

Data Strategy for Health and Social Care: Consultation Paper

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1. Ministerial Foreword

I am delighted to be spearheading the development of Scotland's first Data Strategy for health and social care. As a strong advocate of the use of data to improve the quality of our services in health and social care, empowering the use of quality data to drive high quality services delivery is close to my heart. The Strategy is our opportunity to bring the services across health and social care closer together, ultimately improving the experience of the individual and their treatment.

This Data Strategy will serve to enhance already trusted services delivered by health and social care across Scotland and will continue to look at the ethical and transparent use of data. It will also seek to further empower innovation and research using health and social care data.

We are now seeing an increasing amount of health data being gathered by individuals through wearable devices, smart scales and other technology. People are showing a greater desire to have a say in how their data is used and shared as well as playing an active role in looking after their own health and wellbeing.

This consultation is another step in encouraging the people of Scotland to give their voices and help shape the development the strategy. It builds on engagement that has been ongoing since November 2021 and will continue until August 2022.

There are three parts to the consultation, each aimed at different users and beneficiaries of data. However, it is important to stress that we all fit in to at least one type of user and I would encourage everyone taking part to answer as many questions as you are comfortable with.

We are developing a Data Strategy for health and social care with the primary aim of empowering the people of Scotland and your voices matter. The Strategy has the potential to position Scotland as an internationally recognised country for carrying out data driven research and innovation.

We value the contributions from everyone receiving, delivering, and improving health and social care services across the country. Together we will develop a meaningful Data Strategy that empowers greater use of data to continuously improve the services we provide in health and social care.



A handwritten signature in black ink, appearing to read 'H. Yousaf'.

Humza Yousaf

Cabinet Secretary for Health and Social Care

2. Introduction

2.1. Why are we carrying out a consultation?

The purpose of this consultation is to gather views on how data should be used or managed, across health and social care. These views will help shape the development of Scotland's first Data Strategy for health and social care, due for publication in 2022. The governing principle behind this work is to ensure that data is used responsibly and for the benefit of the people of Scotland. The consultation will be open for responses from 16th May 2022 until 12th August 2022.

The Scottish Government wants the people who access health and social care services to be at the heart of the improvements we make to health and social care data. That is why we are carrying out this consultation, to gather views and feedback on how data should be gathered, stored, and used. The consultation builds on extensive engagement with a wide range of stakeholders and on [research carried out with the public](#).

Quality data is a key component for developing and delivering health and social care services. There is already excellent work underway across the health and social care sector but there is much more that can be done. This includes providing the people of Scotland with secure access to their own health and social care data. It is important to support trustworthy and fair research and innovation to develop the next generation of treatments and technologies, without compromising people's privacy.

The consultation is divided into three broad user groups, people of Scotland; those delivering health and social care services and industry, researchers and innovators. We all fit into one or multiple of these user groups so please complete as many sections as you feel comfortable completing.

You do not have to answer every question, but please consider each question from your perspective – for example, if you are answering on behalf of an organisation, in Part 1 think about what empowering individuals would mean for your organisation, if you are an individual member of the public, in Part 3 think about the role of researchers and their use of your data.

The scope of the consultation and the resulting Strategy will encompass the full range of data utilised by those who deliver and support the delivery of health and social care services and will address a broad range of themes.

2.2. Why are we developing a Data Strategy?

As set out in the [Strategy for Care in the Digital Age](#), we believe that data should be harnessed to the benefit of the people of Scotland. This includes the delivery of better services, greater innovation, and ensuring the people of Scotland have greater access to, and greater control over, their health and social care information.

The use of data has changed in the last few years and the pandemic has played a role in catapulting health and social care data and statistics into everyday discussions. There is an opportunity to learn from our recent experiences of health and social care data. However, whilst we have some world-class data resources at our disposal, there remains considerable data gaps and we are still lacking information in some areas. These are gaps we must address to improve care in the future.

One of the initial drivers of the Data Strategy will be to align the existing work that is already underway to improve both the use and access to data in health and social care for the benefit of the Scottish people. The Data Strategy will seek to minimise duplication of effort and support collaboration at a national level. It will also ensure an inclusive approach to any solution or ambition for those who do not or cannot access services digitally.

There are a range of data with varying degrees of sensitivity and the public, rightly have an expectation that these are used responsibly and in ways that protect individual privacy. The last few years have seen significant research around understanding public perception of the acceptable use of the data that relates to them, including in research we commissioned ourselves in conjunction with NESTA¹
².

