varying periods of time.

We work with the <u>Healthcare Quality Improvement Partnership (HQIP)</u> and other ALBs (arms-length bodies) to deliver 15 audits, each with their own information governance arrangements, that link data across complex care pathways. We host the data landing platform for these audits, the <u>Clinical Audit Platform</u>, and co-ordinate the analysis of data with other stakeholders to produce regular publications for each audit. National audits are vital to understand the trends of current disease management across the NHS, and to inform national policy. Good models of care can be identified, and unwarranted variation can be addressed.



Audits and registries

Clinical audits and registries are developed and delivered by the <u>Clinical Audits and Registries Management Service (CARMS)</u>, working collaboratively with clinical specialists, patient representatives and universities. Audits are commissioned by various organisations including <u>NHS England</u>, the <u>Healthcare Quality Improvement</u> <u>Partnership</u>, <u>DHSC</u> and Royal Colleges.

Collect

The content of collected data is determined by:

- commissioners
- government
- charities
- academia
- professional bodies
- medical royal colleges
- patient groups.

The audits and registries collected are:

- National Diabetes Audit
- National Bowel Cancer Audit
- National Oesophago-Gastric Cancer Audit
- Female Genital Mutilation (FGM) Enhanced Data Set
- National Audit of Pulmonary Hypertension
- Breast and Cosmetic Implant Registry
- National Diabetes Foot Care Audit
- National Pregnancy in Diabetes Audit

- National Diabetes Inpatient Audit
- National Diabetes Transition Audit
- National Audit of Cardiac Rehabilitation
- National Third Molar Audit
- National Orthognathic Audit
- Out of Area Placements
- Diabetes Prevention Programme (Pilot Study)

Each audit and registry has its own information governance arrangements, which can impact on its data collection. For example, when the National Diabetes Audit (NDA) changed from a system in which GP practices had to opt in rather than opt out, participation fell from 71% in 2012/13 to 57% in 2013/14. However, since the introduction of a direction from NHS England to NHS Digital to collect the NDA data in April 2017, practices and specialist services are required to collect the data by law, provided that the patient has not opted out. Participation is currently at 95%.

Other challenges to the submission of data include:

- lack of patient understanding of the benefit of participating in audit
- uncertainty about consent
- workforce pressure
- clarity and ease of submission processes for providers
- lack of electronic patient record systems for some specialties.

Assemble

Data is assembled on the clinical audit platform. This is a secure tool where providers can use data entry screens or upload csv files. The clinical audit platform also has a data landing platform.

Work is often carried out in partnership with other organisations when assembling data, including the Healthcare Quality Improvement Partnership (HQIP), <u>Royal College of Surgeons</u>, the <u>British Heart Foundation</u> and various other organisations.

Analyse and interpret

The clinical audit platform provides instant feedback on data quality. Validation is carried out in house. Analysis varies considerably between audits.

Linking of audits and data sets can be carried out and has enormous potential. As an example, the National Diabetes Transition Audit linked the National Paediatrics Diabetes Audit (commissioned by HQIP and run by the Royal College of Paediatrics and Child Health) with the data from the National Diabetes Audit. A working group was formed that consisted of clinical leads and audit managers for both audits, along with analysts from our organisation and Diabetes UK. Their analysis discovered that the hba1c target (which indicates good blood sugar control) is more likely to be reached before transition from paediatric care to adult care than after transition, and that cholesterol and blood pressure targets were also more likely to be reached before transition. The analysis included patients undergoing transition at any age between 12 and 24, and proved that transition is most effective between 16 and 19 years.

Linkage also allows the size of the audit data sets to be minimised by re-using existing data sources where possible.

Distribute

Audit and registry reports and raw aggregate data can be accessed through our publications system:

- National Diabetes Audit
- National Bowel Cancer Audit
- National Oesophago-Gastric Cancer Audit
- Female Genital Mutilation (FGM) Enhanced Data Set
- National Audit of Pulmonary Hypertension
- Breast and Cosmetic Implant Registry
- National Diabetes Foot Care Audit
- National Pregnancy in Diabetes Audit
- National Diabetes Inpatient Audit
- National Diabetes Transition Audit
- National Audit of Cardiac Rehabilitation
- National Third Molar Audit
- National Orthognathic Audit
- Out of Area Placements
- Diabetes Prevention Programme (Pilot Study).

Customers can commission us to produce bespoke reports, such as management reports and user reports comparing local data against national data.

Change

Health and care organisations who submit data to the audits can use it to monitor how they are doing and look at areas for improvement in care. Researchers, charities, central government, commissioners and others use audit data to improve care for patients. Audits and registries have an important part to play in improving care by:

- identifying and promoting good practice (positive deviance) through benchmarking
- highlighting the gap between actual care and recommended best practice
- identifying inequitable provision of care
- monitoring the effectiveness of a service or intervention
- identifying problems and monitoring progress or trends to inform local or national policy
- identifying at risk groups and enabling product recalls.

Prescribing and medicines

Prescribing is the most common patient-level intervention in the NHS, and covers all sectors of health care, including:

- primary care
- hospital
- public health
- community services.

This is the second highest area of spending in the NHS, after staffing costs, with the overall medicines cost (at list price) in hospitals and the community in England reaching £17.4 billion during 2016/17. Most prescribed items are medicines. Dressings, appliances and equipment can also be prescribed.



Prescribing and medicines

The prescribing and medicines team extracts and analyses prescribing data to identify trends and variations, and to support national policy. We also release open data for analysis by other organisations.

The team works in collaboration with:

- NHS Business Services Authority
- NHS England
- Office for Life Sciences
- Department of Health and Social Care
- Public Health England
- NHS Improvement
- National Institute for Health and Care Excellence.

Aggregate prescribing data is publicly available and is used by other organisations, who can visualise it in a user-friendly format. This allows individual GP practices and Clinical Commissioning Groups (CCGs) to compare their prescribing patterns to other providers.

Collect

Primary care prescribing information is derived from reimbursement to dispensers. This is collected by NHS prescription services, a division of the NHS Business Services Authority (NHS BSA), who enhance the data with additional information, for example the cost of the medicines supplied to the NHS. The data are aggregated at national and provider level. National data is provided directly to NHS Digital. Data at provider level is available through the <u>ePACT2 system</u>, also provided by NHS BSA.

Data for hospital use of medicines is provided by IQVIA (formerly known as QuintilesIMS and previously IMS Health) and is collected from NHS Trusts in England.

Other data required for publications is collected as required from specific providers (such as the Commercial Medicines Unit in NHS England), either via a data request, routine data flow or is previously published (such as World Health Organization or Office for National Statistics data).

Data is also collected about the NHS services provided by community pharmacies.

Assemble

We assemble data in a variety of ways.

Prescription Cost Analysis (PCA)

This covers the number of items and net ingredient costs of all medicines written in the UK and dispensed in the community in England. The data includes prescriptions written by:

- GPs
- hospital doctors
- dentists
- non-medical prescribers, such as nurses and pharmacists.

The net ingredient cost is the basic cost of a drug, not including discounts, dispensing costs, fees or prescription charges, so the amount the NHS paid will be different. This data is assembled into the prescription cost analysis system.

Prescribing costs in hospitals and the community

Data for hospital use of medicines is provided by IQVIA (formerly known as QuintilesIMS and IMS Health) and taken from most NHS Trusts in England. ePACT (electronic Prescribing Analysis and Cost Tool) data for primary care and hospital medicines prescribed in the community is then added, provided by the NHS prescriptions services.

Prescribing for diabetes in England

This data covers all prescriptions written for diabetic medication by prescribers working in primary care in England. This includes GPs, nurses and pharmacists.

Innovation scorecard

The <u>innovation scorecard</u> measures the uptake of new or innovative medicines by the NHS. It uses a variety of data sets:

- primary care prescribing data from prescription services
- hospital pharmacy audit data from IQVIA
- Pharmex data from the commercial medicines unit (NHS England)
- volume purchase data from NHS Supply Chain
- Hospital Episode Statistics (HES)
- mid-year population estimates from the Office for National Statistics
- defined daily doses from the World Health Organization
- cardiac rhythm management devices annual audit (from the National Institute for Cardiovascular Outcomes Research)
- pharmaceutical industry data.

