



# Joint Foreword

Through '[Care in the Digital Age](#)', published in October 2021, we made a commitment to develop Scotland's first dedicated Data Strategy for Health and Social Care. The COVID-19 pandemic demonstrated the important role that maximising data can have in the delivery of health and social care. But it also highlighted the significant gaps in data, particularly in relation to unmet need in social care.

Our Strategy set our vision and ambitions to ensure that the data landscape is best placed to support key priorities. These ambitions will help us in supporting key missions across the health and social care sector, such as improving population health and reducing health inequalities as part of [the Care and Wellbeing Portfolio](#) approach.

This first Data Strategy for Health and Social Care lays the groundwork for transforming the way we as members of the public access and use our data to improve our own health and wellbeing. It also sets out the foundations for improving how health and social care is delivered including delivering improvements

to our systems and infrastructure. Our Strategy has applied the principles of the [Scottish Approach to Service Design](#). This means that people are at the heart of every decision that has been made, and will continue to be at the centre of the Strategy as we evolve and develop it.

The challenge to improving something as complex as our data landscape is understanding our current situation and identifying the priority actions to reach our vision for the future. This first version of the Strategy will not provide all the answers for everyone and we know there is much more that will need to be done over further iterations. Taking a step-by-step approach allows us to adapt and pivot year by year, responding to external factors that may influence change. It also allows us to evolve our approach to delivering this ambitious vision, whilst setting out a clear expectation on the ethical, transparent and trustworthy approach to using and accessing data that we expect across all data initiatives.

Using data to improve health and wellbeing in Scotland will require buy in across our health and social care sector and beyond. We look forward to working with you all to realise the ambitions of our Data Strategy and improve the lives of people in Scotland through better use of data.



**Humza Yousaf MSP**  
Cabinet Secretary for  
Health and Social Care



**Councillor Paul Kelly**  
COSLA Spokesperson for  
Health and Social Care

# Foreword from the Chair of the Data Board for Health and Social Care

The publication of 'Care in the Digital Age' in 2021 presented a unique and important opportunity to clarify and make explicit our aims and goals to improve the quality of health and social care data, and to make it more accessible and shareable. This Data Strategy supports the aims of the NHS Recovery Plan, work to improve population health outcomes through the Care and Wellbeing Portfolio approach, social care reform and the proposed delivery of a National Care Service. By supporting the transformation of our health and care system using data, we will be better able to identify and address the gaps in data and the challenges of data quality.

The Data Strategy will ensure that health and social care data supports the delivery of health and care services, and that it does so in a way that empowers citizens and staff and supports innovation and research.

The Health and Social Care Data Board has been set up to provide oversight and governance of the Data Strategy and its associated delivery plans. Membership has been drawn from a wide and diverse community representative of health and social care to ensure the ambition and reach of the Strategy is achieved in a timely way. It also ensures close alignment with Scotland's Digital Health and Care Strategy, as well as supporting the legislation and ambitions of the new National Care Service.

The growing voice of the research and innovation community, including current and prospective commercial and industry partners, for access to more timely and validated data reminds us of the vital role data must play in delivering better and more equitable outcomes for the people of Scotland and to support our economic growth as a nation.



This Strategy will be a dynamic, evolving, living document to adapt and respond to new and emerging data challenges as well as embracing the need to improve what we have already started when needed. We are committed to delivering the long-awaited improvements that can support short term goals and quick wins. We are also committed through the Strategy, to working out how to address inequalities in the system and some of the complex challenges we know exist in providing good enough, near real-time data as well as validated, robust data for the purposes of service planning and evaluation, and research and statistics.

We must do more to develop the digital and data skills of our system leaders and deploy them where they can affect the most impact and change by working with NHS Education for Scotland, the Local Government Digital Office, and the Scottish Social Services Council. We must also develop and utilise

the wider leadership skills of our workforce, including quality improvement and health and care recipients' safety; and systems leadership through the confident and effective use of data.

Public trust and the ethical use of data for public good is central to this Strategy. We are working alongside colleagues across government to ensure the principles of Open Government are followed as we define and publish key, ethically sound and publicly trusted principles to support the unlocking of the social and economic value associated with the use of public sector personal data in the service of the people of Scotland. In addition, artificial intelligence and machine learning solutions and products will be at the core of data-driven innovation, enabled by our shared ambition and pragmatic approach. The vital work to be taken forward following the review of information governance will further provide a strong, future-proofed

platform for change that will give assurance to the public, and enable those managing and controlling data to work more effectively.

As we launch this first Data Strategy and focus on delivery of its aims and priorities, I invite you to join us and make change happen so that we can achieve our shared ambitions over the coming years.



**Carol Sinclair**

Chair of the Data Board  
for Health and Social Care

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# Introduction

Developing the first Data Strategy for Health and Social Care in Scotland is a shared Scottish Government and COSLA commitment, as set out in [‘Care in the Digital Age’](#) and Scotland’s Programme for Government. This Strategy is the result of extensive stakeholder engagement and public consultation throughout 2022. It seeks to make the best use of Scotland’s health and social care data to improve people’s health and wellbeing through improved, more sustainable, health and social care services.

It remains the Scottish Government and COSLA’s ambition to:

- ◆ empower the Scottish people with greater ability to access and have greater control over how they manage their own health and social care data where it is safe, legal and appropriate to do so,
- ◆ and for health and social care staff to have rapid access to the information they need to deliver the best possible care.

This Strategy is the first step in meeting a greater ambition to improve access to, and sharing of, health and social care data for individuals (adults and children); and across intricately linked areas, such as housing, social security, and education. The Strategy sets a framework for the ethical, transparent use of data by health and social care providers. It also identifies and addresses the first set of challenges we need to resolve before we can begin to address the more complex and detailed challenges that we know exist.

Considerable work is already under way across health and social care to improve the way we gather, store, and open up access to data. The proposed national ambition to develop a National Care Service for Scotland will potentially bring significant opportunities to transform integrated care and set a new direction for how care can be delivered in a digitally-enabled, data-driven future. For the first time, the range of strategic commitments around the use of data are being brought together under one dedicated health and social care Data Strategy.

Similarly, there are opportunities to improve citizens’ access to services and data as key contributors to improving population health and supporting a reduction in health inequalities including through the Care and Wellbeing portfolio approach.

This Strategy introduces, and commits us to, a shared set of ethical principles which will be central to all data considerations going forward. These principles apply equally regardless of whether it is an NHS organisation, a social care organisation, an academic body or a research company looking to utilise health and social care data:

- ◆ We will maintain a people-centred approach and strive to ensure data is collected, organised, and made available in a manner that is intended to suit the individual’s needs, and supports compassionate care.
- ◆ We will work to keep health and social care data safe and secure in order to maintain public confidence and trust in our management of data.

- ◆ We will always be clear about the intended benefits and potential risks that arise from our use of health and social care data for individual care, performance, and research.
- ◆ We will improve and increase individuals' involvement in the development, design and improvement of health and social care data use in Scotland, where it is reasonable and appropriate to do so.
- ◆ We will take an equalities and human rights-based approach, drawing on [the PANEL principles](#), ensuring we always maintain a choice in non-digital routes to access health and social care data.

There are complex and sensitive challenges to explore when it comes to data, and in the levels of digital maturity among health and social care organisations. The social care sector alone has varied levels of data maturity between organisations. There are 32 local authorities holding care data and approximately 1,150 private, third, and

independent sector organisations delivering adult social care services in Scotland. The majority of these (60%+) are small scale services employing fewer than 50 people. They are unlikely to have significant internal resources in terms of IT or HR. Their capacity to move to standardised systems and provide more timely data will be limited, and this needs to be taken into account when planning any changes to staff recording and systems. Scottish Care details the data landscape in independent social care in the [June 2021 report: Seeing the Diamond in Social Care Data](#).

Similarly, there are several thousand private organisations involved in the delivery of NHS care, from high street pharmacists and dentists through to local GP practices – all of which are legally responsible for the data they use. Making data flow effectively across thousands of different organisations, in a safe, secure and transparent way – whilst opening up greater access to the public – is an enormous undertaking.

This Strategy recognises that a single document will not suffice. Instead, the Strategy will be a multi-year effort requiring regular updates and refinement with multiple iterations published over a five-year period. The Strategy document sets out the ambitions and principles with fuller details available in associated appendices. Actions resulting from this Strategy should not be viewed in the short-term: we acknowledge that to truly achieve our vision will require time and incremental change as funding and resources permit. In taking this approach, we will learn from our shared experience and our ongoing stakeholder engagement and participative work with the public to ensure that deliverables are appropriate, proportionate, and achievable.



Consultation and engagement identified challenges within eight priority areas for action:

- ◆ ethical approaches of data;
- ◆ data access;
- ◆ talent and culture;
- ◆ protecting and sharing data;
- ◆ technology and infrastructure;
- ◆ information standards and interoperability;
- ◆ creating insights from data, and
- ◆ supporting research and innovation.

## What do we mean by health and social care data?

In this Strategy, health and social care data is defined as any information about an individual or many people which is needed by any health setting, social work, third and independent social care organisations, family or unpaid carers to help to maintain or improve people's health, welfare and wellbeing. It is information generated by individuals or agencies in the health and social care sector. This can be extended to people using everyday technologies (e.g. fitness trackers), health and social care services or researchers. It can be used to provide care and support or plan services, identify and manage risk, protect individuals or the public. It can also be pooled together ('aggregated data'), to produce statistics or management information. You can read more about the definition of data in the UK Government's National Data Strategy.

This Strategy addresses both the primary and secondary uses of health and social care data. Primary use of data means the processing of personal electronic health data for the provision of health services, to assess, maintain or restore the state of health of the natural person to whom that data relates. This includes the prescription, dispensation and provision of medicinal products and medical devices, as well as for relevant social security, administrative or reimbursement services. Secondary data is the use of aggregated health data from population-level sources such as electronic health and social care records, health insurance claims data, and health registry data to improve personal care planning, medicines development, safety monitoring, research, and policymaking.

# Our Vision

To improve the care and wellbeing of people in Scotland by making best use of data in the design and delivery of services.

## Our ambitions

We will achieve our vision by delivering on three key ambitions:



**To empower the people of Scotland** by giving individuals clear and easy access to, and the ability to manage and contribute to, their own health and social care data where it is safe and appropriate to do so.



**To empower those delivering health and social care services** to have the confidence and ability to gather, safely use, and share data to sustainably improve services and ensure outcomes are being met.



**To ensure fit for purpose data is readily accessible** through secure and safe means for planning, research and innovation. Data will be used for the benefit of individual wellbeing and the public collectively, including the development of new and innovative ways of working, improving care, developing new treatments and technologies.

We have identified eight priority areas for action. Each of these areas is discussed in more detail in the body of the Strategy. Each area sets out the *headline commitments* we want to work to. Annex A details our *Deliverables* which are specific programmes and pieces of work that will be undertaken and counts as our initial Delivery Plan for 2023-24.

**Vision**

To improve the care and wellbeing of people in Scotland by making best use of data in the design and delivery of services.

**Ambitions**

<p><b>Empower People</b></p> <p>by giving greater access to and control over their health and social care data, where it is safe and appropriate to do so.</p>	<p><b>Empower Professionals</b></p> <p>to have the confidence and ability to gather, safely use, and share data.</p>	<p><b>Support Research and Innovation</b></p> <p>by ensuring data is readily accessible through secure and safe means for research and innovation.</p>
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**Priority Action Areas**



# Ethical Approaches to Data

**We want to embed an ethical, open, and human rights-based approach to the use of health and social care data in Scotland which maintains public trust and confidence.**

## Background

Ethical principles and approaches to data are well documented<sup>1</sup>. The Scottish Government, along with partners, has considered the ethics of data use throughout COVID-19, with [a set of ethical values and principles](#) developed to support the use of public data in managing the pandemic. We believe these principles will provide a solid foundation for our use of health and social care data.

This approach is further articulated in the work of the [Ethical Digital Nation](#), a report which recognised that public trust in the way we use health and social care data is essential. To ensure this trust we must embed an ethical, open and human rights-based approach to using data, themes we explored ahead of developing this Strategy with the public [through our Data Dialogues](#). Additionally, [the Caldicott principles](#) form an important part of the ethical governance of health data. The Health and Social Care Standards provide this for social work and social care.



1 For example, the UK Government Data Ethics Framework or the Ethics Self-Assessment Tool used by the Office for National Statistics.

[Data Ethics Framework - GOV.UK \(www.gov.uk\)](#)

[Ethics Self-Assessment Tool – UK Statistics Authority](#)

## Where we are now

In addition to the extensive engagement work undertaken in the development of this Strategy, we continue to explore the priorities, ideas, perspectives, and issues of importance to stakeholders. This includes:

- ◆ Public engagement to explore and understand public awareness and views on ethics and the use of data.
- ◆ A [specific programme of 'Digital Citizen' public engagement](#) in partnership with The Health and Social Care Alliance Scotland and Young Scot.
- ◆ Bespoke engagement on specific related workstreams such as the Digital Front Door.

In addition to our own engagement work, we are aware of significant activity that will also help inform our approach and future priorities. For example, in October 2022 ADR UK in collaboration with [Office for Statistics Regulation \(OSR\)](#) published a [UK-wide public dialogue](#) exploring what the public understands as 'public good' use of data for the purposes of research and generation of statistics.

Closely linked is wider work on digital participation and inclusion, conducted as part of the Digital Strategy for Scotland and recognised as critically important for the health and social care sector in 'Care in the Digital Age'. Ultimately, people will not be able to maximise their use of data if they are unable to access, or cannot meaningfully use, digital technology. A key strand of this is initiatives like the [Connecting Scotland](#) programme. The Scottish Government will continue to invest in digital inclusion, enabling as many people as possible in Scotland to interact with their health and social care data digitally, where they wish to.

We also acknowledge that data also has the potential to exacerbate existing inequalities in our health and social care sector. We recognise the need to collect and analyse data intersectionally in health and social care because inclusive data is intersectional. We will be transparent and use consultative methods when considering new methods of collecting and using data because we know that people who make analytic decisions about data are often not the people whose lived experience is represented in the data. Privacy, particularly of protected characteristics like ethnicity, will be treated sensitively to prevent bias or discrimination. We will assess the fairness and impartiality of data processes and work with experts in systemic racism, disability, and social policy to ensure appropriate analysis, and to mitigate bias and discrimination. Scottish Government has accepted the [recommendations of the Expert Reference Group on COVID-19 and Ethnicity](#) and will be taking forward specific actions to address them.

## Where we want to be

The principles for the collection and use of health and social care data must be:

**Beneficial:** Start with a clear articulation of need, public benefit, and risks.

- ◆ We must articulate and show evidence of how using certain data is to benefit the individual or group, and relates to the quality and impact of services received. And be assured that the public recognise the same risks and benefits.