This consultation builds on that extensive public engagement, and we recognise further work is required on helping the people of Scotland grow their understanding and support of the use of data for the wider public good. We hope for a large and diverse set of responses to this consultation so that we can consider the widest range of insight when developing a Data Strategy fit to serve the length and breadth of the nation and all who live here. Your views, gathered from participation in this consultation, are invaluable in helping us to refine the Strategy's vision and how it is achieved.

¹ [Outcomes from Data Dialogues | Nesta](#)

² [Data Dialogues 2](#)

3. Progress of our Strategy to date

Work originally started in 2019 exploring people in Scotland's opinions and ideas for the use and sharing of health and social care data. This initial engagement and research helped us identify seven 'relationships' that Scottish people have with their health and social care data. These are explored in detail in an interactive tool that explores peoples hopes and fears for the future, read our [findings from Data Dialogues on nesta.org.uk](#).

In November 2021 we began a more detailed programme of engagement on our plans for a Data Strategy that followed on from the previous Data Dialogues.

In the first phase of our engagement, we spoke to stakeholders in the three user groups and asked them what they needed from a Data Strategy for health and social care data. From this first phase of engagement, we heard about eight key themes:

- Communication & Engagement
- Data Access
- Technology & Infrastructure
- Talent & Culture
- Ethical Approaches to Data
- Digital Exclusion
- Information Governance & Security
- Data Standards & Interoperability

We are using the information we gathered from the first phase of our engagement to inform this consultation.

4. The Vision and Ambitions

We have committed to a Data Strategy for health and social care that will include detailed consideration of how to increase peoples' trust and transparency in data sharing. It will also examine how to unlock the value of health and social care data as well as how the tricky challenges around safeguarding our data can be addressed. It will take into consideration ethics, standards, relationships with industry and legislative requirements throughout the Strategy development.

Our current working vision for the Strategy is:

- To improve the health and wellbeing of the Scottish population through innovative, collaborative, and ethical use of data.

To help us achieve our vision we have three ambitions:

- For the people of Scotland: Empower individuals to have greater access to, and greater control over, their own health and social care data.
- For those delivering health and social care services: Empowering the people who deliver health and social care services by giving them the confidence and ability to securely access, gather and share relevant information to make timely decisions and deliver better outcomes.
- For innovators, industry, and researchers: Ensure use of high-quality data to drive the development of new and improved, treatments, technologies, and ways of working for public benefit.

5. Part 1 - Empowering People

We believe people should have greater access to and greater control over their own health and social care data. This includes the ability to view and request updates to information contained in their records, and access information such as test results, letters and treatment and care plans.

Greater access and control

Engagement with individuals, advocacy and representative groups has consistently told us that their experience of data can be repetitive and fragmented when it comes to providing the same information to GPs, hospitals, social care professionals. For example, data provided to GPs may not be routinely available to clinicians and staff in other care settings such as those you interact with in a hospital, nor is it routinely available for health research in the public good. We heard in the recent consultation on the National Care Service that 85% of individuals and 89% organisations who responded, agreed, or strongly agreed³ with the statement: 'There should be a nationally-consistent, integrated and accessible electronic social care and health record'.

We also heard in our engagement that greater access to and control over data will not only empower people to better understand and manage their own wellbeing, but also crucially bring greater transparency. This was particularly true of individuals that had experienced discrimination and stigmatisation. Our ambition is that by giving individuals greater access to and control over their data we can generate increased fairness and trust in our health and social care services. To achieve this ambition, we aim to allow individuals to check and update their personal data, (for example their ethnicity) where it is safe and practical to do so, as part of a development of a 'digital front door' to health and social care services.

Although greater access and control will facilitate the empowerment of individuals, this can only truly be achieved if their data is presented in a way that is accessible and understandable to all. This impacts on how data is recorded by professionals, but also raises important considerations for many people of Scotland. Including children and young people and those people who may not use English as their first language, as well as general concerns over literacy.

Though we know this ambition will empower many individuals, we also understand that many people who do not want the responsibility associated with greater access and control. Some simply may not have the capability or capacity to take advantage of this opportunity. Therefore, we must explore opinion on how this Data Strategy can work for all individuals. Ensuring it does not create greater inequality through a lack of access or through digital exclusion.