General Pharmaceutical Services: England

This report shows information about community pharmacy contractors (community pharmacies) and appliance contractors in England, and the NHS services they provided. Data is incorporated from:

- NHS Digital
- NHS Prescription Services
- NHS England
- NHS Litigation Authority Family Health Services Appeal Unit.

Analyse and interpret

We analyse and interpret information in a variety of ways.

Prescription cost analysis

These are analysed by <u>British National Formulary (BNF)</u> Therapeutic Class. One prescription item is a single item written on a prescription form, known as an FP10. This publication shows greatest granularity per prescription item.

Data is analysed for:

- number of items dispensed
- net ingredients costs
- free versus charged prescribing
- trends in prescribing by therapeutic area
- trends in volumes of prescribing and shifts in cost.

This analysis is interpreted as change against the same figures in recent years to portray trends over the last 10 years.

Prescribing costs in hospitals and the community

Costs from the drug tariff and standard price lists by net ingredient costs are applied to the data. However, trusts often access NHS negotiated price discounts, so these costs are not necessarily truly reflective of what the NHS paid. The costs are compared to the previous year and expressed as percentage annual increase or decrease.

Prescribing for diabetes in England

Prescribing for diabetes examines prescribing trends on medicines prescribed in primary care in England for the treatment and monitoring of diabetes over a 10-year period. This is analysed as a proportion of the total prescribing spend in the UK and split by BNF classifications for differing types of diabetes drugs by number of items and cost.

The prescribing data is interpreted against the prevalence of diabetes over time by financial year and down to CCG level.

Innovation scorecard

The data is analysed by product, condition and geography. The analysis is compared against previous years to monitor the change of use, with the headline interpretation being whether more of these innovative technologies are being used in relation to the previous report.

General Pharmaceutical Services: England

Information about NHS services provided by community pharmacies and appliance contractors in England is analysed. The number of sites, the number of prescriptions, the fees charged, and the average fees are all analysed. The number of dispensed medicines via community pharmacy, appliance contractors and dispensing GPs is aggregated by region.

Distribute

The team produces a range of <u>national and official statistical</u> <u>publications and data releases</u>. We also produce and support answers to parliamentary questions, Freedom of Information requests and other ad hoc requirements.

Change

The data is used to identify trends in prescribing rates and costs. These can reflect the availability of new medicines or changes in the evidence base for the clinical and cost effectiveness of prescribed items. The data allows investigation of cost effective choice of medicines and indicates where there will be future cost pressures.

The data is also used to monitor the impact of changes in policy and for investigations, such as the use of controlled medicines or the use of antibiotics.

Individual GP practices and Clinical Commissioning Groups (CCGs) can use prescribing data to compare their prescribing patterns to those of other providers across the country. This enables them to identify where prescribing patterns vary from the average or from similar organisations, and allows more detailed investigation.

Work is underway to enable the submission of patient level prescribing data. This would allow more granular insights and linkage with other data sets. There are plans to make this data available through the Data Access Request Service (DARS).

Population health

Our population health team collects and analyses data about the health of the UK population. This includes data about NHS screening programmes, immunisations, births, deaths, general health and lifestyle.

This is divided into 4 groups:

- lifestyle statistics
- population, geography and international statistics
- screening and immunisations
- <u>surveys</u>.

We collect, analyse, interpret and distribute data to inform policy and develop public health interventions. The data is also used to monitor the impact of changes to policy and health interventions.

English data is often combined with that of the rest of the UK and contributes to global comparisons as part of the UK's membership of World Health Organization (WHO), Organisation for European Cooperation and Development (OECD) and Eurostat. This enables health care providers and governments to compare UK health performance with other countries around the world.



Collect

Lifestyles statistics

Our team collects data on a range of topics including:

- smoking
- alcohol
- drug use
- obesity
- contraception.

In addition, we also manage the <u>National Child Measurement</u> <u>Programme (NCMP)</u> collecting data on the numbers of underweight, healthy weight, overweight and obese primary school children. Data associated with the national lifestyles surveys is also collected by our team.

Population, geography and international statistics

We collate information from all four UK countries on a wide variety of health-related topics for international bodies such as the World Health Organization (WHO), the Organisation for Economic Cooperation and Development (OECD) and Eurostat.

We also have responsibility for population, births and deaths information, which includes the number of live births, deaths by cause and area, and the number of maternities (number of pregnancies resulting in births).

In addition, we manage the <u>Primary Care Mortality database (PCMD)</u> and <u>Compendium of Public Health indicators</u>, primarily for public health clinicians and analysts in local authorities, but also for wider use. We deal with issues related to geography, including spatial analysis and mapping tasks.

Screening and immunisations

We collect data in relation to breast and cervical screening, and the NHS immunisation programme.

Breast screening data includes information on the number of women invited for screening, numbers screened, and the outcomes of screening (including diagnosis of cancer).

Cervical screening data includes information about the call and re-call system, screening samples examined by pathology laboratories, referrals to colposcopy clinics and subsequent treatment and outcomes.

Immunisation coverage data is collected for routine childhood immunisations at 1, 2 and 5 years, and seasonal flu immunisation.

Surveys

Our surveys team commissions and manages contracts with external organisations to carry out surveys on aspects of health and social care. Surveys cover a wide range of topics and vary in frequency from quarterly to every 10 years.

Morbidity surveys can be complex undertakings, involving in-depth clinical face to face interviews. These must also have procedures in place to advise interviewees if they should seek medical attention.

We offer advice on running or commissioning surveys. Additional questions can be added to existing surveys, or certain demographic returns boosted.

Analyse and interpret

Analysis is undertaken by both the contracted companies that collect the data and by our organisation. Lifestyles data is analysed to provide a broad picture of health issues related to smoking, alcohol, drug use and obesity, and a summary of key findings from the National Child Measurement Programme for England.

Distribute

Publications and data sharing tools are produced by all parts of the team.

Lifestyle statistics

Publications include:

- Health Survey for England
- Smoking, drinking and drugs in younger people
- Infant feeding survey discontinued
- National child measurement programme
- Smoking at the time of delivery
- NHS stop smoking services
- <u>Sexual and reproductive health services</u> (previously NHS contraceptive services)
- Statistics on smoking
- Statistics on alcohol
- Statistics on drug misuse
- Statistics on obesity, physical activity and diet.

We also produce answers to parliamentary questions, Freedom of Information requests and other ad hoc data requirements.

Population, geography and international statistics

We hold <u>vital statistics data</u> on behalf of the NHS. This can be extracted, analysed and formatted for a customer, under disclosure control to minimise risk of re-identification.

Quarterly reports on the <u>number of people registered with a GP</u> <u>practice</u> are published within the General Practice Data Hub. Requests for data from the primary care mortality database must go through the Data Access Request Service.

Office for National Statistics (ONS) population data is provided through the <u>iView data tool</u>. The population statistics database is only available to members of the NHS or Department of Health and Social Care with a valid business need by contacting <u>pop.geog@hscic.gov.uk</u>.

Members of the public can refer to standard tables at:

- Office for National Statistics (ONS)
- World Health Organization (WHO)
- Organisation for Economic Co-operation and Development (OECD)
- <u>Eurostat</u>.

Screening and immunisation

Publications include:

- breast screening
- cervical screening
- child Immunisation statistics.

Further immunisation publications, including uptake of the influenza vaccine in adults, are produced by Public Health England.

Population health

Surveys

Reports include:

Adult Psychiatric Morbidity Survey

Mental Health of Children and Young People

Adult's Dental Health Survey - England, Wales and NI

Children's Dental Health Survey

Personal Social Services Survey of adult carers in England

What about Youth? study.

Change

Data is used to inform policy and to develop public health interventions. It is also used to monitor targets to see if policy interventions are having an effect.

The international work enables comparison of UK health performance with other countries around the world.

Population health data is also used to inform public debate. For example, the 'Autism Spectrum Disorders in adults living in households throughout England Report' from the 'Adult Psychiatric Morbidity Survey 2007' was used to debunk claims of a link between MMR and autism, by showing that autism was no more common in younger people than adults, even though adults at this time had not received MMR vaccinations.

Facilities and estates

Our facilities and estates team work with data and information about the physical NHS estate – its land, buildings and their running costs. Facilities and estates is the third largest cost for the NHS, after staff and medicines. In 2016/17, NHS organisations reported this cost as £8.6 billion.

We also collect and analyse information on surplus land – land that is owned by the NHS but not needed to provide services.