**Responsible:** Recognise the need to behave in a trustworthy way with the use of data and digital technology across systems and processes.

- ◆ We must reach a balance between the benefit of collecting personal or sensitive data to provide personalised health and social care services, while protecting an individual's rights.

**Accountable:** Be accountable and transparent to independent scrutiny and oversight, use reliable practices and work within our skillsets.

- ◆ We must demonstrate accountability and provide evidence that we are adhering to these principles to members of the public and outline the governance groups that have oversight, and are accountable for the ethical use of data.

**Insightful:** Our health and social care data contain insights that can help us improve services. However, we must identify where there are limitations in the data and digital technology being used, and recognise unintended bias, while identifying and ensuring that approved mitigations are in place.

- ◆ We must be honest about the make up of the datasets we use, what flaws may exist, the level of quality, and any bias that may be present – and how this can be addressed.

**Inclusive:** Ensure that data is accessible in formats that are appropriate for everyone, and that access to data is not limited to digital means.

- ◆ To ensure that we are truly inclusive in our approach to giving access to data, we must clearly communicate that digital access is not the only way to gain access to your health information. We commit to providing comparable ease of access for those without digital means and those with digital access.

**Necessary:** Identify reasonable and proportionate requirements to meet the need.

- ◆ We must clearly articulate the ethical rationale for collecting and using data sets.

**Observant:** Implement all relevant legislation and codes of practice.

- ◆ We must clearly demonstrate the legal basis for collecting, storing and analysing data, showing that it is in line with legislation and codes of practice.

**Widely Participatory:** Embed the view of the public, through the routine use of public participation and co-design.

- ◆ We must identify the key points at which the public and or representatives of the public should be engaged. Public engagement should be transparent and open to scrutiny, showing how people's views will be incorporated and where possible, how we can co-design our approaches with them.

These values will guide the collection, storage and use of Scotland's health and social care data, no matter the setting or individual interacting with the data. A bespoke approach to each case is required, ensuring that the level of scrutiny applied is appropriate to the situation presented.

We know that some opportunities have the potential to revolutionise the way we deliver health and social care. They may also require a greater degree of scrutiny and have ethical challenges specific to that technology to consider. For example, AI technologies present unique challenges<sup>2</sup>.

Ethical approaches to data are core to each of the other seven priority areas of this Strategy. As such, our commitments to ethical working are set out in the introduction to our Strategy and underpin all other commitments in this Strategy.

2 The Ada Lovelace Institute, who hold a standing invitation to the Data Board for Health and Care, have undertaken a number of projects exploring the ethical use of AI, including specifically in health settings. <https://www.adalovelaceinstitute.org/our-work/>



# Data Access

**We want to empower individuals and professionals to make better informed decisions by providing access to the right data at the right time.**

## Background

People should have clear and easy access to, and the ability to manage and contribute to, their own health and social care data where it is safe, legal and appropriate to do so. This includes the ability to view and update personal information such as contact details, and to view and request updates to information contained in records such as test results, letters, treatment, and care plans – whilst recognising there will be perfectly valid legal reasons where some data is not accessible to an individual (or is accessible but cannot be changed). It is also essential that staff within the health and social care sector can access the right data at the right time to provide the right care and support.

Empowering people in this way will support greater self-care and enable them to ensure that their records are accurate. It would also create transparency about decisions that are made about the care and the support they receive, enabling them to better access information on their wishes, choices and decisions made about them, and enabling them to better participate in their own care. To truly empower people, we must ensure that the data is presented to people in a way that is accessible and understandable.

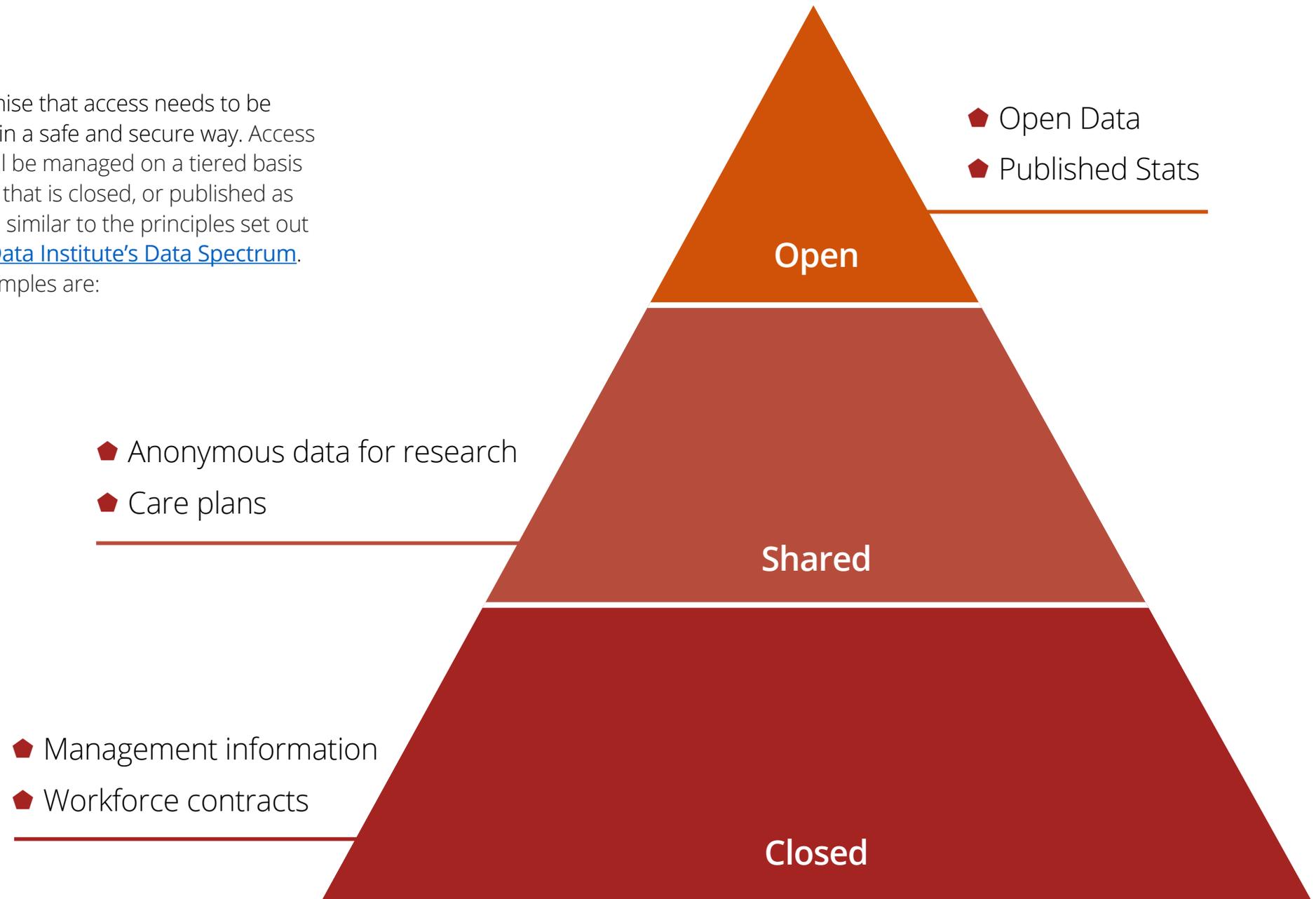
We want to ensure that health, social care and social work staff have access to the data they need, at the right time, to provide the right support to the people they serve. We are aware that information systems do not offer universal accessibility to make it easier to share information; this strategy seeks to illustrate how current

systems can maximise information-sharing to support practice as we consider future innovations to meet this need.

We also recognise that there is benefit in providing access to health and social care data across wider public sector services such as housing, prisons, and social security services to safely improve outcomes. This is in line with our need to improve the quality and completeness of its data and consider the potential of data linkage to improve accountability for outcomes rather than inputs alone. One example of this cross-sector access is the sharing of homelessness data with hospitals to enable targeted support, helping people to secure accommodation and ensuring they are supported with ongoing care after being discharged from hospital.

We recognise that access needs to be managed in a safe and secure way. Access to data will be managed on a tiered basis from data that is closed, or published as open data similar to the principles set out in [Open Data Institute's Data Spectrum](#).

Some examples are:



## Where we are now

**Data access for individuals** is relatively light across Scotland, and mostly relies on people formally requesting access to their information in a time-consuming way. There are notable exceptions: in some areas, people can already provide information about their wellbeing through portals or remote monitoring technologies, but our ambition to enhance citizen access will improve this further – for example, in the same way that the whole population can now access their Covid Vaccination status. Another example of empowering individuals by allowing them to actively contribute to their record is My Diabetes My Way (MDMW). MDMW currently supports people to access their health record online or to upload a reading about their wellbeing. There are opportunities for this to be developed for other conditions or in different settings. Learning from MDMW's success we want to further expand access to data.

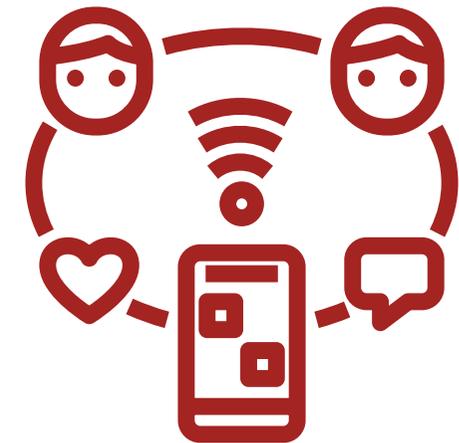
**Open Government.** Through the Open Government Partnership and [Scotland's Open Government Action Plan](#) the Scottish Government has committed to:

- ◆ Enhancing and increasing the involvement of people and staff in the planning, designing, and improvement of health and social care services in Scotland.
- ◆ Supporting Government openness, transparency, and empowerment through open data.

When opening up access to data, where appropriate we will ensure that we publish data that is useful, relevant, and accessible for the public. Public bodies are at different stages of publishing open data. Examples of national open data publication includes:

- ◆ PHS – [Scottish Health and Social Care Open Data](#)
- ◆ Scottish Government – [Statistics.Gov.Scot](#)
- ◆ Improvement Service – [Spatial Data Hub](#)

Organisations such as councils also publish open data locally for example on their websites.





## Case Study - Innovation with Open Data

Open data published on the COVID-19 pandemic was used to create an innovative website to make the data accessible to people with visual impairments. Volunteers from the [Scottish Tech Army](#) created a site that played musical notes to create sonic graphs of COVID-19 cases, allowing visually impaired people to interpret COVID-19 data in a way that worked for them.

**Data access for professionals.** We want to build on the excellent work that is already under way across the sectors. For example, in health, good progress has been made on the sharing of data such as the use of Electronic Health Records and uptake of a clinical portal that provides clinicians with a single view of relevant patient data. However, we recognise that there is still more to be done, particularly where social work and social care services are involved, where information sharing is crucial for support provision in the community.

We are already investing in the infrastructure we need to improve access to, and the use of, data. As above, work is under way to improve GP IT systems and the technology used to store and share data. This will enhance access to GP data, and enable quality data to be stored and reused many times for multiple purposes, to allow us to better understand and improve the provision of care. Improving access to primary care data will serve wider purposes such as enable the monitoring of the health of the population, and support the

planning and delivery of both primary care at a national and local level, and data use in approved research.

Another example of improving data access for professionals across health, social care and social work is collaborating to implement federated access to Microsoft Office 365 across organisations. Empowering the use of tools such as shared calendars, or allowing access to data storage environments such as team SharePoints, is a straightforward way of sharing important workforce data and improving integration and collaboration across multiple organisations. The Scottish Government and Local Government are also working in partnership on the shared commitment within the Digital Strategy for Scotland to increase the use of re-usable common solutions within the public sector.

## Where we want to be

**Data access for individuals.** Work is underway to develop a Digital Front Door which will provide members of the public with digital access to their health and social care information. This will make it easier for people to view the information that is held about them and to exercise their right to update this in instances where the information held is incorrect. Through engagement, we will confirm data sources and data sets that are safe to be consistently shared. Data access will be enabled through the planned Digital Front Door.

To provide safe and secure access to data via digital methods, work is underway to develop a secure service for individuals to prove who they are as set out in [A changing nation: how Scotland will thrive in a digital world](#).

Digital Front Door will provide further opportunities to share data for public benefit. For example, sharing health and social care data with Social Security Scotland to automate the process of getting benefits, or sharing health data with prison services to support vulnerable people such as those who require access to treatment and support for addiction or mental health.

Where information is published for people and it is proportionate to do so it will comply with the [European Accessibility Act](#) and the [W3C Accessibility Principles](#).

**Data access for professionals.** Feedback from the Independent Review of Adult Social Care heard that people had to retell their story multiple times to different professionals. The Scottish Government and COSLA are committed to develop a nationally consistent, integrated, and accessible, electronic social

care and health record. The integrated record will support people to tell their story once and ensure that staff have the right information at the right time to deliver the right care.

To improve professionals' access to the right data at the right time we will set out principles to drive up discoverability, accessibility, interoperability, and reusability. This will make accessing data across organisations easier and enable better, more timely access to essential data across organisational boundaries, supporting staff to provide the best care possible. This will include making use of the planned new Community Health Index (CHI) system to allow better matching of data and enable improved data sharing across the health and social care sector.



## Case Study - CHI Matching

The single community health and care system will ensure that an individual's demographic details recorded include a valid CHI number. This is achieved by the implementation of an active CHI interface.

There are several benefits to those receiving care as well as those responsible for delivering care. This includes the compilation of a single community care record ensuring that lack of access to data is less likely to be a cause of inappropriate or inadequate care provision to individuals.

Practitioners and managers are given access to care history data to support immediate patient care and to understand, for example, longer term trends of service provision. The timely and straightforward access to documents complementing electronic data capture means that it is then available wherever care is administered.

Finally, and crucially, integrated systems will help to reduce duplication, save time, and improve safety, through faster and more efficient sharing of information. The new system is expected to go live in Argyll and Bute Council in 2023 to support them with their existing CHI link between social care and community health care records.

When opening up access to data and creating new systems we will adhere to the legal duties and powers that exist across protective and children's legislation. We recognise the rights and responsibilities that exist for individuals, their carers or proxies, and the interplay these will have in contributing to and extracting from a data sharing system. To ensure that this strategy is taken forward within this legal framework the tiers system of access will require to reflect questions at initial access to ascertain whether powers exist to enable the individual to enter the individual record.