As we seek the grasp the opportunities presented by developments like those in the field of Artificial Intelligence (AI) to better health and social care data usage, we want to ensure our health and social care data is accurate, complete, and up to date. Where biases exist, we must appropriately prevent them, ensuring we do not inadvertently create greater inequalities.

³ [National Care Service: consultation analysis - gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/national-care-service-consultation-analysis/pages/100-to-110.aspx)

Your health and social care data rights

The Data Strategy will also set out our ambition for individuals to have a greater say in how their data is shared. This is particularly important to help individuals in not having to re-tell their 'story' multiple times. Several test projects in the UK health and social care eco-system have explored the possibility of people being able to 'toggle' sharing of their health and social care data on and off depending on who they wish to share with. However, the Strategy must also be clear on the rights that people have to their information, explaining the importance of setting out the legal reasons for collecting the data, how their data will be used and why. It must also be clear on how an individual can easily access and change data where this is appropriate.

We recognise that the public hold subtly different views regarding people from the public/private/voluntary sectors accessing data for various uses – from development and improvement of public services through to the generation of private sector profit.

The Strategy will also consider how individuals rights are properly maintained in situations where age/capacity/capability may make it difficult for the individual to exercise their rights. We have so far heard this is particularly true in situations such as the rights of children versus the rights of parents or the rights of disabled individuals versus the rights of carers.

Digital exclusion

Finally, whilst technology can and does transform lives for the better, we must ensure that no one is left behind. We acknowledge that our Data Strategy must account for those in our society who are digitally excluded and that non-digital routes to access health and social care data must remain an option to all individuals.

5.1. Questions Part A

1. We all have different perceptions of what our health and social care data may be:

1A. When considering the term 'your health and social care data' what does this mean to you and what do you consider it to be?

2. Our ambition is to give everyone greater access to and a greater say over their health and social care data. Health and social care data examples include results from a blood test, a diagnosed condition or interaction with specific health and social care services.

2A. When thinking about accessing your own health and social care data, what data about you would be your priority for having access to and greater control over?

2B. When considering the rights of individuals who are unable to interact with their own health and social care data, do you feel that delegating access to a guardian/carer/trusted individual would be appropriate?

Yes / no/ unsure

If yes, what safeguards need to be in place?

3. We are committed to providing clarity over how your data is used and the need for this to be built on ethical principles. When thinking about the ethical principles ([read our ethical principles on gov.scot](#)) that must be maintained when gathering, storing, and using health and social care data:

3A. What information would you find most useful in providing clarity over how your data is used in a consistent and ethical manner?

3B. To what extent do you believe it is important to collect data to enable our health and social care services to understand how they are serving those with protected characteristics?

Very important / fairly important / neutral / not important

3C. When thinking about health and social care professionals accessing and using your health and social care data, what more could be done to improve your trust?

4. When considering sharing of your data across the health and social care sector:

4A. Are there any health and social care situations where you might be uncomfortable with your data being shared?

4B. Under Data Protection legislation, your health and social care data can be shared in order to administer care. For what other purposes would you be comfortable with your health and social care data being shared within the health and social care sector?

5. More people are using wearable devices to track their own health including sleep activity, mindfulness, heart rate, blood pressure and physical activity.

5A. Do you gather your own health data for example measuring activity, sleep patterns or heart rate through a mobile phone or watch?

Yes / no

If yes, would you want to share this data with health and social care professionals, and for them to use it to improve the services you receive?

6. Part 2 - Empowering Those Delivering Health and Social Care Services

People involved in delivering health and social care services have told us that they should be empowered with the confidence and ability to collect and use high quality data to deliver high quality health and social care services.

To empower those delivering health and social care services, we need to give people the right skills, technology, access, and frameworks. Doing so will empower staff to confidently use data to deliver high quality care and improve services – this is sometimes referred to as data literacy.

Data skills & training

We must build data skills across the health and social care sector recognising that where specific technical data skills do currently exist staff are often subject to extreme workloads and that recruitment and retention has proven difficult.

To build skills in the sector there must be training and guidance on:

- data handling, analysis, interpretation, and manipulation;
- using the right language to explain data to those receiving care, with particular attention to comprehension and age appropriateness;
- understanding the value of data, improving its quality and benefits of its collection;
- how data is being used;
- the ethical implications associated with the collection of poor-quality data;
- upholding privacy, including the importance of access controls;
- privacy enhancing techniques such as anonymisation.