Information on facilities and estates is used for local investment planning, contract negotiation and service management, which improves the efficiency of the NHS.

We also manage the collection of data on the <u>Patient-Led Assessment</u> of the <u>Care Environment programme</u> (<u>PLACE</u>). This looks at how well care environments, for example hospital wards, meet their patients' needs. PLACE provides a way for patients to share their views on the sites where they receive care, so that the information can be used to improve patient experience.

We also manage the Defects and Failures reporting system. This allows NHS Improvement to monitor how well non-medical equipment is working across the NHS.

Estates Related Information Collection (ERIC)

Collect

The Estates Related Information Collection (ERIC) includes information on:

- the number of sites each trust has, and what they are used for for example acute hospitals or mental health facilities
- gross floor area and occupied floor area
- running costs such as cost of food, laundry, portering, cleaning and energy costs
- works backlog and investment required to remediate looking at the money needed where work is required to bring facilities up to standard
- car parking charges
- surplus land land owned by the NHS but not required.

Some data is collected at site level and some at organisation level.

Assemble

NHS trust staff use the <u>Estates and Facilities Management Information</u> <u>System (EFM)</u> to submit data to us.

Analyse and interpret

We analyse data to look at the total cost of running and maintaining NHS sites, and separate this data into suitable metrics, for example the cost of electricity or cleaning. Surplus land sites are analysed for potential housing capacity.

Distribute

Registered users of the EFM system can use it to see real time data, benchmark their own sites and run data reports.

We publish the annual <u>Estates Return Information Collection</u> report and the <u>NHS Surplus Land</u> report.

You can use the <u>Hospital Estates and Facilities tool</u> to view ERIC data from 1999/2000 onwards.

We also produce answers to parliamentary questions, Freedom of Information requests and other ad hoc data requirements.

Change

Local users can use data to see how they are doing in comparison to other sites and to their own targets, to improve their efficiency, safety and quality. Data is used for:

- local investment planning
- negotiation of contracts
- managing services.

Nationally, the collection provides essential information on NHS estates, including:

- safety
- quality
- running costs.

This is used by the government and other organisations involved with health and care for a range of purposes, including policy decisions on investment planning and income generation.

ERIC data was used in the <u>Carter review of productivity in NHS</u> <u>hospitals</u>, and now monitors progress against targets set for each provider.

Estates and facilities data is being linked with activity data such as Hospital Episode Statistics, to generate new insights into use of the NHS buildings.

Surplus land data provides information to the Department of Health, the Homes and Communities Agency and the Government Property Unit on sites that can be sold, contributing to the Government Public Sector Land Disposal Programme.

Patient-Led Assessment of the Care Environment (PLACE)

Collect

Patient-led inspection teams visit the places where patients receive care, and fill in forms based on their assessments of criteria including:

- privacy and dignity
- maintenance
- food
- cleanliness
- accessibility
- suitability for patients with dementia.

Hospitals and hospices providing NHS funded care in the NHS and private sector are assessed.

Assemble

NHS trust staff use the <u>Estates and Facilities Management Information</u> <u>System (EFM)</u> to submit data from the assessments to NHS Digital.

Analyse and interpret

We compare the average score of each area tested to previous years' scores. We also compare the number of assessments in each annual report.

Distribute

We publish the annual <u>Patient-Led Assessment of the Care Environment (PLACE)</u> report.

PLACE data is shared with care providers and the <u>Care Quality</u> Commission (CQC).

You can use the <u>Hospital Estates and Facilities tool</u> to view PLACE data from 1999/2000 onwards.

Change

The NHS Constitution now includes the right to be cared for in a clean, safe, secure and suitable environment. PLACE data tells providers how they are doing, and helps them to improve through action planning.

PLACE data feeds into the CQC risk model, which it uses to make sure services meet quality and safety standards. The CQC also uses the data to help decide which sites it should inspect.

Defects and Failures reporting system

Collect

All faulty non-medical equipment is reported by NHS staff across England.

Assemble

Staff use the Estates and Facilities Management Information System to submit details of faults to us.

Analyse and interpret

We analyse the data for identifying trends, for example: faults occurring on pieces of equipment.

Distribute

We share this data with NHS Improvement.

Change

NHS Improvement use this data as an equipment surveillance system, to monitor safety.

Workforce

Around 1.2 million people make up the NHS workforce in England, all contributing towards the effectiveness of the NHS. Staffing is the single largest cost within the health system, so efforts to improve quality and reduce costs are often dependent on workforce data.

The Health and Social Care Act 2012 places a duty on all organisations that deliver care funded by the NHS, to provide data on their current workforce and to share their anticipated future workforce needs.



Collect

Data is collected on the number of GPs working in England, information on GP practices, GP practice staff, GP patients and services provided, earnings and expenses. Related data is collected from dental practitioners and high street ophthalmic service providers. GP earnings data is based on a sample of HMRC's self-assessment tax database.

Aggregate data is collected on all written complaints, including number of complaints, type of complaint, age of patients, type of service, type of staff involved and whether the complaint was resolved.

Hospital and community health service workforce data is mainly taken from the Electronic Staff Record, and includes staff numbers, bank staff, turnover, earnings, absence and many career details.

Assemble

We assemble data using a combination of processes: secure electronic file transfer, the GP extraction system, strategic data collections solution, Workforce Minimum Data Set collection vehicle, the clinical audit platform and email.

A primary care web tool is used to receive the primary care collection directly from GP practices.

Data for ophthalmic practitioners and services is entered onto the central ophthalmic payments system through the <u>Open Exeter system</u>.

NHS payments to GPs is collected through the Integrated Single Finance Environment (ISFE), and the <u>National Health Applications and Infrastructure (NHAIS)</u>.

Hospital and community health service workforce data is taken from the <u>Electronic Staff Record</u>.

Data regarding vacancies is extracted from NHS Jobs.

Analyse and interpret

Workforce data is analysed in terms of both headcount and full time equivalents.

Analysis of GP earnings is carried out by HMRC statisticians, and aggregated data is supplied to NHS Digital. Investment in general practice is analysed separately by payment for drugs and by costs of other services

The number of dentists is reported and analysed by age group. Dental workforce data also includes their NHS England locality, contract type and gender. The number of children and adults seen by a dentist in the last 24 months is analysed by proportion of those seen in each area. Courses of treatment are analysed by treatment band (1-3 or urgent), by demographic (paying adult, child, non-paying adult) and by type of treatment. Total orthodontic treatments are reported.

The number of ophthalmic practitioners is analysed by gender, job role (optometrist versus ophthalmic medical practitioner) and number per 100,000 population.

Monthly data quality processes are carried out such as The Workforce Validation Engine (WoVen) which is used to identify data quality issues, identified in information held on the Electronic Staff Record (ESR) system.

Distribute

We publish a range of statistical reports, including:

- NHS Workforce Statistics
- Data on the GP workforce
- Publication on NHS written complaints in England
- Publication on ophthalmic practitioners
- <u>Publication on the General Dental Workforce</u>

Additional publications include:

- Annual Dental Earnings and Expenses
- Annual Dental Working Hours
- Annual GP Earnings and Expenses
- Annual Investment in General Practice
- NHS Payments to General Practice
- Dentist survey results
- NHS Vacancies

We produce and issue Doctor Index Numbers (DINs) that allow GPs to prescribe medicines and other products available on prescription.

Hospital and community health service workforce data is disseminated in the form of tables in monthly publications and a web-based tool called iView. Publications include: NHS Staff Earnings (Quarterly)

We also disseminate statistics on NHS staff numbers in the form of tables responding to Parliamentary Questions, Freedom of Information requests and other ad-hoc data questions.

Change

These data sets are used by the Department of Health and Social Care, Health Education England and other organisations for workforce planning and to monitor policy.

They are also used to analyse staff turnover, identify trends for workforce planning and to monitor policy. Staffing is the single largest cost within the health system, so efforts to improve quality and reduce costs are often dependent on this data.

Indicators

Clinical indicators are tools used to monitor the performance of health service and social care organisations. It is estimated there are over 100,000 indicators in use, at different levels within the health and social care system. The Indicator and Methodology Assurance Service was established, following the Francis Enquiry, to ensure that indicators are well defined, based on good data and on transparent methodologies, so that they can help improve patient safety.