Our Commitments	Who is it for?
When opening up access to data for individuals and writing publications about health and social care data, we will describe data and information using plain language.	Public
We will seek to ensure that digital means of accessing data allow those who do not have the desire/capacity/capability to access their own health and social care data to delegate access. We will do this in line with established processes and legislation for determining when proxy access is appropriate.	Public
Our analytic communities in Scottish Government, Local Government and PHS will expand access to analysis and insight of health and social care data by following an open government approach to accessing data. This will enable people to be better informed of their care and to help manage public expectations.	Public Research & Innovation
As set out in Scotland's Digital Strategy, we will make more of our health and social care data available openly where it is safe, practical and lawful to do so. This will include providing an improved framework for open data to enable non-public sector organisations to access data in a safe way. This will support linking and usage of data to develop new insights and support innovation.	Research & Innovation



# Talent and Culture

**We want to attract, develop, support, and retain a workforce that is confident and competent in the use of data. This includes all staff having essential data skills that help us all to better manage the information we all depend upon, and advanced data skills that help us to create more insight from data.**

## Background

The transformation of health and social care services is reliant on the successful use of data and digital technologies. This means that health and social care staff, whatever their role, need to be able to interpret and apply data effectively, securely, and accurately. This requires an ongoing commitment to attracting, developing, supporting, and retaining a workforce that is confident and competent in their use of data and digital.

There is more to be done to support staff to understand the importance of collecting and using data to improve and transform care provision. Without their input, the quality and quantity of data required will simply not be collected.

We need to make data collection easy and proportionate for those working in health, social care and social work. By embedding it in the care delivery process, supported by appropriate digital technologies and solutions that drive cultural change, we can ensure these are more time-efficient and more reliable than non-digital alternatives.

## Where we are now

The [Health and Social Care: National Workforce Strategy](#) made a commitment to ensure that health and social care have the right workforce with the right skills at the right time. We recognise that we need to improve the data literacy skills of the health and social care workforce to increase capability so that data can be analysed, interpreted, and

utilised to inform decision making. The level of skill required will range from all staff having a basic level of understanding of the value and application of collecting, recording, and sharing quality data in their specific role, to providing specialist training for staff in data specific roles. Regardless of the role, everyone working in health and social care should understand the importance of data.

The onset of the pandemic demonstrated that the workforce can adapt quickly to digital technology changes and adopt flexible ways of working to deliver services as effectively as possible. We need to build on that momentum and support the ongoing flexibility and cultural change that is required.

## Where we want to be

Scotland's Digital Health and Care Strategy made a commitment to ensure that data and digital skills are core skills for staff. The Building Digital Skills and Leadership Programme is focused on the skills required by staff to adapt to and use digital technology ethically. This includes ensuring that we equip staff with the appropriate level of data literacy to ensure the safe and secure application, handling and analysis of health and social care data. A detailed action plan is currently being produced to measure progress against the programme. This will provide a focus for the programme going forward, to ensure that data and digital skills gaps are addressed throughout.

We also need to meet the needs of specialist groups of staff, for example:

- ◆ **Information Governance.** The review of the Information Governance Competency Framework will explore and create tailored learning and development options for staff at all levels across health and social care, but also support the needs of those staff specialising in this area.
- ◆ **Knowledge Information and Data Workforce (KIND).** KIND has created a virtual learning academy to support implementation of key priorities and scale-up of digital innovations within this specialist workforce area.
- ◆ **Artificial Intelligence (AI).** We are working in partnership across the UK to explore AI and what it means for our workforce. This includes understanding how data supports and helps develop decision support tools for front line staff and individuals self-managing their care, for example the [Right Decision Support Service](#).

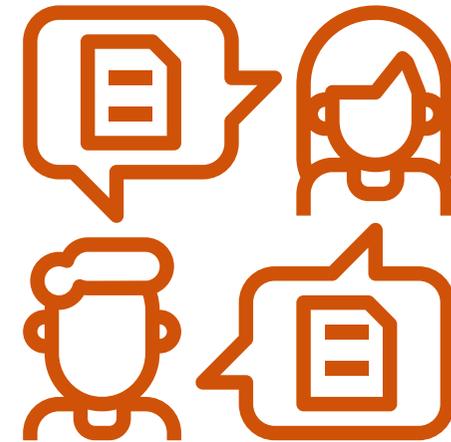
- ◆ **Digital Data and Technology (DDaT) Framework.** We are exploring the application of the DDaT Framework to support consistency across the health and social care sector and provide specialist staff with access to nationally provided learning and development opportunities.
- ◆ **Executive Leadership in a Digital Age masterclasses.** To equip Board-level executives and non-executives with the understanding of digital health, governance and leadership skills necessary to support transforming service delivery.
- ◆ **Webinars for Leaders.** The Exploring Digital Leadership webinar series is designed to build understanding of the skills required for leading in the digital age.

**Leadership.** Digital and data-driven leadership is critical at all levels of health and social care to drive forward service transformation. The Digital Leadership Programme supports participants in developing the strategic leadership skills required to influence the use of digital and data solutions in health and social care delivery. Moving forward, we will champion the expansion of all development programmes to cover data and digital.

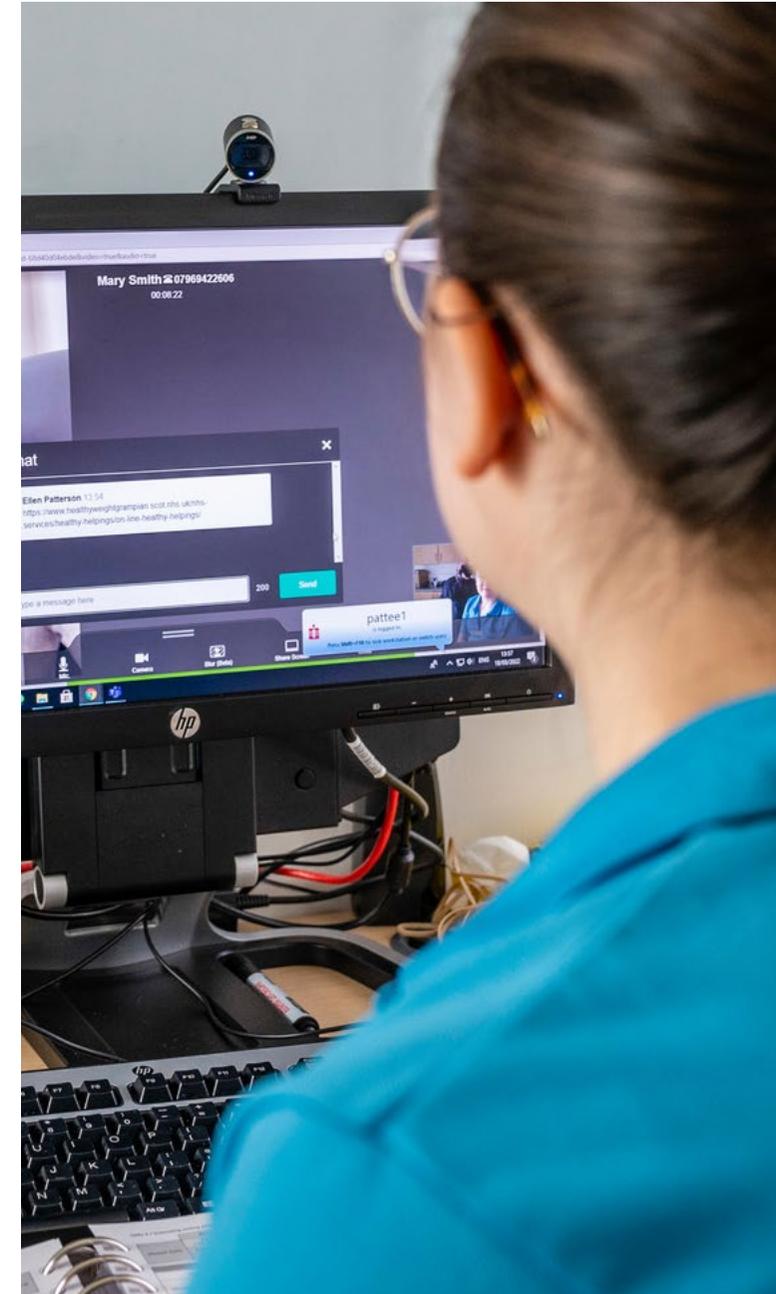
**Education.** We are developing a formal postgraduate programme offering three buildable qualifications, with each course including modules on data:

- ◆ 1 year – Postgraduate Certificate (PGCert)
- ◆ 2 years – Postgraduate Diploma (PGDip)
- ◆ 3 years – Full Masters (MSc)

**Action Plan.** We will publish a comprehensive action plan clarifying the range of **learning and development options** for our integrated workforce. This will detail digital principles, learning outcomes and outputs, evaluation methodology and measurements of progress.



Our Commitments	Who is it for?
We will build confidence in using data by ensuring all staff possess the essential data and digital skills they need to do their job. This includes providing consistent and tailored data and digital skills learning and development for all health and social care staff, incorporating blended training approaches as necessary.	Professionals
We will work with and support senior leaders to gain and further develop the skills to embed digital technology and data literacy across their organisations through our Digital Leadership programmes.	Professionals
We will ensure that there is appropriate level of leadership, skills and capacity, and an appropriately trained and resourced specialist workforce with career development opportunities across the system, to support the design and delivery of enhanced digital services.	Professionals
We will ensure that all workforce development programmes include data and digital.	Professionals
We will invest in our specialist workforce by developing appropriate tools and training resources that are relevant to job roles.	Professionals
Our Digitally Enabled Workforce programme will work with our universities and colleges to shape the future workforce by ensuring curricula prepare students for a digitally enabled health and social care environment, and produces graduates of the future for whom digital is a core skill.	Professionals



# Protecting and Sharing Data

**We want a trusted, secure health and care ecosystem where data is shared, managed and stored securely, consistently, efficiently and transparently.**

## Background

Demonstrating our ability to keep health and social care data safe and secure is crucial to public confidence and effective delivery of care, whilst ensuring relevant data is readily accessible to those who need it for clearly defined purposes.

The protection and sharing of data is managed by information governance and cyber security processes and procedures – these processes are vital to both upholding privacy and reducing the risk of data being accessed by the wrong people. Much of this work is governed by legislation, such as the Data Protection Act and the UK General Data Protection Regulation (GDPR), and is focused on ensuring appropriate safeguards exist to enable good use of data to benefit delivery of integrated care and improved outcomes for the people of Scotland.

Protecting data is partly about being constantly vigilant against advanced and persistent threats from cyber-attacks – all organisations must already actively implement effective security measures and controls – and partly about ensuring all staff understand their personal responsibilities on the safe handling and protection of data. The safe handling extends to appropriate sharing of information: the principle of ‘do no harm’ extends to the management of data, both in respect of ensuring people are not harmed via the careless or insecure use of data, or that harm occurs because our systems and people did not use or share data effectively and appropriately for individual or public benefit.

Our health and social care sector safely manages, secures and shares millions of pieces of data every day, and successfully

defends against cyber attacks on an ongoing basis. There are many examples of good approaches being taken to the sharing of data, but equally many examples of where data has not been shared where it should have been, or delays in getting approval to share data.

[The Scottish Parliament Health, Social Care and Sport Committee](#) and key stakeholders across health and social care have strongly emphasised the need to review how the processes in place to protect and share data could be streamlined at a national and local level. More efficient and consistent ways need to be found to assess appropriately how fair, lawful, and secure proposals for digital and data-driven innovation are, and how information and privacy risks can be better managed with greater transparency and public engagement, highlighting the benefits.

## Where we are now

The diverse nature of health and social care delivery across Scotland – with several thousand different legal organisations (from Health Boards to care homes), makes the protection and sharing of data inherently complex. Each organisation is legally responsible for how they manage and safeguard the data they either control directly, or process on behalf of others. This complexity, and the recognised need to support change, is highlighted in the [“Review of the Information Governance Landscape across Health and Social Care in Scotland”](#) published in April 2022. This describes the current data protection landscape across health and social care in Scotland, and made a series of evidenced-based recommendations for the improvement of the sharing and protection of information – recommendations that are being progressed through this Data Strategy.

In addition, a [cyber resilience framework](#) exists across the public sector that is designed to ensure appropriate levels of cyber resilience are in place. The NHS is subject to additional regulatory controls (the Security of Network and Information Systems (NIS) Regulations) that mandates an approach to managing security of data – and all Health Boards are audited annually against the cyber resilience framework to ensure their systems and procedures are robust and the risk from attack is minimised.

In social care, the Digital Office for Scottish Local Government has an established Security Accreditation Scheme that allows suppliers of Digital Telecare equipment to prove to telecare providers that their business processes and the security controls provided in their products services meet basic requirements.

## Where we want to be

We aspire to create a system for the protection and sharing of data that:

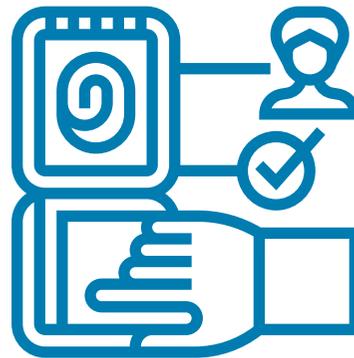
- ◆ Builds trust through participatory engagement, increasing transparency and empowering people;
- ◆ Creates the conditions for a mature approach to ensuring value from information, providing the right tools to staff; and
- ◆ Introduces a more balanced, federated model of decision making, reducing variation across Scotland in terms of what can and cannot be shared.

The vision is to have streamlined governance, assurance, and management of information assets that is more coherent and less fragmented across health and social care, to enable the realisation of benefits from digital and data-driven innovation. This requires a comprehensive approach to enable end-to-end ethical, rich, helpful, secure information across the health and social care sector that provides improvements in key areas, and continues to safeguard data and systems from cyber-attack. The improvements we want to make are:

**Streamlining the current IG model** to secure the right balance in decision-making processes over health and social care data, and ensuring we create a streamlined IG model that allows the public, data controllers, and health and social care organisations to collaborate.

**Bringing greater commonality and clarity in IG across health and social care**, aligning IG processes and responsibilities into a more balanced, federated IG model that ensures leadership and national direction, while recognising the necessary and impactful part that local IG processes make.

**Developing a Code of Conduct on Privacy by Design** for health and social care partner organisations, that would provide the necessary assurance to the public, partner organisations and supervisory authority, as well as enhance trust.



**Co-producing solutions to IG challenges** with our partners, and with truly transformative participation of citizens in the process. We have been and we will continue to engage with a range of organisations on some of the most challenging IG considerations. We will draw the learning for these complex considerations into our development of wider IG solutions.

**Harmonising the understanding of IG and demonstrating IG maturity.** This means providing clarity around what Data Protection legislation means to ensure that data is shared as efficiently and safely as possible; and providing the leadership to continuously improve the maturity of how information governance is carried out across health and social care.

**Setting out a national model for career pathways** and continual development of those who work with the governance of health and social care data.

**Investing in the right national tools** for the IG tasks and processes and continuing to develop sector-specific national IG-related policy and guidelines to help with compliance and improvement.

**Providing added visibility and transparency** towards enhanced management of existing valuable information assets across the landscape, starting with national information assets.