We understand that guidance is required across the health and social care sector to enable staff to understand data terminology and their roles and responsibilities in relation to data, standards and sharing. Through clear guidance, we can help to ease the apprehension staff may feel when being asked to share data across the sector.

Technology & infrastructure

In the [Strategy for Care in the Digital Age](#) we committed to ensuring that technology enables people to interact seamlessly across health and social care services. As a result, there are several programmes underway to improve our technology and infrastructure across the health and social care sector. Our ambition is to have technology and infrastructure that is designed in a way that allows health and social care professionals to easily capture and share quality data.

At present health and social care data is often held in silos. As data is recorded and stored in multiple systems, with limited or no interoperability, this limits the number of people that can access the information. This can also be difficult and time consuming to gather and share information.

We have also heard about the importance of improving the technology used to interpret and visualise data in a way that was meaningful and insightful. This was alongside the need to implement more tools for validating data to improve its quality and enable greater sharing. There is a recognition that improving user confidence should include making data skills training and governance processes around accessing and storing data more accessible.

Our engagement so far has told us that health and social care professionals want systems that are designed in a way that require individuals to capture quality data, for example, templates could be provided to make it easy to record and comply with the new standards. Improved systems are required to allow quality management information to be captured which would allow standardised reports to be produced and shared.

Data standards & interoperability

The Data Strategy will aim to bring greater interoperability to health and social care data and systems by seeking to apply a more consistent approach to data standards. This is aligned with the commitments set out in Scotland's [Digital Strategy](#). We want to facilitate greater consistency in how organisations across health and social care gather, store, and share data. Paving the way for clear guiding principles within which to enable national and local decision making, as well as improved direct clinical and social care.

Improving the consistency of how data is gathered, stored, and accessed across health and social care would allow greater interoperability across the health and social care sector. For example, sharing data between a GP surgery, care home and hospital would reduce the need for individuals to have to answer the same questions from distinct parts of the health and social care system. It would also ensure that professionals have a complete picture of an individual's health and social care record.

Driving the understanding and adoption of standards and establishing ways of managing and governing standards will be essential to improving the way health and social care data and public sector data is used. They will enable health and social care professionals to better understand information assets, connect data from across the sector and innovate.

Reaching a level of consistency in storing and recording health and social care data will facilitate greater access to, sharing of and use of health and social care data. However, without this consistency and complete data, Scotland's health and social care ecosystem will not be able to fully take advantage of the opportunities presented by innovative technologies. It may mean that opportunities to automate processes, speed up sharing of information and provide greater decision support to health and social care professionals are missed.

Information governance

While we aspire for greater access to and sharing of data, we recognise that the security and privacy of an individual's health and social care data is paramount to building trust with the public. We need to be transparent about how data is used and for what purposes, and the way in which people's data is considered when sharing with health and social care professionals, for research purposes and for wider public services.

Privacy by design is part of the data protection law and we will set out a framework of how we ensure information governance is considered at every step of our design. This will include putting the public at the heart of the design so we can ensure that ethical, security, privacy, people's rights, and transparency are all part of the design.

Robust information governance and cyber security measures as well as the knowledge and ability to implement them is key to protecting data. We have

legislative frameworks, controls and guidance which seek to ensure that always we treat personal data responsibly.

The Information Governance Review carried out by Scottish Government in 2021 forms part of the objectives of this strategy and will be fundamental in building a collective understanding amongst the public, health and social care professionals, industry users and researchers. This review found that too many organisations and decision makers find caution easier than recognising the benefits which can be achieved by using – and sharing – data in a responsible, safe, and rapid fashion. It is intended that the Data Strategy will lay the groundwork for an approach that will enable quicker and easier sharing of data in a way that is consistently safe and secure.

Management information

Health and social care professionals, carers, and other people responsible for delivering services told us that in addition to individuals' data the Data Strategy should also include management information. This in turn can then be used to manage and measure the delivery of services. They also told us that operational insight data which helps inform decisions around planning and personnel is also particularly important to the ongoing delivery of, and improvement in, services.

Population health data to improve health and social care outcomes

In addition to facilitating easier access to health and social care data for professionals in the sector, we also want to empower those delivering health and social care services by providing greater access to data that has the potential to improve health and social care outcomes across the entire population. Some examples may include greater access to the valuable data collected by housing providers or data gathered by private devices such as wearables, where individuals wish to share this.