Some indicators are developed by NHS Digital, and many more are developed by other health and care organisations. Other organisations can have their indicators assured by the Indicator and Methodology Assurance Service.

Indicator and Methodology Assurance Service

The Indicator and Methodology Assurance Service assesses indicators against the following criteria:

- 1. **Clarity** is it clear what the indicator will measure?
- 2. **Rationale** are the reasons and evidence for measuring this clear?
- 3. **Data** is the data in the measure fit to support the purpose?
- 4. **Construction** will the methods used support the stated purpose? Is it clear what methods are used and how they have been tested and justified?
- 5. **Presentation and interpretation** is the presentation of the indicator suitable and are all potential users able to interpret the values? Can the indicator be used for quality improvements?
- 6. **Risks** are any limitations, risks or perverse incentives associated with the indicator explicitly stated?

The indicator author submits an application form which is appraised by the team. If appropriate, the indicator is then peer reviewed, through the Methodology Review Group (with multiagency technical representation). Once that group is satisfied, the indicator is sent to the Indicator Governance Board (with senior multiagency representation) for final approval.

Indicators developed internally

The clinical indicators team develop, test, produce and then publish a range of indicators, separated into the following groups.

Clinical Commissioning Group Outcomes Indicator Set (CCGOIS)

These are clinical indicators that provide comparative information for CCGs. These contribute to the five domains of the NHS Outcomes Framework (see below). Promising indicators are assessed by the NICE CCGOIS advisory committee, who make recommendations to NHS England about which should be included.

Thresholds or levels of ambition are not set centrally. Indicators are designed for local interpretation.

Compendium of Population Health Indicators

This is a collection of over 1000 clinical indicators designed to provide a comprehensive overview of population health at a national, regional and local level. These are useful for:

- allowing local providers to compare the profile of their local area with other regions and national averages.
- understanding population health challenges in a local area and how they may be changing over time.
- exploring the diverse range of factors that influence health inequalities.

The Compendium includes a collection of 60 indicators called the Local Basket of Inequalities Indicators (LBOI), which helps organisations to measure health and other factors which influence health inequalities such as unemployment, poverty, crime and education.

Quality Accounts

The quality of services is measured by looking at:

- patient safety
- the effectiveness of treatments patients receive
- patient feedback about the care provided

Reports are then created and published by each NHS funded provider (including the independent sector) and made available to the public. These reports contain 15 mandated indicators and an optional non-statutory indicator. The performance of the provider against these indicators must be reported alongside the national average and a supporting commentary that may explain variation or the provider's plans to improve in the future. These indicators are divided into the five domains of the NHS Outcomes Framework (below).

NHS Outcomes Framework

This workstream develops the sub indicators within each of five areas of quality:

- preventing people dying prematurely
- enhancing quality of life for those with long term conditions
- helping people to recover from episodes of injury or ill health
- ensuring people have a positive experience of care
- <u>treating and caring for people in a safe environment and protecting</u> them from avoidable harm

These 50 indicators are designed to be of use to the Secretary of State for Health and Social Care to hold the NHS to account. They are made available for everyone to view the performance of the NHS and to increase transparency.

<u>Summary Hospital-level Mortality Indicator</u> (SHMI)

The Summary Hospital-level Mortality Indicator (SHMI) is the ratio between the actual number of patients who die following hospitalisation at the trust and the number that would be expected to die based on average English figures, given the characteristics of the patients treated there. Trusts are categorised as having either a 'higher than expected', 'as expected' or 'lower than expected' number of deaths. This is one of several methods of measuring mortality and the methodology is subject to continuous review and development. Known issues are kept under review and are detailed in the SHMI methodology development log.

NHS.uk

Further indicators, created in addition to the NHS Outcomes Framework are produced for presentation on nhs.uk.

Seven-day services

This is a series of experimental statistics published by NHS Digital to provide information on how the NHS can effectively measure both improvement and variation in care provision across the week. This series includes indicators on the following topics:

- mortality within 30 days of admission by week-part of admission to hospital
- emergency readmissions within seven days of discharge from hospital by day of discharge
- length of stay following an emergency admission to hospital by day of admission

The data for these indicators can be collected by other NHS Digital teams and sourced from external organisations, including NHS England, Public Health England and the Office for National Statistics.

Distribute

NHS Digital produces 1500 indicators and 14 sets of official statistics publications each year. Data behind the indicators and their supporting documents can be accessed through the <u>National Indicator Library</u>.

The <u>Clinical Indicator Previewer</u> is an access controlled site where NHS Trusts and independent providers can view and verify their NHS choices and SHMI indicators prior to publication.

National Casemix Office

The <u>National Casemix Office</u> works alongside <u>NHS England</u>, <u>NHS Improvement</u> and other national bodies to determine the cost of approximately £50 billion of healthcare activities and the commissioning of £35 billion of services.

The team creates software to develop clinical grouping methodologies known as Healthcare Resource Groups (HRGs). These are groups of clinically similar activities that use similar levels of healthcare resource. This software collates healthcare provider activity data – a record of what care and services have been provided – into HRGs. This can calculate how much services cost and how much providers should be paid.

Development of the Healthcare Resource Groups

The National Casemix Office use <u>Hospital Episode Statistics</u> and an extensive network of experts to determine definitions for each of the HRGs. This network consists of over 300 senior clinicians, recruited via the Royal Colleges. They meet as 30 expert working groups to discuss specialty-specific HRGs, and make improvements to the HRG design. This ensures HRGs remain clinically relevant and coherent and considers new clinical technological advances.

Patient level costing data is also used in the development process, as well as other data sources outside of the readily available nationally mandated data collections. This results in every diagnostic code found in the <u>International Classification of Diseases (ICD-10)</u>, and every procedure found in the <u>Classification of Interventions and Procedures (OPCS-4)</u>, being mapped directly to a unique HRG group. Each group contains activities and conditions that expend a similar level of expected healthcare resource.

Collect

The activities that a healthcare provider has carried out are recorded in, and extracted from, patient records.

Assemble

We collect and convert this activity data into HRGs by inputting the data into the <u>Casemix Grouper software</u>. This software, referred to as 'the Grouper', can be downloaded, along with instructions, from the NHS Digital website.

Analyse and interpret

The Grouper then validates and runs complex algorithms to determine the HRG or HRGs for the patient record. This is done either to predict the cost of services or to calculate a payment due to a healthcare provider.

Guidance for the costing of healthcare services can be found on the <u>NHS Improvement website</u>.

There is a three year time lag between collecting costs and publishing a new payment tariff to allow sufficient time to test the impact of the changes on the funding structure. The 2017/18 national tariff has been based on the HRG4+ 2014/2015 Reference Costs. The 2019/20 national tariff will be based on the HRG4+ 2016/17 Reference Costs.

Distribute

The <u>National Casemix Office</u> works directly with NHS England and NHS Improvement to <u>develop the payment tariff</u>. Reference Costs are produced by providers and can be found on the NHS Improvement website.

NHS Improvement now publish the <u>reference costs</u> each year. This document sums the total spent in different areas of the health service.

Change

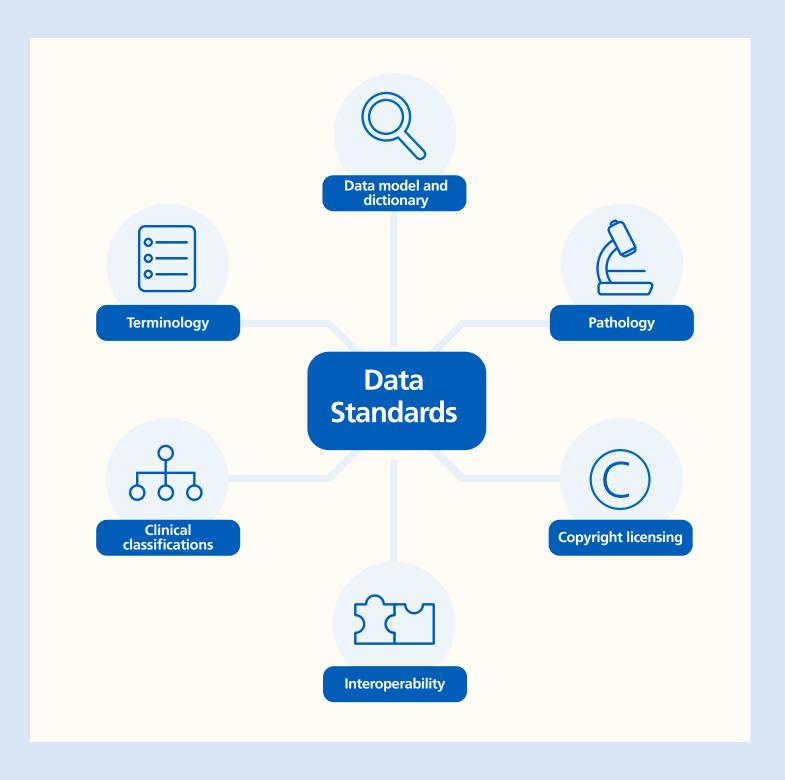
The National Casemix Office enables the NHS to:

- support activity costing to inform the national tariff setting process underpinning Payment by Results
- report on patient activity information to ensure that providers are paid for the services they provide
- provide information to support epidemiological studies and service planning – for example HES data has been interpreted with HRG software to understand the total cost of a disease to an area, or the total cost to the NHS
- enable providers and commissioners to use HRGs to benchmark and performance manage, and redesign services.