**Scaling up what works well in IG.** Successful models from the COVID-19 pandemic, such as the governance model of the Vaccinations Programme, will be expanded to other areas. Examples of good practice/guidance across the wider ecosystem will be shared.

**Continue monitoring and managing the risks** that arise in relation to data and new technologies, such as Artificial Intelligence, automated decision-making, and use of data from wearable technologies.

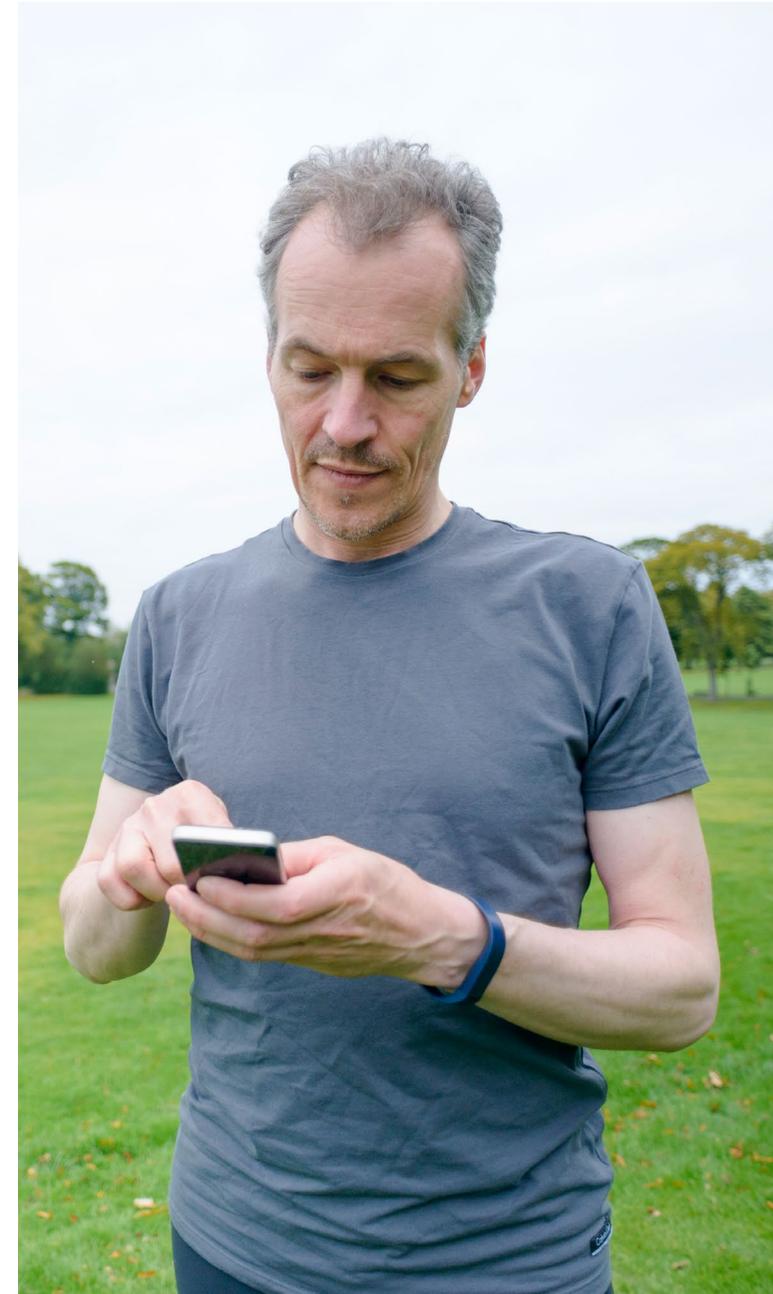
**Taking a strategic approach to cyber security.** The Cyber Centre of Excellence

(CCoE), based in the [Abertay University cyberQuarter](#), is part of our strategic aim for Scotland-wide management of cyber security services, delivered pro-actively, securely, and consistently across all NHS Scotland Health Boards. The Digital Office for Scottish Local Government and Scotland Excel have initiated a procurement process for a shared Security Operations Centre for local government that will provide an equivalent to the NHS CCoE.

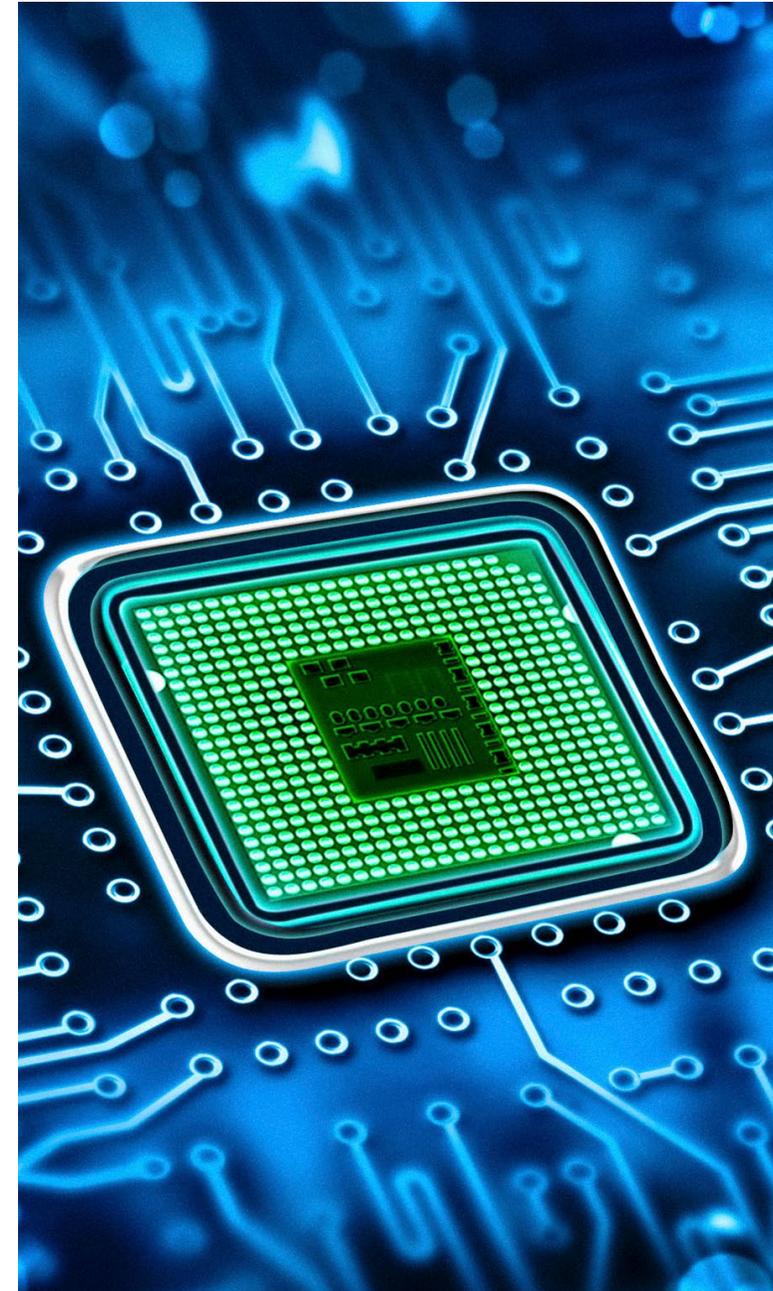
**Making best use of the NIS audit reports** to identify gaps in cyber security maturity and approaches, to ensure those gaps are closed.

**Further development of cyber standards** as part of the wider IG maturity work outlined above.

**Developing** further our **governance structures** and continuing our collaborative engagement practices with the National Cyber Security Centre (NCSC) and across our wider community of public sector organisations including close working with Defence, Security and Cyber Resilience Division in the Scottish Government.



Our Commitments	Who is it for?
We will engage effectively with the public, and health and social care delivery partners, to co-produce improvements and bring greater clarity to the current federated IG model.	Public Professionals
The CCoE will lead the continual improvement of the security of NHS systems and grow our specialist workforce by focusing on key enablement pillars including centralised security, 24/7 monitoring, threat hunting, incident response and training and awareness.	Professionals
Secure data environments must continually improve cyber security controls to ensure an appropriate level of authorised access to data at all times, as set out in the Cyber Resilience Framework.	Professionals
The Scottish Government Health Competent Authority (SHCA) will continue to assess annually the cyber resilience practices of all NHS Scotland Health Boards. We will use the findings from the yearly audits to set strategic direction, with a focus on mitigating practices for the areas of greatest risk.	Professionals
We will enhance our cyber security tools and responses and actively promote security controls and regulatory requirements.	Professionals
The Scottish Government will continuously review and refresh national guidance and codes of practice for the governance of information and data, in topic areas such as: confidentiality, records management, information sharing, privacy by design, ethics, security, and others including charters for safe havens, and patient rights. For example, <a href="https://www.gov.scot/publications/charter-for-safe-havens-in-scotland-handling-unconsented-data-from-national-health-service-patient-records-to-support-research-and-statistics/pages/1-2.aspx">Charter for Safe Havens in Scotland: Handling Unconsented Data from National Health Service Patient Records to Support Research and Statistics</a> . - gov.scot (www.gov.scot)	Professionals Public Research & Innovation



# Technology and Infrastructure

**We want to make sure that we have the technology and infrastructure in place to equip us to better collect, store and use data. This includes: structured data held within databases, unstructured data and information held in paper records, near real-time data from sensors and the Internet of Things.**

## Background

Our strategy 'Care in the Digital Age' sets out our vision, aims and objectives for how technology and infrastructure will evolve and integrate. We know we need to modernise some of the data infrastructure that is currently in use across health and social care to allow us to make the most of innovative technologies and ways of working. We will require the technology and infrastructure in place to best collect, store and use data, including unstructured data and information held in paper records.

At present, health and social care data is recorded and stored in multiple systems, and whilst there are some examples of

good interoperability and shared access, more often than not, systems offer limited or no interoperability. This limits the number of people that can access the information. We want to work to the principle of capturing data once and using it many times. Having the right infrastructure will be critical to this.

## Where we are now

Historically, our health and social care systems have been procured, developed and/or implemented separately from each other. There are, however, common core parts to many of our data systems. For example, within the NHS we currently make use of the Community Health Index (CHI) system, which holds the main demographic information

about all patients. All Health Boards use this system as the basis for patient management, and a number of local authorities have successfully linked their management information system to the CHI system.

The current **CHI system** has been in use since the 1970s and is no longer sustainable or capable of supporting our future needs – including the needs of data-driven care. A programme of work to upgrade and modernise CHI is underway, so that services always know who an individual patient is and can match their information to their record. By modernising the CHI system, we will be better placed to support our data infrastructure, allowing better matching of data and enabling better data linkage across the health and social care sector.

As part of our overall approach to modernising our infrastructure, we have a number of key national developments already underway. This includes the development of **National Digital Platform**, and its associated National Clinical Data Store (which provided the foundation for consistent, and public, access to vaccine information). These are being developed in line with the overall 'Cloud First' policy, which emphasises a requirement to consider the use of public cloud services first, before other options, when introducing new services or updating existing ones – and we will develop a specific action plan for the use of Cloud technology across health and social care. The National Digital Platform and its related developments form a critical component of both providing staff with access to relevant information, whichever organisation they are from, and providing the public with access to their information.

There are multiple technical developments underway, all of which will be set out in a Technical Roadmap for Scotland, but some examples covering specific systems that are designed to use data in a better way include:

◆ **Using data to improve patient care**

– we are implementing a Laboratory Information Management System (LIMS) to effectively manage laboratory data, ensuring operational efficiency. Data will be pulled together into a standardised format, resulting in improved data quality and making the data easier to find, use, and share.

◆ **Using data to deliver more proactive care and support at home**

– we continue to progress a significant modernisation programme to transfer current analogue technologies used in social care, over to a digital infrastructure. This will affect in excess of 180,000 people in Scotland in

receipt of these services, and have the potential to support greater data insights, health and care integration, and data sharing. The development of a shared Alarm Receiving Centre (ARC) provides the opportunity to improve the resilience of services, allowing for increased access to data between local authorities.

◆ **Using data to support analysis and planning to improve outcomes**

– we are further developing and modernising our 'Seer' platform as part of the National Digital Platform, providing national health and social care insight, working hand in hand with the NCDS. This will bring together and manage national data assets in a secure and trustworthy computing environment, alongside the technologies required by analysts and innovators to generate new insights and ideas and improve outcomes.

## Where we want to be

Ultimately, we want our technology to provide more rapid access to the right data at the right time, to support developments in innovative new approaches, and to support access for people to their own data. To achieve this, we will explore:

◆ **Adopting innovative technologies** – [Scotland's AI strategy](#) sets out the vision for Scotland becoming a leader in the development and use of trustworthy, ethical, and inclusive AI. Health and social care services have vast data sets which AI technologies could potentially analyse and uncover patterns and insights that humans could not find on their own. Algorithms can be used to help professionals make better business and clinical decisions, generate additional capacity and ultimately improve the quality of health and social care services. Utilising AI can bring many benefits such as early detection of disease; it can also help with diagnosis and prediction of treatment effectiveness. As

decision support tools such as [The Right Decision Service](#) mature, we will integrate them with innovative technologies such as AI to allow us to support health and social care professionals with validated evidence/guidance, create a learning health and social care system and reduce unwarranted variation, harm, and waste from inappropriate decisions. We will also seek to adopt other innovative technologies, such as Internet of Things sensors, that can be used to empower self-care and alert caregivers to deterioration in a person's wellbeing. Data from these sensors can help build a whole system picture of how we can improve health and wellbeing in Scotland.

◆ **Improving data quality across the health and social care** – The Scottish Government and COSLA will encourage organisations to transform their data to improve outcomes. This will begin with assessing their data maturity and reflecting on how they can improve the quality, completeness and use of their

data to achieve the ambitions of the Strategy. Improving data maturity will also be underpinned by introducing new technologies and infrastructure where needed. For example, in health, by adopting a national GP IT solution, alongside the introduction of SNOMED CT, we can begin to address the historical challenge in storing and accessing GP data. This improved technology will provide faster access to data and speed up some administrative tasks, leading to more consistent recording of health information and enable teams to work better together. In doing so, we will improve key data that is at the heart of many health and social care interactions, allowing us to deliver quality insights and deliver better outcomes.

To support this, we will work closely with planning and procurement colleagues to ensure that health and social care contracts contain the requirements necessary to drive forward the infrastructure required for care in the digital age.

In implementing our target technologies and infrastructures for the future, we must keep a focus on ensuring the safety of those we provide care for. We are committed to ensuring that safety and security of systems is embedded throughout health and social care, noting that all software classed as a medical device must be compliant with current UK regulations. This includes continuing to be alert to regulatory changes on software and AI as a medical device and engaging with partners. This will be achieved by monitoring [the current change programme being run by The Medicines and Healthcare products Regulatory Agency](#) and taking part in initiatives such as [Multi-Agency Advisory Service for Artificial Intelligence \(AI\) and data-driven technologies](#).