6.1. Questions Part B

6. Considering skills and training opportunities for those delivering health and social care services:

6A. What are the top skills and training gaps relating to data in Scotland's health and social care sector?

- Data visualisation
- Understanding/use of management information by managers
- Understanding of what data exists and where to find it
- Knowledge of how to access data
- Confidence in using data
- Understanding of governance
- Other

6B. How do you believe they should be addressed?

6C. What actions must be taken as a priority to ensure that the public have access to health and social care data that they can understand and use?

7. Thinking about improving the quality of data that is used by health and social care services:

7A. What three things are needed to improve quality and accessibility?

7B. If you are responding on behalf of an organisation, what role do you believe your organisation has to play in improving accessibility and quality of health and social care data?

7C. What data, that is generated outside of the health and social care sector, do you think could be made available to health and social care professionals to improve health and social care outcomes in Scotland?

8. We have heard that a more consistent approach to data standards will help improve insight and outcomes for individuals:

8A. To what extent do you agree with the proposal that Scottish Government should mandate standards for gathering, storing, and accessing data at a national level?

[agree, disagree. Unsure]

8B. What data standards should we introduce?

9. When considering the sharing of data across Scotland's health and social care system:

9A. Do you agree with the idea that greater sharing of an individual's health and social care data between the organisations in the health and social care sector will lead to better quality services?

[agree, disagree, unsure]

9B. If you are a clinician – how could we improve patient safety through better sharing of data and information?

10. Thinking about the actions needed to improve the quality of management information and internal reporting data across health and social care:

10A. What are the priority pieces of management information needed (that are not currently available) to provide better health and social care services?

10B. What is needed to develop an end-to-end system for providing business intelligence for health and social care organisations in Scotland?

11. Thinking about improving the quality and ability to reuse data sets across health and social care setting and for innovation & research:

11A. What key data sets and data points do you think should be routinely reused across health and social care to reduce duplication of effort and stop people having to re-tell their story multiple times?

7. Part 3 - Empowering Industry, Innovators and Researchers

We have an ambition to ensure opportunities for innovation, industry and research are driven by high quality data. This in turn will support the delivery of outstanding health and social care services that are able to integrate the findings of innovation and research.

Access to data for research and innovation

Our experience is that worthwhile projects often require large volumes of data and/or the joining of multiple datasets. However, identifiable personal information is not required for most research and innovation purposes. We know that by collaborating with industry, innovators, and academia we can create not only economic value for Scotland. We can also take advantage of opportunities to significantly improve our health and social care services with innovative technologies and approaches.

Engagement with professionals working in health and social care innovation, industry and academia has so far told us that Scotland's health and social care data should be recognised as a national asset. The value of this data to Scottish society and its economy is being examined and debated. We heard from industry and innovators that there is support for a 'Once for Scotland' approach to information governance, reducing the need for the work to be duplicated, therefore speeding up the time it takes to access data in a timely manner. That is why our Strategy will outline how we will work with the newly formed organisation, [Research Data Scotland](#), to improve access to Scotland's health and social care data for research, whilst building on some of the truly world-class data-enabled research initiatives in Scotland such as [EAVE II](#).

Our engagement also told us that there is widespread public support for harnessing data for public benefit (such as creating new drugs to combat Covid-19). However we also heard that there is less certainty over the sharing of data for some purposes, such as marketing, financial gain for others, or activity that could be perceived as amounting to 'privatisation' of health and social care services. We recognise these concerns and aspire to further develop a system which allows seamless and efficient access to data for research with well understood outcomes and benefits for people. One that is completely transparent and builds trust by people in the way innovators and researchers use health and social care data for the public good⁴.

Infrastructure

To facilitate appropriate access to health and social care data for research, we must create the right infrastructure that enables access in a manner that is both timely but also safe and secure. Engagement has told us that this is a precursor to greater innovation and use of data. The outcome of engagement sessions so far has shown that there is a strong appetite for real-time data sets (meaning data that is available for use immediately or shortly after being generated) for research and innovation use. Use of real-time data has the potential to benefit the ability to continuously improve services. We have heard that initial ambitions for the Strategy should be to create an infrastructure that allows researchers to access structured, and in some cases, real-time national health and social care data.