Data standards

The data standards team work on national and international standards for recording and categorising information to support:

- care delivery
- statistical analysis
- research
- the reimbursement of health and care providers



Data standards

Effective data standards, applied when data is collected, make every subsequent step in the lifecycle (assembly, analysis and interpretation, distribution and change) easier for each system and organisation involved. Standards that are fit for purpose are, therefore, directly related to improved patient outcomes from both primary and secondary uses of data.

Effective data standards benefit the health and care system in various ways, including:

- vital information can be shared consistently within and across health and care settings to support delivery of high quality care
- comprehensive and high quality information supports clinical decision making and can support more extensive clinical audit and research to enhance the evidence base
- reducing the risk of misinterpretation of records in different care settings, leading to improved patient safety and care

Interoperability is the ability for products or systems to function with other products or systems, in an unrestricted way. A lack of interoperability limits the exchange of information, has a negative effect on the care of citizens and is inefficient to system users. Good data standards allow for systems to be designed to interoperate with other products or systems.

The team also provides the development, maintenance and support of <u>NHS Information Standards</u>, listing them within the online <u>Data Dictionary</u>.

The <u>Diagnostics Data Service</u> team are working to improve the information quality of diagnostics service outputs to improve the provision of healthcare in the NHS.

Diagnostics services include:

- pathology
- endoscopy
- imaging
- physiological measures
- genomics

Terminology products

The core terminology products in the team are <u>SNOMED CT</u> and the <u>dictionary of medicines and medical devices (dm+d)</u>.

Snomed CT

SNOMED CT is a structured clinical vocabulary for use in an electronic health record. It represents care information in a clear, consistent, and comprehensive manner.

SNOMED CT aims to be implemented in primary care on a phased approach, starting in April 2018. Other systems involved in direct patient care should implement SNOMED CT before 1 April 2020.

<u>Dictionary of medicines and medical devices</u> (dm+d)

The dm+d provides:

- a unique SNOMED CT code for all drugs and devices
- a standard description for all drugs and devices
- additional coded information related to each device

Dm+d is used within:

- Electronic Health Records (EHRs)
- electronic prescribing and medicines administration
- pharmacy distribution
- Summary Care Records (SCR)
- eDischarge (hospitals communicating with primary care)
- <u>GP2GP</u> (general practitioner transfer of patients between practices)
- electronic Yellow Card Scheme (for notifications about adverse drug reactions)
- data extraction
- data reporting

It's covered by the SCCI0052 standard and the implementation date for this standard in all NHS systems was 30 June 2017.

Classifications

The clinical classifications OPCS-4 (for interventions and surgical procedures) and ICD-10 (for diagnoses) are NHS Information Standards. Both are mandated nationally for use across the NHS and consist of groupings of concepts (codes), plus definitions and business rules for their use.

Once clinical information is coded using these national classifications, it's then used in an aggregated, non-identifiable form, to allow for:

- statistical and epidemiological analysis
- reimbursement of hospitals
- planning of health and care services

NHS Data Model and Dictionary Service

The NHS Data Model and Dictionary Service is responsible for the development, maintenance and support of NHS Information Standards, contained in the NHS Data Model and Data Dictionary. This provides a reference point for approved Information Standards Notices to support health care activities within the NHS in England.

Copyright Licensing Service

The <u>National Clinical Content Repository (NCCR)</u> is a service operated by the copyright licensing service team, enabling users to access certain copyrighted clinical assessment tools and outcome measures for use within health and social care. There are currently 28 available, including the 'Brief Parental Self-efficacy Scale'.

Other tools are available directly from third-party owners, and this service signposts users towards these sources. Further details are available on the NCCR website.

Data Standards Assurance Services (DSAS)

The DSAS is hosted by NHS Digital. It supports the <u>Data Coordination</u> <u>Board (DCB)</u> and the Data Coordination Sub Board (DCSB) in providing detailed assurance and appraisal of proposals for Information Standards, Collections and Extractions (ISCE) requiring publication under the Health and Social Care Act 2012.

DSAS ensures that, within the development of an ISCE:

- all obligations under the Health & Social Care Act 2012 have been met by the developer
- any burden on the system is acceptable in relation to benefits
- the assured ISCE is aligned and complies with existing published standards
- risks and impacts are considered, addressed and mitigated, within the development of the ISCE
- the ISCE can be implemented across the system
- any data required to flow across the system as a result of the ISCE has a legal basis, addresses any information governance requirements and ensures that fair processing has been considered

The DCSB makes the recommendation to DCB to publish after scrutiny of DSAS assurance and appraisal of the proposal and acceptance of its recommendation.

Health and care organisations in England (including adult social care) must pay due regard to information standards published under the Health & Social Care Act 2012.

MOD Defence Medical Services Activities

The NHS Digital Defence Medical Services (DMS) Team provide consultancy support to the Ministry of Defence around delivery of armed forces healthcare.

Data Services for Commissioners

The Data Services for Commissioners (DSfC) team helps the NHS make the most of its data to improve NHS commissioning and ultimately patient care.

We do this by ensuring that commissioning decisions and the insights that support them are based upon robust, standardised data that has been processed efficiently and is accessed legally.

Under the Health and Social Care Act 2012 and the Care Act 2014, Commissioning Support Units (CSUs) do not have a legal basis for holding patient identifiable data.

DSfC teams are run by staff from CSUs seconded into NHS Digital. This allows us to access, analyse and process patient identifiable data, which is then used by Clinical Commissioning Groups (CCGs) to improve their commissioning.

We aim to reduce regional variability and ensure that all local commissioners conform to the same standards when applying for data from NHS Digital. We do this by encouraging them to use standard data application models.

Collect

We collect patient identifiable data and produce aggregated or anonymised outputs. CCGs use this information to improve their ability to commission appropriate and effective services.

Analyse and interpret

Commissioners analyse the data and use the insights for various purposes, including:

- **risk stratification** highlighting patients at risk of adverse outcomes, so we can contact and offer these patients care or intervention that may reduce this risk, for example those at risk of a cardiovascular event or of developing diabetes
- **invoice validation** before commissioners can pay providers of care or services they need to ensure that the activity claimed for each patient is their financial responsibility
- **needs assessment** helping commissioners understand the needs of the population and develop the type and distribution of health and care services that will bring the greatest benefits to most people

Distribute

The DSfC programme has identified legal ways for data to be shared with CCGs, local area public health teams and <u>NHS England</u> to help commissioners undertake their statutory duties.

Change

We aim to improve NHS commissioning by ensuring that commissioning decisions, and the insights that support them, are based upon robust, standardised data that has been processed efficiently and is accessed legally.

Data quality

The ability of data to improve health and care relies on its quality. NHS Digital's data quality team assesses the quality of data submitted by providers. We summarise findings within the Data Quality Maturity Index (DQMI) and report findings on a quarterly basis.

If poor data quality is identified by the DQMI, our team work with providers to encourage greater attention to data collection and submission.

A data quality steering group, made up of 5 arm's length bodies, meets regularly to discuss changes to the way data quality is measured, and investigates ways to improve data quality throughout the system. The arms length bodies are:

- NHS Digital
- NHS England
- NHS Improvement
- Public Health England
- Care Quality Commission

Analyse and interpret

NHS Digital's data quality team assesses the quality of data submitted by providers using four metrics:

- 1. coverage
- 2. completeness
- 3. validity
- 4. use of default values

The definition and calculation of these metrics can be found within the Data Quality Assurance Policy. Other metrics to help assess data quality are being considered by the data quality steering group with a focus on timeliness and consistency.

