Data Strategy for Health and Social Care

Analysis of Consultation Responses

Digital Health
& Care Scotland

Date: November 2022

Contents

Executive Summary

Introduction

A public consultation to inform the development of Scotland's first Data Strategy for health and social care ran from 16 May to 12 August 2022. This was an opportunity to understand a wide variety of stakeholders' views on how data should be gathered, stored and used, and will shape the final Data Strategy, due for publication in early 2023. The consultation contained six closed and 26 open questions and received 162 responses; 62 from individuals and 100 from organisations.

Part One: Empowering people

Key finding: Transparency and consent were recurring themes. Respondents stressed the importance of being aware of what data is collected from them, how it is stored, what their data is used for, and by whom. This information should be available in clear and accessible formats to allow for informed consent and the sharing of relevant data.

When asked what they consider health and social care data to be, and what types of data they were most keen to have access to and control over, respondents typically perceived health and social care data as an individual's medical history, comprising: clinical notes from GP and hospital visits; diagnosis history including treatments offered and their outcomes; test results; and medication, prescriptions and vaccination history. Personal information was mentioned by some respondents, covering name, date of birth, contact details, next of kin or emergency contacts. Some stated they would like to access relevant information that could affect their treatment or care, or that would impact their ability to make decisions about their care or self-management of conditions. Types of data respondents felt uncomfortable sharing included: sexual health, mental health, non-anonymised data or information which could identify an individual; and historical information not relevant to current care needs.

Respondents were asked what would provide clarity on how their data is being used in a consistent and ethical manner, and how professionals using the data could improve trust. The importance of transparency over what data is being collected, how it is being stored, who is accessing it and what it is being used for was most frequently highlighted. Providing this information in clear, consistent and accessible ways, allowing consent to be sought and given, was a recurring theme. Other ways to improve trust included improving public understanding, information governance and data quality, and staff training in data literacy. Reflecting on situations where individuals are unable to interact with their own health and social care data, the most common theme was that existing legal safeguards such as Power of Attorney or Guardianship could be used as examples to create new safeguards.

There was widespread support when asked if data should be collected to help understand how health and social care services support those with protected characteristics. When asked what other purposes their health and social care data could be used for in the sector beyond administering care, respondents were broadly supportive of it being used for research and healthcare innovation, performance management and service improvement.

Responding specifically about the usefulness of data from wearable devices, there was recognition that this could be useful for monitoring conditions and highlighting a need for early intervention, though some health bodies questioned the reliability and usefulness of data collected by non-clinical devices.

Part Two: Empowering those delivering health care

Key findings:

There is a need for user-friendly platforms, interoperable systems, linked data and data standards to improve the accuracy, completeness, consistency and accessibility of data. These would allow for a joined-up approach that is scalable and flexible across services and lead to better quality services.

Practitioners can be empowered through investment in training to give them a better understanding of data processing, the value of data in health and social care, and of governance and ethics.

The consultation paper presented respondents with a list of six data skills and asked which were most in need of additional skills and training in the sector. Understanding what data exists and where to find it was identified as the key skills and training gap, followed by knowledge of how to access data and an understanding of governance. The need for further resources to address skills and training opportunities was mentioned by several respondents. Others noted the importance of training staff both in data literacy and security including GDPR, and also the need for improved understanding of the importance of collecting accurate and timely data.

To ensure the public can access, understand and use health and social care data, respondents highlighted the need for accessible and intuitive interfaces. Some noted the value of understanding service users’ needs before designing systems and platforms. Concerns about digital exclusion were mentioned by some who stressed that those without digital access to their data should not be further disadvantaged as a result. Other themes suggested in response to being asked about how to improve the quality and accessibility of data included interoperability, shared systems and linked data, and training, targeted recruiting and technical support. Many respondents noted that infrastructure improvements, both hardware and software, would be needed to improve the quality of data collection and accessibility.

Respondents were widely supportive when asked about mandating standards for gathering, storing and accessing data at a national level. A common reason for support included improved consistency and reduced duplication though using standardised terminology and data collection methods. This would provide a foundation for interoperability and ensure high quality data capture. Respondents supported standards for coding, governance and data protection, and for access and transparency about data usage. Existing standards, codes and guidance were suggested by several respondents.