⁴ [Defining the Public Good in Applications to Access Public Data – Office for Statistics Regulation \(statisticsauthority.gov.uk\)](#)

Innovative technologies

One area of innovation the Scottish Government wants to capitalise on is the use of Artificial Intelligence (AI), as set out in [Scotland's AI strategy](#). AI techniques such as machine learning solutions are transforming the way healthcare is being delivered. The Data Strategy's focus on trust, ethics and inclusion will inform its position on use of AI in health and social care. Health and social care services have accumulated vast data sets in the form of health records and images, population data and clinical trial data. AI technologies are well suited to analyse this data and uncover patterns and insights that humans could not find on their own. With deep learning from AI, healthcare organisations can use algorithms to help professionals make better business and clinical decisions and improve the quality of health and social care services in Scotland. However, for this technology to be effective, the data must first be of a high quality, or its use risks having a detrimental impact on our services, both operationally and ethically – potentially increasing inequalities. Crucial to adopting these technologies is that their use is transparent, explainable, and justifiable to the recipients of health and social care services. We want to seek your views on this technology and understand what it means to you.

Sharing Scottish data with the rest of the UK

Occasionally there is also a need to share data out with Scotland (and for data from out with Scotland to be shared with us). This frequently arises when individuals move from Scotland to elsewhere in the UK. The response to Covid-19 has shown the benefits of sharing certain data across the UK, for example – including public health surveillance data to help model the impact of Covid-19 and vaccine information to help understand the impact on people with certain clinical conditions. Some sharing also relates to the regulatory nature of healthcare at a UK level, including in the regulation of healthcare professionals, medicines, and medical devices. Sharing Scotland's health and social care data and collaborating with our partners across the four nations of the United Kingdom we can better understand how to improve health and social care services and improve outcomes for individuals across the United Kingdom. We want to ensure we can continue to collaborate on shared endeavours with the rest of the United Kingdom in a safe and ethical way.

7.1. Questions Part C

12. When considering the ethics of accessing health and social care data for commercial, development and research purposes:

12A. How do you think health and social care data should be used by industry and innovators to improve health and social care outcomes?

We, at the Advanced Care Research Centre (ACRC), believe that data should be anonymised, but with definable datasets (age/gender/location/other conditions etc) in order that the use of the data can identify trends to improve the range for what it can be used for. Ongoing studies into minimum datasets, such as [Dacha](#) (Developing resources And minimum data set for Care Homes' Adoption) can inform this.

There are important issues of consent to be addressed in this data sharing. For people in receipt of public funds, then legislation that allows for the sharing of data without consent (for specified purposes) is more clearly justifiable than it is for care home residents who are self-paying. This will require careful consultation and implementation. As with sharing within the NHS, an assumption of secure and controlled sharing with the right to opt-out under

specified circumstances is potentially the most optimal model, in terms of balancing the needs of different stakeholders.

12B. How can industry and innovators maintain the trust and confidence of the people of Scotland when using their health and social care data for research purposes?

The single best way for industry to show trust and confidence is by using the data to come up with new innovations that prolong healthy life, and ensure later life has fewer interventions.

While most research institutions already do this, an explicit declaration should be required, where data has been accessed, that an ethics committee has looked at any proposal to ensure it is worthy.

12C. What do you believe would be unacceptable usage of Scotland's health and social care data by industry, innovators, and researchers?

Anything that has not been approved by an ethics committee.

Anything that means the data is identifiable (without previous explicit consent).

Any data sharing for commercial/advertising purposes without consent

12D. How should industry, innovators and researchers be transparent about their purposes in accessing, and the benefits of using, health and social care data?

Sources of data should be acknowledged within any publications, perhaps with a breakdown, but not too specific as to be identifiable. (e.g: We used a dataset held by NHS Lothian covering adults from EH postcodes between the ages of 55 and 65 etc)

Furthermore, a plain language explanation should be provided describing the purpose and potential benefits of each research proposal. This should allow for cases where the use of data for Purpose A shows that the data could also support a previously not considered Purpose B – if a plain language explanation is offered each time, then any interested parties can track what data has been used for.

13. We want to create an infrastructure that supports access to data for research and innovation in a safe, secure, and transparent way:

13A. How should the Scottish Government seek to store and share health and social care data for research in order that it can best facilitate easier access that is still safe and secure?