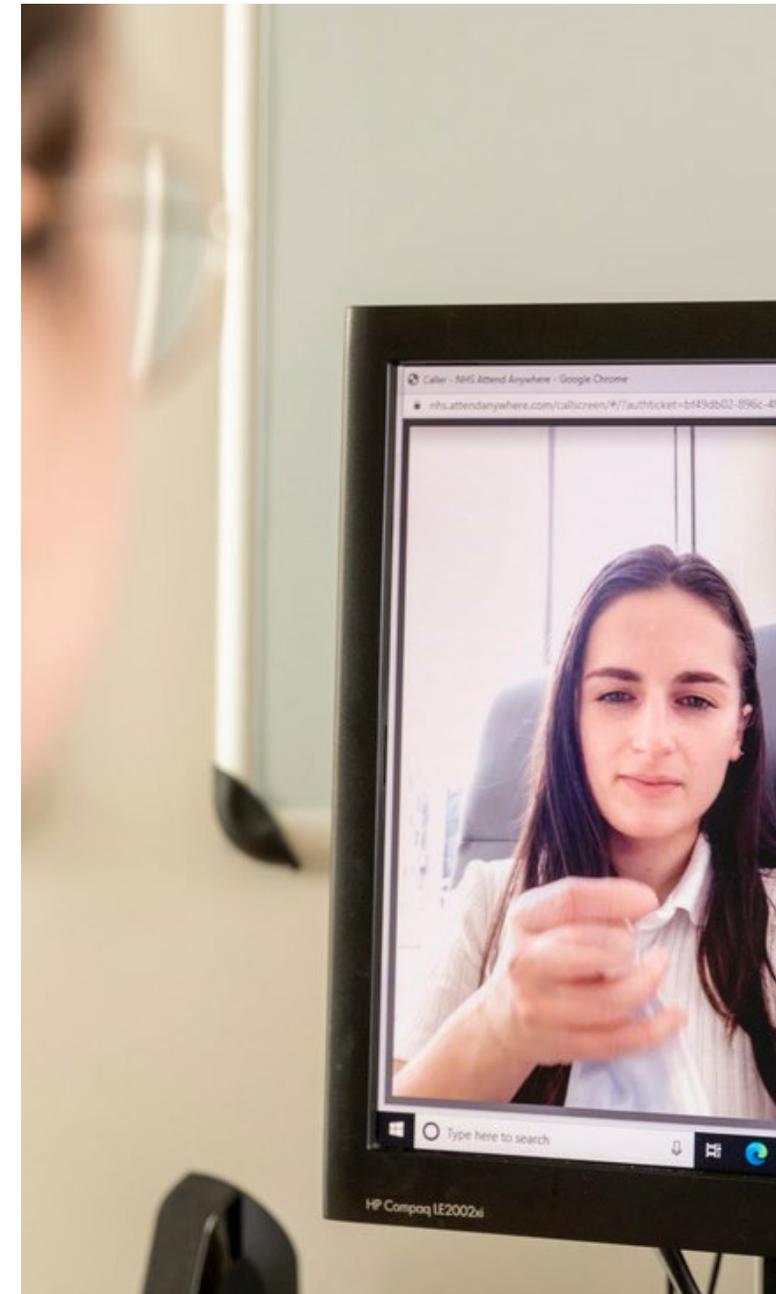
As we introduce new infrastructure and technologies for the future, we must also be part of Scotland's coordinated approach to making a just transition to net zero by 2045.

The NHS has set out its [plan to become a service which is both environmentally and socially sustainable](#). As local government have responsibility for social work and social care, these services will come under local authority plans to make a just transition to net zero by 2045. Across health and social care, we can make a positive contribution to achieving net zero by:

- ◆ Reducing the amount of duplicated data, and the use of legacy infrastructure used to host data in our health and social care sector.
- ◆ Capturing data in digital formats, as this reduces our use of paper. For example, by moving to digital prescribing and converting notes, consent forms, and appointment booking forms and letters to digital formats.
- ◆ Seeking to host data in data centres powered by green energy.



Our Commitments	Who is it for?
We will embed a climate-considered approach to our management of health and social care data.	Public Professionals
The Scottish Government, COSLA, and partners including the Scottish Innovation Centres will work collectively to ensure that health, social care and social work benefit from innovations based on IoT and AI.	Public Professionals
We will ensure that clinical safety and security of our systems are embedded throughout, noting that all software classed as a medical device must be compliant with current UK regulations. This means ensuring we provide the public and professionals with the assurance they need that digital technologies are used to deliver care in a safe manner.	Public Professionals
We will collect data once, and support appropriate access and use multiple times.	Professionals
We will promote a continuous improvement approach to improving the quality and completeness of data as well as making better use of the data we already have.	Research & Innovation Professionals



# Information Standards and Interoperability

**We will improve the quality of our health and social care data, and increase interoperability through adoption and use of common standards, making it easier to re-use and link data.**

## Background

There is currently a lack of consistency in the way data is recorded across the health and social care sector, which increases the risk of poor data quality. As a result, interoperability of data and services can be difficult. This Strategy is an opportunity to begin working towards common standards and principles. This will make it easier to exchange data across health and social care, helping us to get the best possible value out of the data we hold. It will take time to agree and implement this common approach to data but is essential for getting the most from health and social care data.

Implementing more consistent information standards across our health and social care system represents a major undertaking

for our health and social care sector. This Strategy recognises that our approach must be multi-year and take account of the varying degrees of readiness across the sector. A shared commitment across organisations to apply the new ways of working will be challenging as the current landscape is diverse, fragmented and of differing levels of data maturity. Implementing information standards will require agreement of preferred standards (and in some circumstances mandating), adjustments to existing systems; and the conversion of existing data to new standards. However, this work is essential in identifying, promoting, and aligning with wider work on regulating and legislating for better health and social care data.

## Where we are now

It is currently challenging to share data effectively across health and social care organisations. This is because there are many different organisations who collect information in diverse ways using different systems or processes. Some organisations currently keep paper-based records and have no ability to store information electronically. This makes it difficult for humans and computers to interpret the information and match it up with data being produced elsewhere to inform appropriate responses.

Improved sharing of data will be addressed through adopting common approaches to describing, storing, and making information findable and re-useable. The first step in this journey is agreeing and implementing information standards across the health and social care sector. Information standards are a shared language for collecting, describing, and storing data, which minimise the time needed to find, combine, and share information across the sector. Some work has been done in this space for example, the Scottish Social Services Council implemented a core minimum data set for workforce and provider information in 2008 to facilitate consistent data collection, supporting workforce planning at a national level.

Information standards will enable organisations to use data sets for multiple purposes and enable links and trends to be identified across multiple data sets. They will also support the identification of data sets that may not have existed previously but now have a vital role in delivering better services.

Additionally, implementing a preferred set of information standards will assist data analysis, and help organisations break down national data sets to suit their individual needs. Improving the quality of data recorded and the ease in which data can be exchanged will support health and social care professionals to access the right data at the right time, to deliver quality services.

### **Where we want to be**

We need to adopt robust data principles for how we collect, store, and use data across health and social care. The scale of this task is significant and will require utilising experience across the UK health and social care as well as international case studies and good practice.

The [National Digital Strategy](#) outlines the need to adopt information standards across the public sector. Moving forward, we expect all health and social care organisations to also start working to the FAIR principles (Findable, Accessible, Interoperable, Reusable).



The FAIR data principles outline ways to make data:

- ◆ **Findable** – people who need data know that it exists and where to find it.
- ◆ **Accessible** – people understand the conditions to access the data safely and ethically.
- ◆ **Interoperable** – people can readily use the data in their systems and combine it with other datasets.
- ◆ **Reusable** – people curate data in a way that allows it to be re-used wherever it is needed.

These principles provide a usable framework to improve the use and sharing of data. By committing to managing data according to these principles, the sector will improve the efficiency with which agencies can work together.

Additionally, we must begin to improve the use and interoperability of data in the health and social care sector as follows:

- ◆ **Making better use of data** in a more holistic, cultural, and proactive way.
- ◆ **Improving the consistency** of how data is gathered, stored, and accessed and re-used across health and social care. Proactively develop and implement preferred information standards at a national and local level as needed.
- ◆ **Enabling better sharing of data** across organisations – a coherent approach to data which requires a joined-up approach across the wider landscape.
- ◆ **Implementing the FAIR data principles** standards for the collection of data.
- ◆ **Having assets that are discoverable** across the sector and public sector.
- ◆ **Providing timely and trusted access** to authoritative data as a service. This requires a more coherent approach to be taken when recording data and assigning

unique identifiers. This will mean that the information can be made available in ways that allow multiple organisations to use the data for a variety of different purposes.

**Information Standards.** Organisations across health and social care must work together to agree, adopt, and implement information standards to bring commonality and drive-up interoperability, enabling data to be used effectively. There are various standards that have different purposes such as:

- ◆ **Record** standards, which set out the minimum information that needs to be recorded from a health and social care perspective.
- ◆ **Terminology** standards ensure that a common vocabulary is used when recording information. For example, SNOMED-CT sets out clinical phrases that convey information about diagnosis, treatment, and symptoms. The use of SNOMED-CT for social care is also being explored in other countries as a means of supporting consistency and enabling effective integrated care.

◆ **Classification** standards such as International Classification of Diseases (ICD) 10 and Office of Population Census and Surveys (OPCS) are used to record episodes of care for statistical and epidemiological purposes. **Technical** standards such as Digital Imaging and Communications in Medicine (DICOM), FHIR and OpenEHR set out specifications that ensure systems can exchange information.

Setting out preferred standards will bring greater clarity to expectations when capturing and using data across health and social care, and clearly signal to suppliers what to expect when supplying technology and services in Scotland.

The [National Care Service \(Scotland\) Bill](#), currently at the earliest stage of the Parliamentary process, has provision for mandating information standards across social care and health. Ahead of this power, the Scottish Government will explore the

use of preferred standards. [The Data Board for Health and Social Care](#) will oversee and approve the initial programme to identify preferred standards. This work will be done collaboratively with partners across health and social care to ensure standards are fit for purpose and do not negatively impact local flexibility. The Digital Office and Improvement Service are working in partnership to establish a new Data Standards Board for Local Government that will adopt a more holistic approach to management of data standards within Local Government and will be key partners in this work.

There are varying degrees of maturity and readiness for standards across health and social care. Organisations will need to reflect on their capability to use data and assess their data maturity by completing digital maturity assessments every two years. This will enable organisations to target data improvements so that they can deliver better on outcomes. Funding to support identified

areas of improvement, both nationally and locally, will be made available based on these assessments.

In addition to sharing data across the health and social care sector within Scotland, occasionally there is also a need to share data outwith Scotland. For example, to ensure people's data moves with them from Scotland to elsewhere in the UK; or sharing data with the WHO for statistical processing of morbidity and mortality information; or enhancing our understanding of how to improve health and social care services and improve outcomes for individuals across the UK. To ensure that we can collaborate with the rest of the UK in a safe and ethical way we will align with the standards used across the other four nations where practical to do so.



## Case Study – ICD 11 Implementation

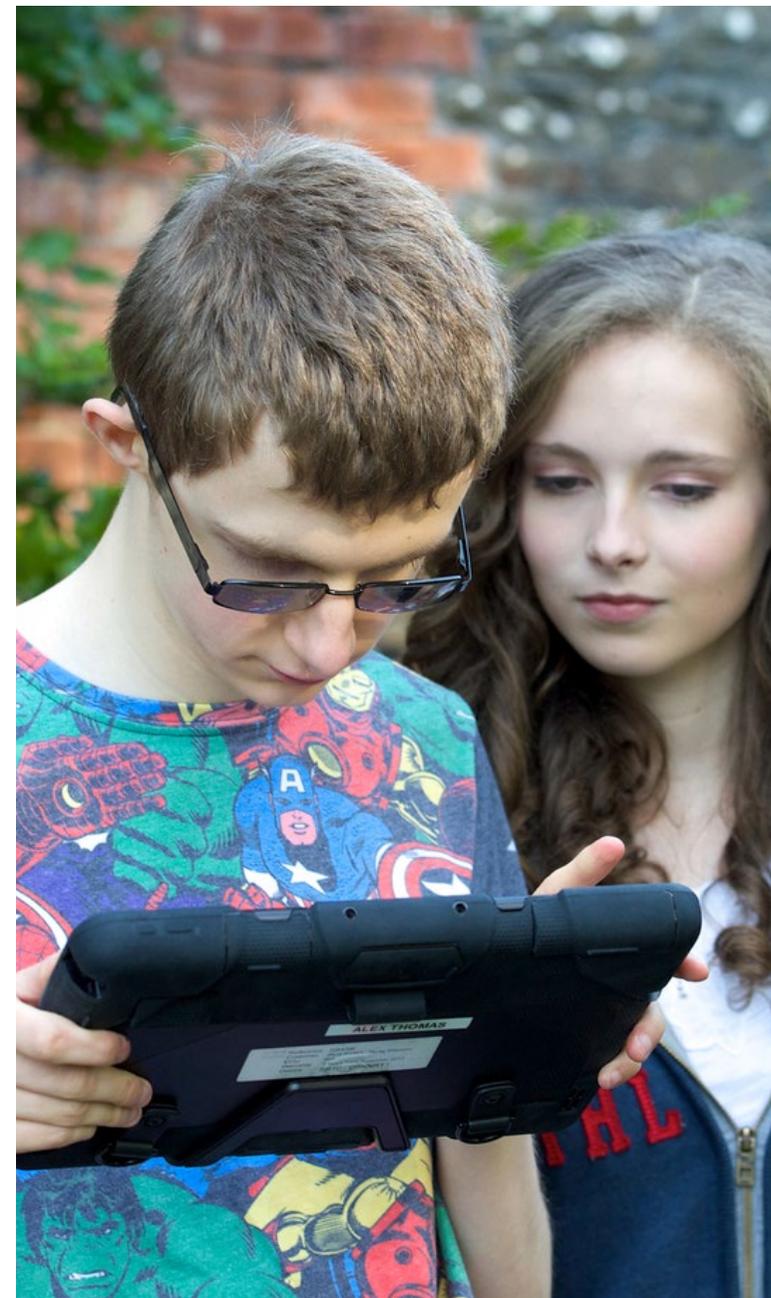
The International Classification of Diseases (ICD) provides a common language that allows health professionals to share standardised information across the world. The eleventh revision (ICD 11) is now entirely digital, and contains around 17,000 unique codes and more than 120,000 codable terms. The previous transition from ICD 9 to ICD 10 took several years and the intention was to ensure a swifter transition to ICD 11.