Questions about considerations for an end-to-end system for providing business intelligence led many to highlight that removing barriers to data sharing was a key requirement. Respondents suggested a national, interoperable, central hub with a single access point or a digital front door. A few respondents suggested it needs to integrate old legacy systems as well as use interfaces between applications. The importance of using a single identifier for service users, such as the CHI number, to enable information to be linked across organisations was raised by a small number. Several mentioned trained staff were needed to develop a new system, i.e., upskilling current workers or hiring those with expertise in delivering end-to-end systems, health and social care data, hardware and software infrastructures and governance and data ethics.

There was support when asked about using a range of externally sourced data sets, with the most suggested being housing data, information from wearable technology, socio-economic and demographic data, and interactions with other services. Respondents noted the value this could provide in building a fuller profile of service users and improving patient outcomes. Reflecting on what positive outcomes could result from the better sharing of data, respondents described improved service user safety and better quality services where practitioners could meet the needs of service users more fully through more holistic and timely sharing of data. When asked about the priority pieces of management information required, there was recognition that this would also require improved collection and use of operational data such as Demand, Capacity, Activity and Queue (DCAQ) information, dynamic risk assessments, workforce size data and future service plans, as well as information about service user outcomes and data about protected characteristics.

Part Three: Empowering innovators, industry and researchers

Key findings:

There was broad support for using anonymised data to help drive medical advancements, evaluate the impact of health and social care interventions and shape future policy and planning. Conversely, some repeatedly opposed data being shared or sold to private organisations for commercial gain or for activities which are not in the public interest.

The use of safe havens and trusted research environments, international standards and interoperability were seen as vital to sharing data for research purposes, but challenges around the disparate nature of existing data sets were noted.

Respondents were asked how health and social care data could be used by industry and innovators, how this could be done transparently to maintain trust and confidence, and what would be considered an unacceptable use of data. Several ways in which data could be used to improve health and social care outcomes were suggested. The most prevalent theme was to drive medical innovation and advancements through research, followed by evaluating the long-term impact of health interventions, and shaping policy and planning. The most common objection to the use of health and social care data by industry was a concern the data would be used solely for commercial purposes or financial gain. Specific examples included using data for: market research and targeted advertising; developing and selling products and services; and predictive technologies such as insurance. Some noted that they were not wholly opposed to commercial bodies profiting from the use of population data if there were demonstratable benefits for the public or patients. Several felt it would be unacceptable to grant access to health and social care data for any research that is not in the public interest or does not have the support of NHS or the government, for example activity that promotes harmful health behaviours.

The most common suggestion for how industry and innovators can gain the trust and confidence of the public when using their health and social care data was through being open and transparent about how their data will be used and processed. Many suggested trust could be built by ensuring researchers only have access to aggregated and non-identifiable data. Another prominent suggestion was strict compliance with data protection legislation and ethical codes of conduct. Some felt trust could be built through innovators and industry making greater efforts to communicate the benefits of using the public's health and social care data.

A wide range of suggestions were made in response to questions about creating an infrastructure that supports access to data for research and innovation. These included: the value and role of safe havens or trusted research environments; ensuring infrastructure complies with international standards; interoperability; comments on cloud storage and open platforms; and independent auditing of infrastructure. Different views on ease of access to data were evident – some argued that processes should be clear and simple to engage with while others stressed that security should be prioritised. Respondents called on the Scottish Government to: provide clarity on key issues such as responsibilities, governance and security; allocate resources to build the framework or expand existing resources; and establish or allocate responsibility for infrastructure management and governance to a national body. Data needs and gaps faced by industry included the disparate datasets held by different organisations, data linkage, complex procedures to request data access, and concerns around data quality. Small numbers identified gaps in data relating to protected characteristics, equalities, and the social care sector.

Mixed views were expressed when respondents were asked about using Artificial Intelligence (AI) to improve the delivery of health and social care services, though on balance the majority of respondents were in favour. Many expressed a generally positive view, noting benefits such as earlier diagnosis and better treatment, the more efficient use of resources and the ability to derive new insight from large data sets. Several caveated agreement with an assumption that AI would be used in line with all relevant governance, regulation and codes of conduct, and alongside safeguards such as ensuring human oversight and recognising and addressing any bias in the data or setup.