Commissioning Data Sets (CDS) are linked directly to payment, so providers have an increased incentive to submit higher quality data, leading to a better average quality for secondary care data.

Some of the latest data sets, however, need their quality assessed by members of our team. This is often due to the complexity of their design, and the limited time providers have had to improve their frontend collection systems and reporting processes.

Processes to interpret the quality of data sets are automated for some, for example CDS that have been in place for some time.

Distribute

Our data quality team assesses the quality of data submitted by providers and summarises findings in the Data Quality Maturity Index (DQMI).

Reports are provided in different formats, including CSV and Power BI, and are published quarterly on NHS Digital's website.

Separate DQMI reports are sent to providers for each of eight data sets to allow comparison.

Data quality reports are part of regular publications.

Change

Improving the quality of data collected leads to improvements in health and care services and better outcomes for patients.

We flag poor DQMI to a hospital trusts which often leads to improvement. If this is not successful, the concern is escalated to a more senior recipient.

The corporate data quality team offer help to providers to improve data quality. This is often flagged when a data set is submitted that is significantly different to previous submissions for that provider. This may be explained by a change in service provision or service responsibilities.

Staff within data set teams carry out most of the work to liaise with providers. We are using the Customer Relationship Management system (CRM) to record contact with providers about data quality, to give a broader picture of data quality issues across the system.

Data dissemination

Our Data Access Request Service (DARS) allows healthcare providers and researchers to apply for patient level data that is held centrally. We deal with requests for data sets, linked data sets, tabulations, bespoke linkage and patient tracking. We can provide access to a wide range of products and services, giving clinicians, researchers and commissioners the data required to help improve NHS services. Visit our DARS pages to make a request.

The DARS team makes sure we only supply sensitive patient level data to organisations that look after it according to <u>Information Governance</u> (IG) requirements, and use it to improve health and care services.

The aim of DARS is to prevent the inappropriate release of data, while making the data dissemination process as efficient and timely as possible. <u>Case studies</u> are available that illustrate the benefits of the process.

The process is split into application, approval, access, audit and deletion. Over the last three years, the process has been improved, resulting in a reduced average length of time to get applications approved while applications have increased by 35 per cent in 2018. Applicants often need significant support from the team to ensure that this is done legally, ethically and safely.

The <u>Independent Group Advising on the Release of Data (IGARD)</u> is an advisory body that oversees all new applications to DARS. They meet once a week and discuss approximately 5-10 applications.

The vision for DARS is to make the data dissemination process as quick and efficient as possible whilst preventing the inappropriate release of data and maintaining public trust. The DARS team have worked with the Research Advisory Group to tailor their advice to particular user groups. For example, they have produced a guide to obtaining data for health research, with the Medical Research Council and NHS Health Research Authority, aimed at researchers.

DARS sub-teams

The <u>Personal Demographics Service (PDS)</u> is the national database of patient demographic information in England, Wales and the Isle of Man, holding approximately 80 million records. The demographics team are part of the broader DARS team and provide support to the PDS and guidance on the use of the <u>NHS Number</u>. The <u>National Back Office (NBO)</u> sits alongside the demographics team and has the principal role of resolving data quality issues on the PDS.

The demographics team ensure a high-quality service that is relied upon throughout the NHS. Without this a significant clinical risk would exist, particularly for patients receiving services outside of their local area. Safeguards such as those around child protection, as well as systems for referrals between services and e-prescribing, rely fundamentally on the ability to accurately identify people across the system. This also supports the linkage of patient records for research.

Application

Organisations and individuals wanting to use certain kinds of data need to show they meet strict data governance standards by completing our <u>DARS application process</u>.

Requests to DARS are submitted through the <u>DARS online portal</u>. All requests must cover:

- the purpose of the request
- the legal basis around whether the data can be shared
- the security and governance around how the data will be stored and processed
- evidence of funding
- detailing any commercial enterprise that is involved

Requests for DARS are evaluated against a transparent set of requirements.

We provide guidance to customers to use our application process or applicants can contact the DARS team or attend one of our regular webinars.

We make charges to cover the costs of managing applications, processing data and providing access. <u>View our latest charging guidelines</u>.

Requests for access to data from analysts within NHS Digital do not need to go through DARS. Internal teams apply to the Information Asset Owner (IAO) responsible for each data set. Where data sets are produced, DARS will, where possible, load them into the Data Management Service, allowing external organisations to apply for access.

Approval

Applications first need to be approved by the IAO in the relevant department. The IAO will then formerly present the application to the Independent Group Advising on the Release of Data (IGARD). This group consists of information specialists, doctors, lawyers, researchers, ethicists and lay members.

Applications are assessed for purpose, whether consent is required and whether the correct legal basis is in place. In certain circumstances, it would be impractical to seek consent from patients to process their data in a specific way, although the benefits of doing so would be significant. This situation is recognised in law through section 251 of the National Health Service Act 2006 where the common law duty of confidentiality can be temporarily lifted if the benefits of doing so outweigh the risks of intrusion into privacy. For example, when linking the paediatric and national diabetes audits to create the National Diabetes Transition Audit, section 251 approval was obtained. Patient identifiable information was required to link patient records, and yet the time frame of 10 years and the large number of patients involved made seeking consent impractical.

All applications that are made under section 251 must also go through the Confidentiality Advisory Group (CAG) of the <u>Health Research Authority</u>.

Access

Once approval has been granted, a data sharing agreement must be signed between the applicant and NHS Digital, covering the legal responsibilities that recipients agree to abide by. Data from any patients that have opted out of sharing their data is removed. The data is then transferred to the applicant by secure file transfer or the Hospital Episode Statistics Data Interrogation System. It can take up to 60 days to process complex requests. A dashboard analysis of our performance in managing requests to DARS is in production and will be available soon.

Our <u>Data Release Register</u> is a record of all the data we have shared with other organisations. Published every quarter, it provides information on data released under <u>Data Sharing Agreements</u>. It covers activity for the preceding three months plus any amendments/additions to older releases.

Where applications are rejected, it's usually because there was no legal basis to share the data requested.

Audit

Not all requests are audited, but DARS reserves the right to undertake an audit with respect to the use and storage of the data to ensure the terms of the Data Sharing Agreement are abided by. You can see our recent audits.

The Director of Information Governance, Burden and Audit at NHS Digital is charged with auditing the compliance of customers to their responsibilities with the data.

Deletion

Following the expiry of a Data Sharing Agreement, data must be deleted safely in line with the guidelines outlined within the certificate of destruction. The certificate of destruction must then be sent to NHS Digital to confirm this has taken place.

Future work with data

The work we do has evolved over 30 years. It has developed into a complex range of standards, submission portals, data collections and dissemination mechanisms.

An even more complex system supports how providers collect data, and how it is used to improve health and care. We have begun major programmes of work to transform existing NHS Digital Data Services into a system that will make things easier for our stakeholders, improve data quality, and speed up the data cycle, to increase clinical benefits and value to the health and care system. You can read more about this work on our <u>Data outcomes for research and oversight page</u>, part of our response to Personalised health and care 2020.

We plan to merge existing data sets into a single data architecture which will include reusable modules, small groups of data, rather than large data sets, improving efficiency and flexibility. As a patient is treated, information about their care will flow from the organisation that Is providing the care, onto a single Data Services Platform (DSP). This will make data available more quickly, as well as making data submission easier for care providers.

The DSP will improve both access to data and data security by providing a Data Access Environment, a web-based portal giving secure access to users with the right permissions, and the ability to anonymise patient data. This will create the platform for a learning health and care system.

We will also deliver targeted advanced analytics to improve health and care through the innovative uses of data team.

We are working on these improvements now. The new system will be fully functional by 2020. It will automate, simplify, speed up and improve data use in health and care services, and it will reduce the cost and burden.

Data architecture

Across the whole health and care system, there are thousands of data sets flowing, with some duplication and limited re-use of data once collected. Linkage between data sets is time consuming and resource intensive.