ICD 11 has a new user-friendly format and multilingual capability that reduces the chances of error. It has been compiled and updated with input from over 90 countries and an unprecedented involvement of health-care providers, enabling evolution from a system imposed on clinicians into a truly enabling clinical classification and terminology database that serves a broad range of uses for recording and reporting statistics on health.

Scotland is one of the first countries worldwide to take steps to implement and promote ICD 11. The first stage of implementation commenced in November 2022. The next phase of implementation will focus on the coding transition from ICD 10 to ICD 11 for data sets used in Scotland. This is an example of Scotland taking the lead on implementing national data standards to improve interoperability and, as a result, improve an individual's interaction with health and social care services.



Our Commitments	Who is it for?
We will put the FAIR data principles and quality data at the heart of all data work in health and social care.	Professionals
We will work with organisations across the health and social care sector to ensure information standards are fit for purpose, and horizon-scan for good practice and developments in standards; for example, <a href="#">Open Referral UK</a> and <a href="#">SAVI</a> standards. As we do so, we will always strive to recognise local needs and the varying implementation challenges in both health and social care.	Professionals
We will set clear information standards when specifying new system requirements, with system providers as part of programme procurement and implementation.	Professionals Research & Innovation



# Creating Insights from Data

**We want to work in partnership with health and social care to adopt a whole-system approach to creating insight from data that allow us to improve services. This includes the creation of insight to: inform communities, inform policy, identify, measure and monitor differential outcomes, experiences and access to services for different population groups, target interventions and support, improve services and improve partnership working.**

## Background

Improving our use of health and social care data is not only needed to help us provide the best care possible for people, but also on a national and regional basis, to ensure that the decisions made are based on quality, up to date information. Sharing information across organisations in near real-time, such as the number of available hospital beds across regions, social care capacity, rate of infection of emerging diseases, or efficacy of certain treatment options, is key to ensuring the delivery of responsive and fit-for-purpose services.

The analysis of the consultation for the Strategy highlighted that there are acknowledged difficulties in appropriately sharing 'near real-time' data for the purposes of timely planning and decision-making. To address this, we must ensure that the data is recorded in a consistent manner to enable the interoperability that allows staff to access the right data at the right time. This includes secondary uses of health and social care data such as official statistics, reasons of public interest such as protection against serious cross-border threats to health, and supporting public bodies to understand and improve services.

Data is often held in multiple places, making it difficult for people providing care and support across health and social care to access the most relevant, up-to-date information. This makes safe and effective delivery of care, and continuity of care across different service providers more challenging, particularly as care needs change over time. It also hampers strategic planning, service improvement and Research and Innovation (R&I).

## Where we are now

### Strategic Planning and Service Improvement

Our experience during the COVID-19 pandemic has shown us that the public have an increased appetite for accessing insights into health and care data. This is demonstrated clearly by the fact the PHS COVID-19 Daily Dashboard has accrued 51 million views. Deriving insight from our health and social care data is also crucial in achieving our principle of being accountable, transparent, and open to independent scrutiny. That is why the Scottish Government and Public Health Scotland publish official statistics, in line with [Code of Practice for Official Statistics](#), explaining insights from our health and social care sector.

At present there is no 'single line of sight' or 'route of access' into management information across health and social care in Scotland. This makes visibility of data for service delivery and improvement difficult,

with sources being disparate, and limiting us from improving the care we provide by achieving the true potential of the data produced and held. This is exacerbated by the fact that we do not currently have a single data mart for the management of information data. To achieve our goal of greater discoverability, accessibility, interoperability, and reusability of data, planners need to have better access to appropriate and near real-time data, to better analyse, understand and improve processes and services at different levels and better inform strategic planning priorities.

The timeliness of our data for service delivery and improvement also makes it difficult to take data-driven decisions in near real-time on a consistent basis. This is because we face a trade off in the timeliness of data versus the quality and cleanliness of that data. To make timely data available, we need to understand our appetite for using data that has not been fully cleansed.

## Where we want to be

A key aspect of our vision is to create a complete system approach that will facilitate the understanding of the issue, the context, and the wider system. This will allow management information data to be utilised in a timely manner to improve services by providing insight to decision makers and the public. Our approach to collecting and supplying data for this purpose will be reviewed, focusing on the following:

- ◆ **how we provide data** as part of an analytical pipeline; removing siloed structures, produced once and used for multiple suitable purposes
- ◆ **setting clear pathways** to commissioning analytical work
- ◆ **moving towards a whole-system approach** to developing intelligence that can be utilised to improve health and social care.

The development of a whole-system intelligence model for health is already in progress. As part of this, we will consider how we can reinvent the way we approach intelligence, including how we can improve our ability to use near real-time data. Data integrity must be balanced with our ability to act on it effectively and efficiently.

Improving the accessibility, connectivity, and visibility of data for service delivery and improvement will also be crucial to deriving the greatest possible insight and improving our service delivery. That is why it is important that we review the data sets that are currently available to us, considering where the greatest gaps lie; and to where we could more routinely link data to give as full a picture as possible. When doing so we will build on work that is already underway, for example:

- ◆ The work of the [Equality Data Improvement Programme](#), the actions being taken forward following the recommendations of the [Expert Reference Group on COVID-19 and Ethnicity](#) or the current review of the suite of official statistics.
- ◆ Work is also under way in the Local Government Digital Office to develop a Blueprint Library that will contain a shared library of blueprints for data analysis, analytics, and visualisations developed by individual local authorities, so that they can be re-used and replicated by other local authorities.
- ◆ The e-Rostering programme for the NHS, to improve workforce data and make staffing safer; or theatre optimisation technologies to maximise efficiency and combat waiting times.

Data is collected and stored across several organisations, we recognise that combining insights from across the health and social care sector will allow us to have the greatest impact on care provided. In order to do this, we need to strive towards greater federation of our data infrastructure, allowing third and independent sector data to be used alongside national public sector data.

Having data available for modelling, planning and projections is also crucial to ensuring our health and social care sector is able to provide the best possible services. Modelling is key to workforce planning and supporting the sector to navigate periods of high demand such as Winter or for resilience purposes for developing strategies to deal with ad hoc changes in demand, such as with COVID-19. Completeness of data also supports the identification and monitoring of differential access, experience, outcomes and health needs between different population groups, including equality groups – which is essential to improve our services.

We want data in our health and social care sector to adhere to the principle of collecting once and using many times, reducing the administrative, technological, and environmental burden of siloed data. Key to this will be good data governance and making use of unique identifiers that support linkage and interoperability of data, such as CHI or Unique Property Reference Number (UPRN).

We must also ensure that we support our analysts to deliver the insight required from data. This will mean ensuring that we have the right technology and software, that we are clear on a common language across professions, and that we deliver the right training and upskilling to our analytic community. The Local Government Digital Office and NHS both facilitate communities of practice for the sharing of learning and best practice. Encouraging communities of practise is essential to creating an environment that allows our practitioners to share their experience for the benefit of health and social care.

It is also essential that the information we do create from our health and social care data is translatable and digestible for its intended audience, including, where relevant, the public. That is why we will ensure that analysis includes professional consideration of the 'so what' arising from its results, helping users to understand what actions must be taken based on the intelligence being presented to them.

We must also ensure that data is being captured and used effectively to plan the workforce needed to deliver services. We are already gathering data that helps us identify the demographics and geographical spread of our workforce. However, we must strive to continually improve the quality and granularity of the data we collect, especially on the unregistered workforce, and adapt our planning accordingly.





## Case Study – Cancer Medicines Outcomes Programme (CMOP)

Scotland has introduced many new cancer medicines in recent years. It is safe and effective to prescribe medicines after they have undergone clinical trials. Patients in clinical trials may differ from patients receiving these medicines in routine care (or 'real world patients').

As proof of concept, CMOP focused on immunotherapy which is a new treatment used for several cancer types.

Collaboration and clinical engagement across the health boards enabled these data to be reported 'once for Scotland'. CMOP were able to link nationally-held datasets with prescribing data and were able to describe some patient characteristics of the Scottish population who received immunotherapy treatments, including: age, gender, diagnosis, and fitness for treatment. CMOP reported outcomes that supported healthcare professionals to provide more personalised care.

This example shows how the CMOP links health data to report and understand the outcomes of cancer medicines, enhancing the information available for patients and for the clinicians making treatment decisions.



Our Commitments	Who is it for?
We will use modern technology to support the timely analysis and understanding of Scotland's Health & Social Care system.	Professionals
We will take a more joined-up approach to funding and commissioning, ensuring analytic communities are joined-up. This includes encouraging communities of practice for the sharing of learning and ways of working.	Professionals
We will invest in the people we need to help deliver the data, growing our workforce to use timely analysis to deliver the intelligence and insight that is needed to improve health and wellbeing in Scotland.	Public Professionals
When publishing analysis, we will always ensure we help readers to understand the key insights being derived from the analysis of data.	Public Professionals
We will support the sharing of data analysis and insights across the public, independent and third sector organisations to deliver improved services.	Public Professionals
We will be smart in our approach to creating insight from data, making the most of the data already available. We will take a collaborative approach to learning, sharing, and developing our data and insights.	Professionals



# Supporting Research and Innovation

**We will support research and innovation by facilitating safe access to health and social care data for industry, innovators and researchers, so that we can work together to develop better ways of working, better treatments, new medicines and improved services for care in Scotland**

## Background

Our health and social care services are under huge pressure as we recover from the pandemic and we must harness research-driven innovation if we are to: address the backlog in care; meet the ongoing healthcare needs of people across Scotland; and tackle long standing health inequalities. By working in partnership across the health and social care sector, academia and industry, we can prioritise the development and adoption of high impact innovations that can deliver longer, healthier, happier lives.

The data that is generated through the delivery of health and social care provides a wealth of opportunities for research and innovation that can:

- ◆ improve understanding of health, wellbeing, ill health, inequalities, poverty and the factors that influence them;
- ◆ monitor and assess the safety and effectiveness of care;
- ◆ support individuals, carers and clinicians to manage health conditions more effectively;
- ◆ evaluate new approaches to detect, prevent and treat diseases;
- ◆ develop new improved tests, medicines, and health and social care services;
- ◆ allow people to participate in health and social care research studies and trials through digitally supported enrolment and follow up, accelerating research delivery;
- ◆ assess progress towards reducing inequalities of access, experiences and outcomes.

In Scotland, we benefit from having five Data Safe Havens (also known as Trusted Research Environments or Secure Data Environments) that are operated by specialist staff often in collaboration with Scottish Universities. Data Safe Havens operate under the governance of the NHS with strict controls on data access, with use restricted to approved researchers and only for approved projects. The five Safe Havens are comprised of four regional safe havens in Aberdeen, Dundee, Edinburgh, and Glasgow, alongside our national safe haven run by Public Health Scotland and hosted by the Edinburgh Parallel Computing Centre.

Furthermore, [Research Data Scotland](#) was launched by the Scottish Government and partners to promote health and social wellbeing in Scotland by enabling access to public sector data, including health and social care data.

## Where we are now

Throughout our [engagement](#) and [consultation](#) on this Strategy we heard broad support for using data for research and innovation, and that research and innovation is vitally important to transforming care, improving population health and brings wider societal and economic benefits in partnership with industry. It is widely acknowledged that the wide range of data collected by social care organisations, local authorities, the NHS and the ability to link health data through the CHI number (and its next iteration) has huge potential as a resource for research and innovation. However, it is also recognised that data assets are not used to the full, and that challenges to their optimal use exist, including:

- ◆ discovering what data exists and where to look for it
- ◆ bringing data together that is often separated and in unstandardised forms, needing extensive processing before being research and innovation ready

- ◆ access and approval routes may be not well understood, and may be challenging for researchers and innovators to navigate
- ◆ more clarity is needed on the terms for engagement, access and use of NHS generated data for industry projects
- ◆ using data to offer opportunities for people to participate in health research studies and trials and for more efficient research delivery.

It is vitally important that we address these challenges in order to make the most of the opportunities for research and innovation, and to realise the consequent benefits for patients, population health, the health and care system, and the wider society and economy of Scotland.

Many of the developments set out elsewhere in this Strategy will help to address these challenges including plans for streamlining information governance, updating clinical coding arrangements, new infrastructure such as the National Digital Platform, National Clinical Data Store, Seer and the launch of

Research Data Scotland. In this respect, it is important that use of data for research and innovation is built into the design of all new developments set out in this Strategy and that this includes the data generated from new and emerging healthcare technologies such as AI, genomic sequencing and remote monitoring. This will be supported by an end-to-end innovation pathway that brings together our regional Test Beds and national Accelerated National Innovation Adoption programme. Achieving this will only be possible through prompt access to NHS data and its effective analysis. Nevertheless, there are a number of areas where further specific action in support of research and innovation is needed.

Under the Administrative Data Research (ADR) Scotland programme and the Health Data Research National Core Studies programme, a significant number of datasets have been brought into the National Data Safe Haven. These can be used to service multiple research projects. Currently, a researcher can discover what data is available through the [Research Data Scotland data catalogue](#).

Researchers then put together an application form for use of that data to a Public Benefit and Privacy Panel.

There are robust safeguards and controls in place, protecting individual privacy and confidentiality and demonstrating use in the public interest. The safeguards include:

- ◆ restricting and de-identifying data so information which is not required for the research and which would allow individuals to be identified is stripped away;
- ◆ making data available through our Data Safe Havens;
- ◆ mandatory approval of research and innovation projects before they begin following review by experts such as those of the Public Benefit and Privacy Panel for Health and Social Care.



## Case Study – Public Benefit and Privacy Panel for Health and Social Care

NHS Scotland Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP) is a governance panel that scrutinises applications for access to NHS Scotland health data for non-direct care. Its role is to ensure that applicants have thought through the public benefit and privacy implications of the proposal.

This means a research applicant must complete one form for the necessary scrutiny process, and work with a set point of contact in Public Health Scotland (PHS) electronic Data Research and Innovation Service (eDRIS) to help develop their application and bring together the necessary authorisations, permissions, and certifications to be in position to access NHS Scotland national data.

The HSC-PBPP balances public benefit with potential risk to privacy and ensures that the public interest will be furthered by the proposal, as well as demonstrating that the social need for the processing of the data requested will result in tangible benefit for society.

## Where we want to be

We want Scotland to have national health and care data that empowers research and innovation throughout health and social care. This means giving researchers and innovators from the public and private sectors clear, ethical and efficient routes to access and use data to take forward projects that support the modernisation of our health and social care service and deliver public benefit. However, in doing so we are committed to only allowing safe access to data where intended public benefit is clearly demonstrable. Access to Scotland's health and social care data will not be approved purely for commercial purposes, such as marketing, financial gain, or the adjustment of insurance policies. We must also acknowledge that by collaborating with industry, innovators, and academia we can create economic value for Scotland in the form of high value jobs and investment, as well as social value in the form of improved public services and health outcomes.