Whatever source, or sources of securely held data there are, there needs to be adequate resourcing and infrastructure so as not to impose additional burdens on existing staff. It is essential that any increase in requirements e.g. for data to evidence improvement, is accompanied with appropriate resourcing of staff including the necessary technology (computers, wifi, links to online servers) and training (database skills, data management, quality improvement methodology, teaching and training), and that this is done in a supportive and non-blaming culture, with improvement and regulation having distinct input. By implementing systems that are maintained adequately, and accessed and managed by appropriately training professions, researchers can carry out secondary analysis of

routinely collected data that will lead to higher quality services at a lower risk to those involved.

It is imperative that any system utilized in one area *must* be able to talk effectively to other systems so that all data can be viewed comparatively with minimal disruption or sorting out by the end user.

A unique identifier (e.g. Community Health Index number, CHI) should be used across all health and social care records, to make data linkage robust and comprehensive. There should be key opportunities for individuals to be informed about the anonymised use of these data, how they can contribute to data driven research, or opt out if they wish (eg when registering at GP, dentist, etc., attending hospital, organising new social care or moving into a care home etc.).

13B. What do you believe are the key data needs and gaps that are faced by industry, innovators, and researchers when it comes to Scotland's health and social care data?

Data is not a panacea, but good data and improved understanding are key building blocks in making health and social care better, and a necessity for health and social care integration. We need better social care data that can be linked to health and other data to improve our understanding of the needs of some of our most vulnerable citizens. Better data and understanding are critical, but have to be used effectively to improve the quality, safety and experience of care in later life. Collecting data from multiple sources can create a comprehensive picture of the needs of each person, illustrating what support (mental, physical, social, adaptations) they need now, or in the future.

Social care sector is already significantly behind the health sector. In the health sector, primary care is behind secondary care.

Currently, poor quality data, poor integration and poor communication between systems create an unnecessary burden on users at either end of the data journey, health professionals and researchers. In previous consultations, we have mentioned how care home residents and those receiving care-at-home are poorly represented in routine data, reflecting the wider marginalisation of the social care sector and the people who need social care. People in receipt of adult social care are among our most vulnerable citizens, but we cannot systematically improve their care without understanding their needs and current patterns of care.

A lack of ethics reviews available to researchers interested in care home research is a key gap that affects researchers' ability to carry out research that involves care home staff and residents, who are a historically underserved population. This gap puts researchers off considering involvement of care home staff and residents, particularly those who lack capacity to consent to participate, which only perpetuates a knowledge and understanding gap that made the management of the Covid-19 pandemic more difficult.

14. Used appropriately and well, technologies such as Artificial Intelligence can help to improve decision making, empower health workers and delivery higher quality

health and social care services to citizens, improving how you receive health and social care services:

14A. What are your views on the benefits of using AI to improve the delivery of health and social care services?

AI is one of the key pillars upon which the Advanced Care Research Centre is based. The potential for AI's role in improving health and social care services is vast, and we are fully supportive of this to continue.

14B. What safeguards do you think need to be applied when using AI?

The same as for data – ethical review, a plain language explanation of the purpose and aims of each proposal.

8. Next Steps for the Data Strategy for Health and Social Care

8.1. What will we do with your responses?

Your responses will be gathered and analysed to input directly into the development of the Data Strategy for Health and Social Care. We will publish responses on the [Citizen Space](#) platform in line with Scottish Government's commitment to openness and transparency (See [section 9.2](#) for more information). While this consultation is live, we will continue our engagement across the health and social care sector, through workshops, presentation, and open engagement session.

8.2. When will the Data Strategy be published?

There will be a phased approach to achieving the vision of the Data Strategy and phase one, setting out the vision, ambitions and actions will be published by the end of 2022.

Further phases will be published as we continue work on the Data Strategy over the coming years. Additional actions and delivery plans will be published until the overarching vision has been met.

9. Information about the consultation

9.1. Scottish Government consultation process

Consultation is an essential part of the policymaking process. It gives us the opportunity to consider your opinion and expertise on a proposed area of work.

You can find all our consultations online by using the Scottish Government's consultation hub, Citizen Space. Each consultation details the issues under consideration, as well as a way for you to give us your views, either online, by email or by post.

Responses will be analysed and used as part of the decision-making process, along with a range of other available information and evidence. We will publish a report of this analysis for every consultation. Depending on the nature of the consultation exercise the responses received may:

- indicate the need for policy development or review
- inform the development of a particular policy
- help decisions to be made between alternative policy proposals
- be used to finalise legislation before it is implemented

While details of circumstances described in a response to a consultation exercise may usefully inform the policy process, consultation exercises cannot address individual concerns and comments, which should be directed to the relevant public body.