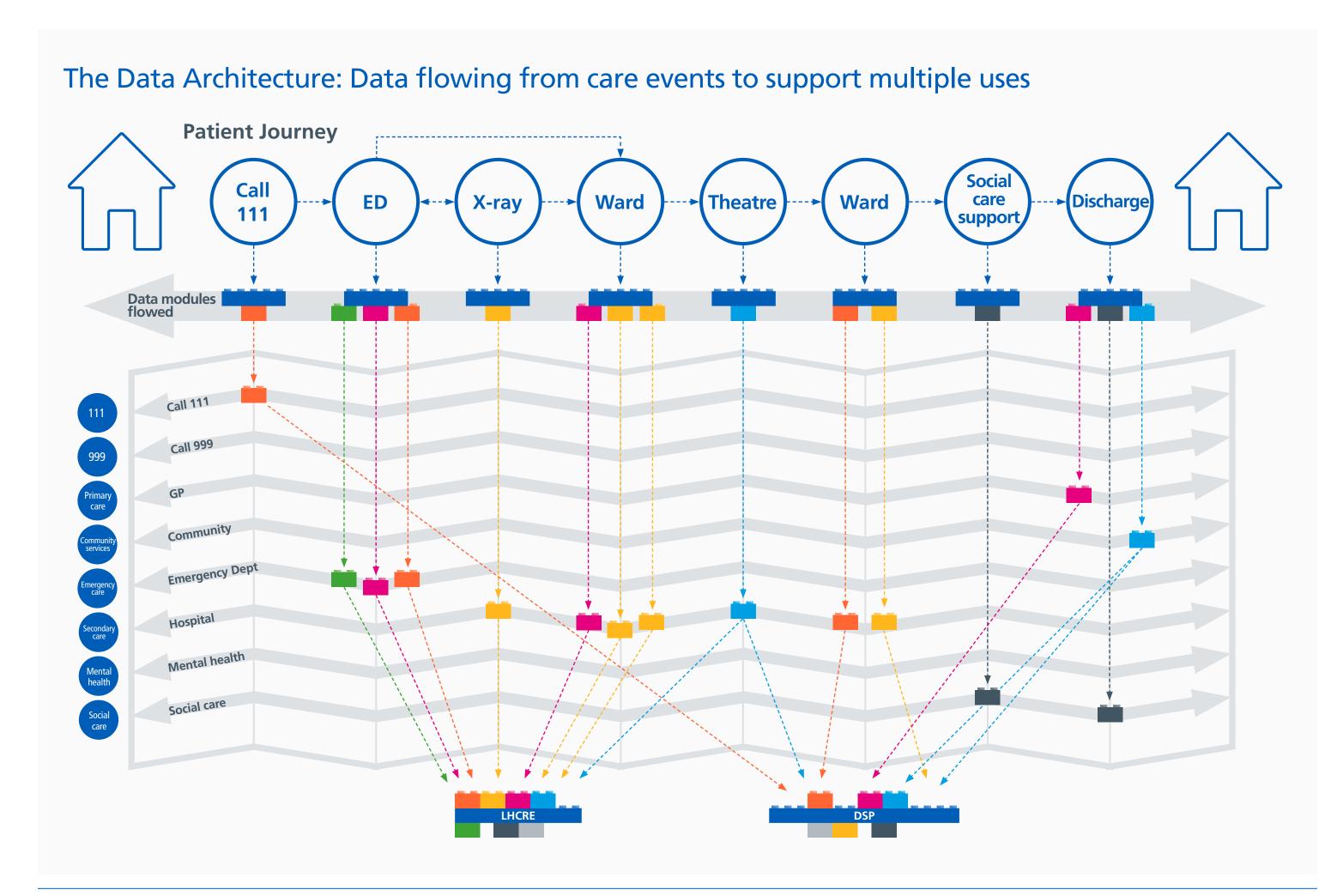
The Data Architecture Programme will replace this approach with a comprehensive and extendable modular data architecture. Existing data sets will be broken down into modules that contain a small group of fields describing a characteristic or patient level care event. This will enable sharing of health and care information as patients move between different parts of the NHS and social care.

Modules that are common across data sets will be combined to reduce duplication. Modules can then be linked to make existing data collections available, or to create new ones to answer a research question or inform a policy or management decision.

Our new, modular, data architecture will improve health and care by:

- reducing the time it takes organisations to submit data, by collecting data once to be reused many times, freeing up resources for frontline services
- making it easier, quicker and cheaper to collect and link data, improving efficiency
- creating faster and higher quality flows of data, which will make innovative analysis and interpretation possible
- making it easier to answer new questions by adding modules or combining them in new ways rather than creating whole new collections

Better, cheaper, faster and more flexible data has great potential to improve research, policy making, commissioning and management decisions.



Data Services Platform

The Data Services Platform (DSP) is a new system we are developing, that will transform the way that NHS Digital assembles, analyses, interprets and disseminates data. It will provide:

- a single landing portal for data from providers
- a way of identifying patients in multiple data sets
- a standard governance framework
- a system for de-identifying and re-identifying data
- a remote access environment enabling those with permission to access data without it leaving NHS Digital

This will allow data to be used more effectively for research into the prevention and treatment of disease and planning of health and care services. This is crucial for the productivity and sustainability of health and care systems.

This integrated system will:

- reduce the burden on providers and on those who access data by making processes more efficient and reducing duplication in data collection, submission, analysis and dissemination
- improve access to information
- speed up data flows for analysis, creating new analytic possibilities, including prediction, decision support, health surveillance and innovative research methodologies, with associated clinical benefits
- improve the security of health and care information storage and dissemination
- link health and social care data to provide a more complete picture of health and care

- enable safe connection and sharing of patient information across geographic boundaries and health and care settings – providing enhanced analysis of individual patient journeys and a clearer national view of health and care
- be the technical platform for a national Learning Health System

Protecting patient information

The DSP will end dependence on temporary data sharing arrangements and make sure external stakeholders have the right legal basis and appropriate level of access to patient information.

It will be a secure, centrally managed system that reduces the burden of local data transfers between providers and commissioners. The quality and safety of data sharing will be improved through a consistent collection process that removes the risk of identifiable information being sent to the wrong person.

DSP will provide a standardised, secure and seamless method of deidentifying, and where appropriate re-identifying, patient information. It will make sure that the sharing of identifiable patient health information is protected and reduced in accordance with our duties as the trusted safe haven for Personal Confidential Data (PCD).

The key components of DSP

DSP is made up of several individual components, which are being developed independently but will work together to transform the process from data collection to dissemination.

Component	What is it?	Business outcomes
Data Landing Portal	Web application that supports local data transfers between data senders and data recipients	Standardisation / consistencyImprioved safety and security
Master Patient Service	Patient tracing system that utilises the Personal Demographic Service (PDS) and enhanced matching algorithms	Improved match ratesIncreased reliability / efficiencyConsistent and automated
Data Architecture Management	System of processes, governance, policies and standards applied to incoming data to ensure consistent descriptions of data content and consistent processing	Improved data qualityGreater transparencyFlexibility and speed of on-boarding
De-ID / Re-ID	Nationally consistent de-intentification (De-ID) and re-identification (Re-ID) tool	Improved linkage capabilityProtection of patient privacy
Data Access Environment	Safe and secure data repository, enabling users (permission-based) to access data quicker whilst reducing the need for data to flow out of NHS Digital	Intuitive access to all data setsSecure linkage across data setsControlled dissemination
Core Platform	Single pipeline, supporting the consistent data colletion, processing and utilisation in line with the future operatin model for data services	Efficient standardised approachTransparent secure processingImproved data availability

Core Platform (Core data management engine)

The core platform provides the fundamental framework joining the different parts of the DSP together, to provide the capabilities that will transform how data is used in health and care. It is the underlying component that facilitates and supports data automation, governance, policy application, security and system efficiency.

Data Architecture Management (DAM) (Data Catalogue)

DAM sets the logic and rules that we apply to all incoming data. This means data can be processed consistently, lawfully and fairly, leading to improved data quality and transparency.

Master Patient Service (MPS) (Person-Match/Patient-Match)

MPS will trace patients to improve the matching accuracy of data we receive. A single, consistent matching process also creates a unique identifier that can be used for linkage across patient-level data. MPS uses improved algorithms and automated processes to improve the speed and success rate of traces.

Patients can visit multiple places where they register to receive care or treatment. They move, change marital status and go on holiday. At any given time, we can store hundreds of thousands of duplicate medical records in various systems across health and care. This can be challenging, but MPS will match the right patient with the right record with a 99% accuracy rate.