We will transparently demonstrate and explain the safeguards in place and how they support research and innovation in the public interest, working with RDS, the four regional Data Safe Havens in Scotland, and the PBPP. In the future RDS will require researchers to clearly publish the anticipated public benefits arising from their use of health and social care data through their work on creating a searchable log of uses of data for research. The log will include the data involved, anticipated public benefit, and anticipated outcomes from the research.

To enhance our research and innovation offering and overcome the challenges currently faced, we must work in close partnership across Health Board Research and Development, e-Health, and Information Governance. By doing so, we will be best placed to explore the standardisation of our research infrastructure and examine how we can create an offering more representative of Scotland's population.

RDS is leading work to transform the current health and care data access process with the aim of making access to data for research faster, simpler and more predictable. A new Information Governance approach will be introduced in 2023 which will mean that simple projects with precedent will be approved by eDRIS team staff rather than the PBPPs. RDS is working with partners to digitise the application process to reduce effort from researchers, to develop synthetic datasets that would help researchers form data requests and code, and to make changes to the way data is stored that reduces the time to assemble data for researchers once their request for data is approved. These changes will be delivered across 2023 and 2024.

Building on these developments and recognising the importance and value of strong partnership working between the Scotland's care sector, NHS, Universities and the life sciences industry to drive research and innovation, we will clarify the terms for access and use of health and social care generated data for industry projects. This includes the approval and controlled access pathways to ensure ethical use in the public interest. This will be refined by the conclusions of the Scottish Government's Unlocking the Value of Data programme led by an [independent expert group on Unlocking the Value of Public Sector Data](#) to guide how public interest of use of data by industry is assessed.

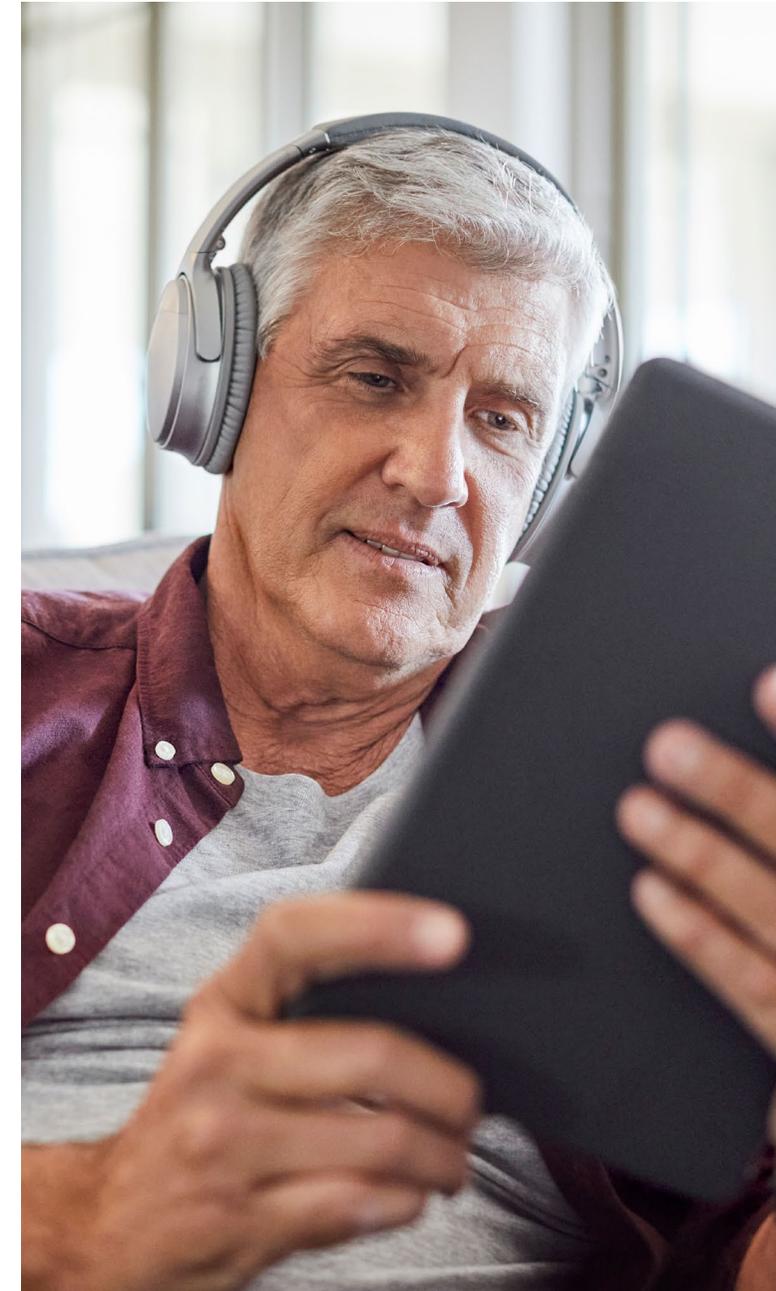
The Scottish Government will also work with NHS Research Scotland on how we might better capitalise on health data to support more efficient delivery of

clinical research, including data enabled approaches to assessing study feasibility, and the identification, recruitment and follow up of research participants. This includes building on initiatives such as the Scottish Health Research Register (SHARE) that provide a route for people to volunteer for research, broadening the opportunities for research participation.

In making these improvements to the research and innovation environment, we must also acknowledge that the collection, storage and use of health data for research and innovation is at a more advanced stage than is the case for social care data. Further work is required to understand what social care data is required, with the additional complexities associated with much care data being generated outside of the public sector.



Our Commitments	Who is it for?
We will seek to maximise the opportunities for data-driven research and innovation, with broad public support, to accelerate realisation of the public benefits.	Research & Innovation Public
We will openly demonstrate and describe the uses, safeguards, and benefits of the use of health and care data for research and innovation.	Research & Innovation Public
We will support access to health and social care data through trusted research and innovation environments, such as Scotland's 'Safe Havens', with appropriate approval processes providing assurance that data is used in line with ethical principles.	Research & Innovation Public
We will consider the use of data for research and innovation in the design of all new developments set out in this Strategy to maximise the opportunities and public benefits.	Research & Innovation Professionals



# Aligning Our Work to Scotland's Priorities

Scotland's National Performance Framework (NPF) sets out our vision for how we create a more successful Scotland. It focuses on how the wellbeing of people living in Scotland can be increased across a range of economic, social and environmental factors.

Our Data Strategy for Health and Social Care contributes to the vision of the NPF predominantly in the areas of 'we are healthy and active', and 'we live in communities that are inclusive, empowered, resilient and safe'. However, this Strategy seeks to contribute across each area of the framework. For example, in taking an ethical, open, and human rights based approach to the use of health and social care data in Scotland, or in its acknowledgement that by collaborating with industry, innovators, and academia we can create economic value for Scotland in the form of high value jobs and investment, as well as social value in the form of improved public services and health outcomes.



Nested with [Scotland's Strategy for Care in the Digital Age](#), this Strategy directly contributes to our vision to improve the care and wellbeing of people in Scotland by making best use of digital technologies in the design and delivery of services. It does so by working to the aims of the Strategy for Care in the Digital Age:



**Aim 1:** Citizens have access to, and greater control over, their own health and care data – as well as access to the digital information, tools and services they need to help maintain and improve their health and wellbeing.

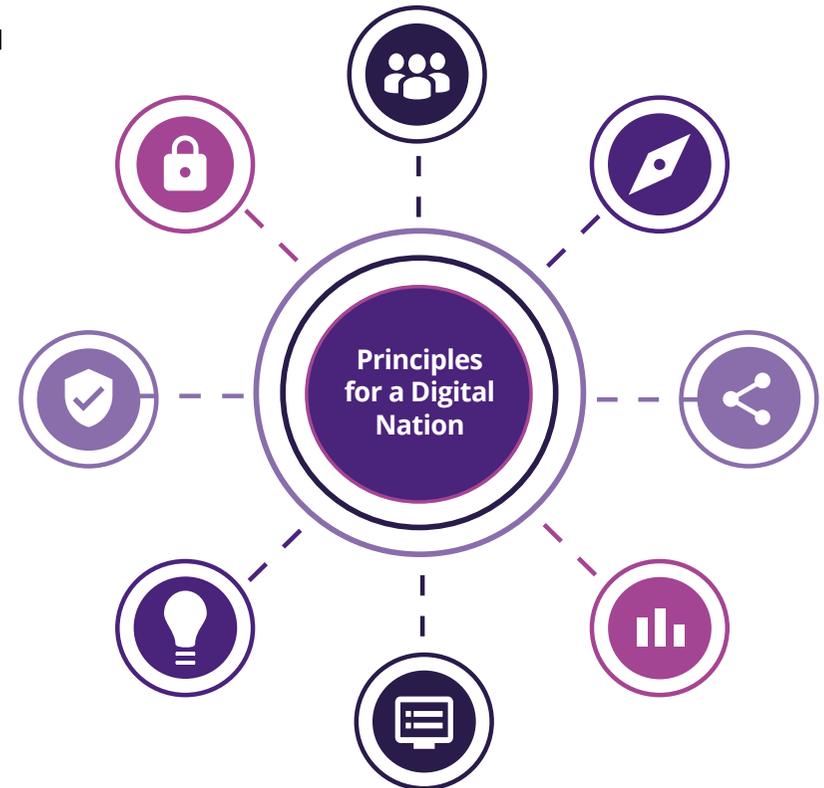


**Aim 2:** Health and care services are built on people-centred, safe, secure and ethical digital foundations which allow staff to record, access and share relevant information across the health and care system, and feel confident in their use of digital technology, in order to improve the delivery of care.



**Aim 3:** Health and care planners, researchers and innovators have secure access to the data they need in order to increase the efficiency of our health and care systems, and develop new and improved ways of working.

In doing so, it also aligns with the principles of [being an Open Government](#), the overall Digital Strategy for Scotland ([A Changing Nation: How Scotland will Thrive in a Digital World](#)) and its associated strategies such as the [AI Strategy for Scotland](#).



# Annex A – Delivering Our Strategy

To achieve our vision and ambitions we have focused our Strategy on eight priority areas. For each area we have outlined the initial actions we will seek to take under the priority areas. As we continue to build on the Strategy we will expand and refine these deliverable actions, and ensure they are aligned with the overall [Delivery Plan for Digital Health and Care](#).

## Ethical Approaches to Data

We want to embed an ethical, open, and human rights-based approach to the use of health and care data in Scotland which maintains public trust and confidence.

### Our Deliverables:

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will improve the quality and consistency of protected characteristics data, including ethnicity data, to ensure that we provide equitable care for everyone who requires care in Scotland. This will be supported by RDS developing the Equality Research Dataset to improve the ability of researchers to study issues of access to, and outcomes from, the health and social care systems for different protected characteristics.	Scottish Government Public Health Scotland Research Data Scotland	Year 1	 Professionals  Research & Innovation
We will improve the provision and signposting to information about how individuals' data is used by the health and or care services they are accessing.	Scottish Government NHS24 COSLA	Year 2-4	 The Public

<p>Through our programmes of work on Digital Inclusion, a National Information Governance Programme and the development of a Digital Front Door, we will articulate how non-digital access to data will be facilitated, ensuring individuals' rights to data about them are always upheld.</p>	Scottish Government COSLA	Year 2-4	 The Public
<p>We will continue to encourage the use of well-defined ethical frameworks when accessing and using health and social care data, ensuring fairness for the people of Scotland. This includes building on the work of our Ethical Digital Nation and Unlocking Value of Data programmes to update the principles contained in this Strategy.</p>	Scottish Government COSLA	Ongoing	 The Public

## Data Access

We want to empower individuals and professionals to make better-informed decisions by providing access to the right data at the right time.

### Our Deliverables:

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will create a new Digital Front Door, that will support individuals in accessing a range of self-serve health and social care services from a digital source. Digital Front Door will be incrementally built to increase access to health and social care data and services. A first release of the Digital Front Door will be launched in late 2023.	<p>Scottish Government</p> <p>COSLA</p> <p>Digital Office for Scottish Local Government</p> <p>NHS National Services Scotland</p> <p>NHS Education for Scotland</p>	Year 2-4	 The Public
We will co-create a means for the public to contribute to their health and social care records, giving them a voice in the information that is presented to health and social care professionals through the Digital Front Door programme of work.	<p>Scottish Government</p>	Year 2-4	 The Public

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
<p>We will improve GP IT systems by adopting cloud-based solutions, and improving the technology used to store and share data to unlock the value of primary care data, including for research.</p>	<p>Scottish Government</p>	<p>Year 2-4</p>	<p> Professionals</p> <p> Research &amp; Innovation</p>
<p>We will work together to develop and maintain clear and easy to use documentation on data sources. For example, developing a central data catalogue that can be used to describe data that is available on an open or shared basis. This will build on existing catalogues; develop a shared set of interconnectivities and definitions to manage data as a national data set.</p>	<p>NHS National Services Scotland</p> <p>Public Health Scotland</p> <p>NHS Education for Scotland</p> <p>Care Inspectorate</p> <p>SSSC</p>	<p>Year 2-4</p>	<p> Professionals</p> <p> Research &amp; Innovation</p>

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
<p>We will develop a consistent model for public participation and engagement as we explore the use of health and social care data. In line with the participation principles highlighted above this will see the routine use of co-production methods. Our engagement will be transparent and inclusive, highlighting how views will be incorporated. This approach will encourage wider public understanding, awareness and trust, and build upon our ongoing engagement in line with Open Government principles.</p>	<p>Scottish Government COSLA NHS Education for Scotland</p>	<p>Ongoing</p>	<p> The Public</p>

## Talent and Culture

We want to attract, develop, support, and retain a workforce that is confident and competent in the use of data. This includes: all staff having essential data skills that help us all to better manage the information we all depend upon and advanced data skills that help us to create more insight from data.

### Our Deliverables:

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
Through wider work set out in 'Care in the Digital Age'. we will support, further develop, and expand our specialist Digital, Data, and Technology (DDaT) professional workforce by conducting a review of roles, career pathways and training needs to inform recruitment and retention.	Scottish Government Digital Office for Scottish Local Government NHS Education for Scotland	Year 1	 Professionals
NES will lead, with a range of stakeholders on the development of a national learning and development resource for data and digital skills that can be accessed by all health and social care staff across Scotland.	Scottish Government NHS Education for Scotland	Year 2-4	 Professionals
Through the National Information Governance Programme we will create clear guidance on data handling and sharing to empower staff to effectively access and share data.	Scottish Government	Year 2-4	 Professionals

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
<p>We will equip our staff with the ability to understand and interrogate data-driven recommendations and decision support tools, including those powered by Artificial Intelligence.</p>	<p>Scottish Government Health Improvement Scotland NHS Education for Scotland</p>	<p>Year 2-4</p>	 Professionals
<p>We will ensure that appropriate processes, networks, and channels are in place to facilitate and support the sharing of good practice relating to digital technologies and digital skills.</p>	<p>Scottish Government Digital Office for Scottish Local Government NHS Education for Scotland SSSC</p>	<p>Year 2-4</p>	 Professionals

## Protecting and Sharing Data

We want to improve the efficiency, consistency and transparency of how our IG practices are evaluated with an increased focus on public engagement.