9.2. How to respond

We are inviting responses to this consultation by 12 August 2022.

Please respond to this consultation using the [Scottish Government's consultation hub, Citizen Space](#). To access and respond to this consultation online, please see follow the link to the consultation webpage on Citizen Space. You can save and return to your responses while the consultation is still open. Please ensure that consultation responses are submitted before the closing date of 12 August 2022.

If you are unable to respond using our consultation hub, please complete the Respondent Information Form to:

Digital Health and social care: Strategy & Policy Unit
Scottish Government
Basement Rear
St. Andrews House
Edinburgh, EH1 3DG

9.3. Handling your response

If you respond using the consultation hub, you will be directed to the About You page before submitting your response. Please indicate how you wish your response to be handled and whether you are content for your response to be published. If you ask for your response not to be published, we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

If you are unable to respond via Citizen Space, please complete and return the Respondent Information Form included in this document.

To find out how we handle your personal data, please see our webpage on privacy policy.

9.4. Next steps in the consultation process

Where respondents have given permission for their response to be made public, and after we have checked that they contain no potentially defamatory material, responses will be made available to the public on our consultation hub, Citizen Space. If you use the consultation hub to respond, you will receive a copy of your response via email.

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us. Responses will be published where we have been given permission to do so. An analysis report will also be made available.

9.5. Comments and complaints

If you have any comments about how this consultation exercise has been conducted, please send them to the contact address above or email to HSCDatastrategy@gov.scot

10. Impact Assessments

The following assessments are being carried out as part of the development of the Data Strategy. These will be published in full ahead of the strategy publication date.

- **Ethics**
- **Children's Rights and Wellbeing**
- **Equality**
- **Island Community**

11. Glossary of terms

Glossary of Terms: Special, unusual, or technical words or expressions used in relation to the Data Strategy for health and social care.

A		
	Anonymised Data	Data that has been processed in such a manner that personal data cannot be attributed to a specific individual.
	Algorithm	A process or set of rules to be followed in calculations or other problem-solving operations, especially by a computer.
	Artificial Intelligence (AI)	Artificial Intelligence (AI) uses computers and machines to mimic the problem-solving and decision-making capabilities of the human mind.
D		
	Data Accessibility	The extent to which people can use data available to them.
	Data-driven	Determined by or dependent on the collection or analysis of data.
	Data Point	An identifiable element in a data set.
	Data Standards	A technical specification that describes how data should be stored or exchanged for the consistent collection and flow of data across different systems, sources, and users.
	Data Strategy	A Data Strategy is a long-term, guiding plan that defines the people, processes, and technology to put in place to solve data challenges and support organisational goals.
	Deep Learning	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.
	Digital Health and social care	Digital health is a field that includes digital care programs that are related to enhancing the delivery of health and wellbeing products and services.
	Direct Care	A clinical, social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals
F		

	Fairness	Consistent treatment of the people of Scotland, empowering individual voices
H		
	Health and Social Care	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.
	Health and Social Care Data	Information about an individual or many people: health and social care data is information generated by individuals or agencies in the health and social care sector. This can be people using fit-bits, health and social care services or researchers. It can be used to provide a care package or plan services. It can also be pooled together (“aggregated data”), for example to produce statistics or management information.
I		
	Innovation	New ideas or methods.
	Interoperability	The ability of computer systems or software to exchange and make use of information.
M		
	Machine Learning	The use of data and algorithms automatically by machines to gradually improving their accuracy in a desired output without explicit instructions.
	Management Information	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.
P		
	Protected Characteristics	Protected characteristics are specific aspects of a person's identity 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.
T		
	Transparency	A systematic approach to communication, arming individuals with meaningful information.

12. Respondent Information Form

Please Note this form **must** be completed and returned with your response.

To find out how we handle your personal data, please see our privacy policy: [privacy policy on gov.scot](#)

Are you responding as an individual or an organisation?

- Individual
 Organisation

Full name or organisation's name

Phone number

Address

Postcode

Email

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

- Publish response with name
 Publish response only (without name)
 Do not publish response

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

No

Information for organisations:

The option 'Publish response only (without name)' is available for individual respondents only. If this option is selected, the organisation name will still be published.

If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.



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