Data Landing Portal (DLP) (Data transfer alternative for email – Data Landing)

DLP is a web-based application that will improve security, standardisation and quality of data. It will replace current local email data transfers between providers and commissioners. It enables Data Services for Commissioners Regional Offices (DSCROs) to set up data specifications that are used to validate submitted data from health and care providers. If the data passes validation, the DSCROs can access

and download the data. If it fails validation, the data sender will be told what's wrong, so that they can correct the problem and resubmit, improving the quality of data.

This will also allow NHS Digital to see local data flows and improve how PCD is handled and shared.

De-identification (De-ID)/Re-identification (Re-ID) (Confidential Data Management)

When data is required for research and planning purposes, our deidentification process will protect patient privacy by 'de-personalising' patient records.

This process will enable us to easily link de-identified data across different care settings and geographic boundaries, creating a richer and broader data set that can be used for research and planning without revealing a patient's identity.

De-identified data can be re-identified if needed for direct care.

Data Access Environment (DAE) (Self-Serve Access)

The Data Access Environment (DAE) is a secure environment that allows customers to remotely access NHS Digital data through a single system. It enables enhanced linkage of de-identified health and care information across data sets and provides faster access to better linked data. As a single source for NHS Digital data access, DAE will reference a consistent data catalogue, apply appropriate information governance and use an agreed set of tools to retrieve data. Customers with the appropriate authorisation will be able to access the permitted data when they need it.

It ensures the right person, with the appropriate permissions gets the right data for their needs. DAE will remove the way we manually prepare and provide data, making access to data easier and quicker for users.

Innovative uses of data and data science

The Innovative uses of data (IUod) team aims to improve information analysis and reporting within NHS Digital, by using novel data science techniques. This will allow new insights from data that work to improve health and social care. Products will be focused on the needs of patients, clinicians and organisations within the health and social care sector, to increase the likelihood of delivering real benefits that will improve patient outcomes.

How to make better use of data

This will be achieved in three ways, by:

- 1. **getting better value from data** providing analytical services for the NHS and researchers, reducing the costs of procuring these services from somewhere else
- 2. **doing more with data** increasing the types of analysis of data to develop additional insights
- 3. **increasing access to data** using the power of technology to give insights to users and stakeholders in a way that they can understand, without relying on advanced technical or analytical skills

Analytics is critical to improving health and care and there is a shortage of skilled analysts in the sector. Most large NHS organisations have a dedicated informatics unit and most have additional contracts with external analytics providers. Much of their time is spent producing baseline analytics and most are only scratching the surface of how they might use data to improve care for patients (see this Cambridge University Hospitals NHS Foundation Trust (CUH) publication). Many smaller organisations would like to use more data, but do not have enough analytical capability or systems in place to keep patient level data secure.

The Innovative Uses of Data (IUoD) team are tackling these issues.

Baseline analytics

We undertake baseline analytics, such as:

- benchmarking
- dashboard preparation
- prediction
- data linkage

These can be used by many organisations, freeing them to focus on more bespoke work on improving care or efficiency.

Cutting edge analytics

In collaboration with partners, we will demonstrate cutting edge analytics to tackle complex clinical and administrative challenges in health and care.

Increased access to data

We will increase access to data by providing technology to deliver intelligence to stakeholders who do not have analytical skills and systems. This might include graphical interfaces to data and the ability to create natural language queries.

When we look at the data cycle, these areas of work will provide a significant increase in analytical capability, new functionality at the interpretation stage and quicker, more accessible, and more efficient ways of feeding data back into the system. This will help drive change to health and care.

Patient safety

Health and care organisations, clinicians and patients will use our new tools to help them make decisions about the health and care of groups and individuals. We will make sure that data is accurate and interpreted correctly, to avoid the risk of suboptimal care or harm to patients. To do this, we will develop systems to make sure patient safety and information governance issues are addressed throughout the planning, development, deployment and maintenance of our new tools and analysis.

We will also make sure there is early and ongoing clinical input, so that interventions are clinically effective and relevant, making front line teams more likely to use them.

Professor Trish Greenhalgh at Oxford University, in collaboration with NHS Digital, has created a self-assessment version of her framework for Nonadoption, Abandonment and Challenges to the Scale-Up, Spread and Sustainability of Health and Care Technologies. We will use this framework to assess interventions, determine how likely they are to be adopted, and simplify them where possible, to improve uptake.

Project themes

We aim to look at the following themes:

- **demand management** making use of linked data to evaluate the level of demand on STPs and Vanguards
- **predictive models** using novel analytics, including analysis of NHS111 data, to help providers understand the likelihood of rehospitalisation, and to improve cost benchmarking.
- data driven subscriptions analysing care pathways, and using technological advances to provide data to stakeholders
- **global analysis** developing tools that make international comparisons, and allow us to learn from worldwide best practice
- machine learning techniques exploring their potential applications
- mortality dashboards to improve the accessibility of data
- Trust picker/peer finder tool to be created with NHS Improvement
- **Pareto analysis** for example: a new pareto analysis dashboard for winter preparedness has been built and quality assured
- **risk stratification** addressing the legal, technical and data barriers of sharing data, to allow sharing of identifiable risk stratified patient information with GPs, and so improving patient care.

Collaboration with central bodies

The Virtual Data Science Centre, hosted by NHS Digital, is a collaboration between the Department of Health and Social Care (DHSC), Care Quality Commission (CQC), NHS England, Public Health England and others. Members meet once a month to share learning and progress and plan collaborations.

Support for the life sciences

Our data has huge potential for research, and we want to support the life sciences to use this to the full. We are working with other organisations in the health and care system to make sure the value of the work of the DIS team, and the data we hold, can be maximised.

Increasing the range and availability of data

We are working collaboratively to provide life sciences and research access to a wider range and volume of data. This includes:

- **Direct care data** a Life Sciences Direction is being prepared, that would make available data including <u>Spine data</u> (1bn messages a month), <u>NHS e-Referral Service (e-RS)</u> (550k referrals a month) and <u>pathology messaging</u>, via the Data Access Request Service (DARS), providing a new dimension for researchers to study
- **GP data** we are supporting the cross-system 'GP data for research working group', set up by the <u>Office for Strategic Coordination of Health Research (OSCHR)</u> Informatics Board in response to feedback from researchers, such as from the recent <u>UK Biobank International Phenomics Conference</u>
- <u>Prescribing data</u> we are actively working on methods to make both hospital and community prescribing data available, as access to hospital data is currently limited
- <u>Public Health England (PHE) data</u> an implementation board has been formed to take forward findings of the recent <u>McNeil review</u>, on bringing PHE data together with NHS Digital collections
- National clinical audits and registries we are working to make more of this data accessible for research
- NHS data registers we've launched an external service of reference data, in partnership with the Government Digital Service, which lets researchers access this data via an API

• NIHR Health Data Finder (HDF) – we support this initiative to help researchers find out about data sets that can be used for research, and how to access them

Streamlining legal and ethical approvals

We are working with the <u>Medical Research Council Regulatory Centre</u> and the <u>Health Research Authority (HRA)</u> to simplify the process for researchers to get legal and ethical approvals, by:

- contacting research studies to make sure they have considered their legal basis for processing data from NHS Digital, in line with General Data Protection Regulation (GDPR)
- continuing work with partners, including PHE, <u>Clinical Practice Research</u>
 <u>Datalink (CPRD)</u>, Health Research Authority (HRA) and <u>Confidentiality</u>
 <u>Advisory Group Health Research Authority</u> (HRA CAG), to harmonise
 and streamline approvals at macro and micro level
- beginning discussions with the <u>Information Services Division (ISD)</u> in Scotland, to understand opportunities to learn and share best practice

Supporting clinical trials

We already provide support for clinical trials, such as the ORION-4 clinical trial at Oxford University, and are consulting with partners including National Institute for Health Research (NIHR), HRA, Cancer Research UK, and CPRD, on providing more services to help clinical trials find out about feasibility and recruitment (identification and optional invitation) of participants. We've had positive feedback welcoming these proposals, and we're looking into whether it would be useful to flag participation in a clinical trial on a patient's health record.



Data, insights and statistics

Find out more www.digital.nhs.uk/DIS

Information and technology for better health and care

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