We want to keep health and social care data safe and secure and to maintain public confidence and trust in our management of data.

### Our Deliverables:

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will set clear National IG direction for health and social care by establishing a National IG Programme, aligning relevant strategies and strengthening the IG ambition to maximise the realisation of benefits from digital and data-driven health and social care innovation.	Scottish Government COSLA	Year 1	 Professionals
We will develop a cyber security strategy for health and social care, which we will publish to help drive collective effort from all the parts of the health and social care system.	Scottish Government NHS National Services Scotland	Year 1	 Professionals
We will develop a privacy by design code of conduct for use in the health and social care sector.	Scottish Government	Year 2-4	 Professionals

## Technology and Infrastructure

We want to make sure that we have the technology and infrastructure in place to equip us to better collect, store and use data. This includes: structured data held within databases, unstructured data and information held in paper records, near real-time data from sensors and the Internet of Things.

### Our Deliverables:

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will set out a Technical Roadmap for Scotland which sets out the target architecture for improving data infrastructure across the health and social care sector.	Scottish Government COSLA	Year 1	 Professionals
We will adopt a national approach to the ethical, transparent consideration of adoption and implementation of AI based tools, products and services. This includes beginning work to create a national policy framework for the use of AI, including the viability of an AI Hub for the NHS in Scotland.	Scottish Government	Year 1	 Professionals
We will review technology solutions for identity access and monitoring with a view to being able to offer NHS staff the ability to access multiple platforms through a single sign-on.	Scottish Government NHS Education for Scotland NHS National Services Scotland	Year 1	 Professionals

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will maximise use of existing infrastructure, and support moves to hosting data and infrastructure in the Cloud. This will include developing a Cloud Strategy for the adoption of cloud technologies in health and social care.	Scottish Government COSLA Digital Office for Scottish Local Government	Year 1	 Professionals
We will enhance our ability to capture health data once and share many times by expanding the National Clinical Data Store.	NHS Education for Scotland	Year 1	 Professionals
Through the National Digital Platform, we will publish a registry for APIs in use in Scotland's health and social care sector.	NHS Education for Scotland	Year 1	 Professionals   Research & Innovation

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will enhance our capability for statistical analysis, reporting and use of predictive analytics, moving to cloud-hosted data storage and reporting system (Seer platform).	NHS National Services Scotland Public Health Scotland	Year 1	 Professionals
We will establish a national decision support service by and embedding the Right Decision Service across health and social care. The programme will support professionals within Health Boards, HSCPs and care organisations to make the right decisions for the people they support.	Digital Health and Care Innovation Centre Healthcare Improvement Scotland	Year 1	 Professionals
We will support the health and social care sector to make use of innovative technology to automate the collection of data and set out a clear intention for the use of automation in the health and social care sector.	Scottish Government Digital Office for Scottish Local Government	Year 2-4	 Professionals

## Information Standards and Interoperability

We want to improve the quality of our health and social care data, and drive up interoperability through using common standards, making it easier to re-use data.

### Our Deliverables:

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will create clear governance on decision making regarding adapting current standards and agreeing implementation of new standards. We will develop a roadmap that outlines the direction of travel for data owners in the health and social care sector and software vendors.	Scottish Government	Year 1	 Professionals  Research & Innovation
We will encourage organisations to reflect on their capability to use data and assess their data maturity by completing digital maturity assessments. This will enable organisations to target data improvements so that they can deliver better on outcomes.	Scottish Government Digital Office for Scottish Local Government	Year 1	 Professionals

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
<p>We will set out information standards for Scotland’s health and social care sector to improve the quality of data and enable successful outcomes of sharing. The proposed National Care Service will consider suitable standards to be implemented in social care, following in-depth engagement. This will precede development of an approach to standards for the safe and effective sharing of information across health and social care, under the powers proposed by the National Care Service (Scotland) Bill.</p>	<p>The Data Board for Health and Social Care  Scottish Government</p>	<p>Year 2-4</p>	<p> Professionals   Research &amp; Innovation</p>
<p>We will begin a programme of work to implementation of ICD 11 for disease classification. Implementation of SNOMED CT for clinical health terminology will continue as set out in the <a href="#">Strategy for Care in the Digital Age</a>.</p>	<p>Scottish Government  NHS National Services Scotland  Public Health Scotland</p>	<p>Year 2-4</p>	<p> Professionals   Research &amp; Innovation</p>

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
<p>We will publish metadata that clearly describes information held by organisations, supported by APIs, to aid data discoverability across the health and social care data sources.</p>	<p>NHS Education for Scotland</p> <p>NHS National Services Scotland</p> <p>Public Health Scotland</p> <p>Care Inspectorate</p> <p>SSSC</p>	<p>Year 2-4</p>	 Professionals
<p>Through collaboration between NHS National Services Scotland, NHS Boards and Scottish Government, traceability of medical devices and tracking of medical equipment across Scotland will be improved alongside the adoption of GS1 standards following the implementation of the NHS Scotland Scan for Safety Programme.</p>	<p>NHS National Services Scotland</p> <p>Scottish Government</p>	<p>Year 2-4</p>	 The Public   Professionals

## Creating Insights from Data

We want to work in partnership with health and social care to adopt a whole-system approach to creating insight from data that allow us to improve services. This includes the creation of insight to: inform communities, inform policy, target interventions and support, improve services and improve partnership working.

### Our Deliverables:

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will review our current data to understand where collection needs to stop, new collection needs to start, and what approaches to collection, curation and storage need to be adapted to support our vision.	Scottish Government COSLA Digital Office for Scottish Local Government Care Inspectorate NHS National Services Scotland Public Health Scotland	Year 2-4	 Professionals

## Supporting Research and Innovation

We want to support research and innovation by facilitating safe access to health and social care data for industry, innovators and researchers so that we can work together to develop better ways of working, better treatments, new medicines and improved services for care in Scotland.

### Our Deliverables:

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will explore how approvals for access to data for research might be accelerated through best practice and standard setting for the operation of data safe havens. We will also consider potential benefits of independent assurance of operating standards in conjunction with the National IG Programme and our work on cyber security.	Scottish Government Research Data Scotland NHS Research Scotland Public Benefit and Privacy Panel	Year 1	 The Public  Research & Innovation
We will improve research access to health and social care data by launching a Researcher Access Service that provides streamlined, lawful, fair and safe access and linkage of data for the public good; working with the research community to identify the health and social care data with highest research value; maintaining an up-to-date catalogue of datasets available for research; and publishing a delivery plan for making this data research ready.	Research Data Scotland	Year 1	 Research & Innovation

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
We will work with partners to outline use cases for industry and research access to data, being clear for each about the benefit and risks to the population of Scotland.	Scottish Government	Year 1	 The Public  Research & Innovation
We will formalise industry and research representation in strategic governance of health and social care data, ensuring the perspective of research and innovation is consistently represented.	Scottish Government	Year 1	 Research & Innovation
We will explore greater use of data-enabled approaches to assessing research study feasibility, and the identification, recruitment and follow up of research participants.	Scottish Government NHS Research Scotland	Year 1	 Research & Innovation
We will explore (year 1) how to increase and then seek (year 2) to expand the population and data coverage of data safe havens (Trusted Research Environments) to support data-driven research and innovation at greater speed and scale.	Scottish Government Research Data Scotland NHS Research Scotland	Year 1-2	 Research & Innovation

What we will deliver	Who is leading this work	When it will be delivered by	Who is it for?
<p>We will work to create clarification of the terms for access and use of data for industry projects including the approval and controlled access pathways to ensure ethical use in the public interest. This will be refined with the conclusions of the Scottish Government's Unlocking the Value of Data programme once completed.</p>	<p>Scottish Government Public Health Scotland Research Data Scotland NHS Research Scotland NHS National Services Scotland</p>	<p>Year 2-4</p>	<p> Research &amp; Innovation</p>
<p>We will consider the impacts and opportunities to support research and innovation in the design and monitoring of the progress of developments set out in this Strategy.</p>	<p>The Data Board for Health and Social Care</p>	<p>Ongoing</p>	<p> Research &amp; Innovation</p>
<p>We will examine how we could support collaborative data-driven research and innovation across the UK and internationally where this has public benefits for Scotland, there is suitable agreement and it is ethical to do so.</p>	<p>Scottish Government Research Data Scotland NHS Research Scotland</p>	<p>Ongoing</p>	<p> Research &amp; Innovation</p>

# Annex B – Your Health and Social Care Data Rights

We want to empower the people of Scotland to have greater ability to access and manage their own health and social care data, where it is safe and appropriate to do so.

We all have the right to privacy and for our personal data to be protected when using health and social care services. A breakdown of an individual's rights with regards to health and social care data include:

- ◆ the right to ask for copies of your personal information
- ◆ the right to ask to rectify information that is inaccurate
- ◆ the right to ask to erase personal information in certain circumstances
- ◆ the right to ask to restrict the processing of your information in certain circumstances

- ◆ the right to object to processing in certain circumstances
- ◆ the right to ask for a transfer of the information from one organisation to another
- ◆ the right to request access to your health and care records
- ◆ the right to tell health and care professionals if you do not want your personal information to be shared in a particular way or with specific people.

This Strategy aims to make these rights easier to exercise by providing you with greater access and management of data about you. These rights are not absolute, and there are exceptions and conditions for application which mean health and social care organisations must balance your rights with their responsibility to protect data.

Consent for use of health and care data about you will not always be required but will always be sought where it is appropriate to do so. Reasons for not requiring consent include accessing and sharing data for delivery of care in an emergency or carrying out specific tasks that are in the public interest as is laid down in law, such as research on rare diseases. You can [read more about Public Task](#) on the ICO website.

Greater detail on your health and social care data rights, including the legislation and guidance they arise from, can be found through [NHS Inform](#), the [Charter of Patients' Rights and Responsibilities, information published by the Information Commissioner's Office](#) and the [Care Inspectorate](#).

# Annex C – Glossary of terms

A		
	<b>Anonymised Data</b>	<p>Anonymous data is data that does not relate to an identified or identifiable individual. This could include data that never included anything identifiable – for example, an anonymously filled in opinion survey. Anonymous data may be presented as general trends or statistics. Information about small groups or people with rare conditions could potentially allow someone to be identified and so would not be considered anonymous.</p> <p>Source: <a href="#">ICO</a></p>
	<b>Algorithm</b>	<p>A sequence of logical instructions for carrying out a task. In computing, algorithms are needed to design computer programs.</p> <p>Source: <a href="#">BBC</a></p>
	<b>Artificial Intelligence (AI)</b>	<p>Artificial intelligence is technology that enables a computer to think or act in a more ‘human’ way. It does this by taking in information from its surroundings, and deciding its response based on what it learns or senses.</p> <p>Source: <a href="#">BBC</a></p>
	<b>Application Programming Interface (API)</b>	<p>An API is a software which can be used by other software, to communicate with other software or hardware.</p>
C		
	<b>Caldicott Guardian</b>	<p>A senior person in an organisation responsible for protecting the confidentiality of patient and service user information and enabling appropriate information sharing by providing advice to professionals and staff.</p> <p>Source: <a href="#">UKCGC</a></p>

D		
	<b>Data Accessibility</b>	The extent to which people can use data available to them.
	<b>Data-driven</b>	Determined by or dependent on the collection or analysis of data.
	<b>Data Point</b>	An identifiable element in a data set.
	<b>Deep Learning</b>	Deep learning is a type of machine learning that trains a computer to perform human-like tasks, such as recognising speech, identifying images, or making predictions.
	<b>Direct Care</b>	A clinical, social, or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals.
F		
	<b>Fairness</b>	<p>Consistent treatment of people in Scotland, empowering individual voices.</p> <p>Source: <a href="#">Scottish Government</a></p>
H		
	<b>Health and Social Care</b>	A term used to describe services that are available across health and social care in Scotland. It includes services provided by NHS, local authorities, third, and independent sectors.
I		
	<b>Information Standards</b>	<p>An information standard is a document, produced by the Scottish Ministers, setting out how certain information is to be processed.</p> <p>Source: <a href="#">Scottish Government</a></p>

	<b>Innovation</b>	New ideas or methods.
	<b>Internet of Things</b>	The Internet of Things (IoT) means the network of objects and devices that have embedded with sensors, software, and other technologies for the purpose of connecting and exchanging data with other devices and systems over the internet.
	<b>Interoperability</b>	The ability of organisations as well as software applications or devices from the same manufacturer or different manufacturers to interact towards mutually beneficial goals, involving the exchange of information and knowledge without changing the content of the data between these organisations, software applications or devices, through the processes they support.
<b>M</b>		
	<b>Machine Learning</b>	Machine learning uses algorithms to identify patterns within data, and those patterns are then used to create a data model that can make predictions. With increased data and experience, the results of machine learning are more accurate—much like how humans improve with more practice.  Source: <a href="#">Microsoft</a>
	<b>Management Information</b>	Management information is data that relates to business activity. Management information can be used to inform business needs, planning and decision-making. For example, information relating to NHS waiting times or availability of staff in care settings.
<b>P</b>		
	<b>Protected Characteristics</b>	Protected characteristics are <b>specific aspects of a person's identity</b> defined by the Equality Act 2010. The 'protection' relates to protection from discrimination. Everyone in the UK is protected, whether they identify with a minority or majority expression of a characteristic.  Source: <a href="#">UK Government</a>

	<b>Primary use of data</b>	The processing of personal electronic health data for the provision of health services to assess, maintain or restore the state of health of the natural person to whom that data relates, including the prescription, dispensation and provision of medicinal products and medical devices, as well as for relevant social security, administrative or reimbursement services
<b>S</b>		
	<b>Secondary use of data</b>	The processing of electronic health data for purposes other than the direct delivery of care. For example, in producing management information to improve services.
<b>T</b>		
	<b>Transparency</b>	A systematic approach to communication, arming individuals with meaningful information.  Source: <a href="#">Scottish Government</a>
	<b>Trusted Research Environment.</b>	Trusted Research Environments (TREs) are a secure space for researchers to access sensitive data. Commonly referred to as 'data safe havens', TREs are based on the idea that researchers should access and use data within a single secure environment.  Source: <a href="#">Understanding Patient Data</a>
<b>U</b>		
	<b>Unstructured Data</b>	Data is said to be unstructured if it isn't recorded in a pre-defined, organised way. An example in health and social care could be digitised PDF documents containing patient notes in free text.  Source: <a href="#">BBC</a>



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