Conclusions

Many individuals and stakeholders with detailed knowledge took part in the consultation, sharing their views on how health and social care data could be gathered, stored and used. Their views will provide a useful evidence base to draw on when shaping Scotland's first Data Strategy for health and social care.

Introduction

Background

The importance of high quality data in developing and delivering health and social care services is well known. As set out in the Strategy for Care in the Digital Age, the Scottish Government believes 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.

Development of Scotland's first Data Strategy for health and social care is underway. The Data Strategy aims to empower the use of quality data to drive high quality service delivery, bringing services together and improving the experience of the individual and their treatment. Extensive public engagement on the use of data has already been undertaken by the Scottish Government, but there is recognition that more work is required to help people improve their understanding and support of the use of data for public good.

A public consultation ran between 16 May and 12 August 2022. This was an opportunity to understand a wide variety of stakeholders' views on how data should be gathered, stored and used, which will shape the final Data Strategy, due for publication in early 2023. The consultation contained six closed and 26 open questions, covering three areas:

- Part One: Empowering people: asks for views from individuals, advocacy and representative groups on access to personal health and social care data, as well as topics surrounding data control and privacy.
- Part Two: Empowering those delivering health care: is aimed at those who work in health and social care services with questions about how to gain confidence in accessing, gathering and sharing relevant information to enhance outcomes.
- Part Three: Empowering innovators, industry and researchers: focuses on those who can deliver new technology to work for the public benefit.

Profile of respondents

In total, 162 consultation responses were received. Most were submitted via the online consultation platform, Citizen Space. Those received in an alternative format, for example, a PDF document, were entered into Citizen Space by the Scottish Government.

Individuals provided 62 responses to the consultation; the remaining 100 were from organisations. Organisations were asked to select from a list which sector their organisation belonged to, and 14 individuals also indicated the sector they worked in. The largest share of responses came from 53 public bodies, of which 28 were NHS boards, organisations or networks[1] or health related public bodies, and 13 were Health and Social Care Partnerships (HSCPs). Third sector organisations (20), representative bodies (16)

---

[1] Although not all of Scotland's Health Boards responded directly to the consultation, they are all represented in some way by a response; for example NHS Scotland Board Chief Executives and Board Chairs Groups' response represents all the boards.

and academia (10) were also represented. Appendix A details the sectoral profile of respondents who took part in the consultation.

Analysis approach

The Lines Between was commissioned to provide robust, independent analysis of the consultation responses. This report presents the range of views expressed by consultation respondents under each section of the consultation document. A public consultation means anyone can express their views; individuals and organisations with an interest in the topic are more likely to respond than those without. **This self-selection means the respondents' views do not necessarily represent of the views of the population**.

Quantitative analysis

There were six closed questions in the consultation. However, because respondents did not answer every question, the quantitative analysis presented in this report is based on those who did answer. A full breakdown of the number and percentage response to each question is in Appendix B. Note that figures may not add to 100% due to rounding.

Qualitative analysis

Qualitative analysis outlines the key themes identified in responses to each question. The analyst team coded each response against a coding framework which was developed based on a review of the consultation questions and a sample of responses. In a small number of instances where alternative format responses contained information that did not align to specific questions, analysts exercised judgement about the most relevant place to include this material for analysis purposes.

A few organisations provided detailed responses reflecting their subject matter expertise. There is not scope in this report to fully summarise these responses; however, the responses are referenced where possible. Where appropriate, quotes from individuals and organisations are included to illustrate key points and to provide useful examples, insights and contextual information. Full responses to the consultation, where permission for publication was granted, can be found on the Scottish Government's website.

Weight of opinion

Qualitative analysis of open-ended questions does not permit the quantification of results. To assist the reader in interpreting the findings, we use a framework to convey the most to least commonly identified themes across responses to each question:

- The most common / second most common theme; the most frequently identified.
- Many respondents; more than 30, another prevalent theme.
- Several respondents; 20-29, a recurring theme.
- Some respondents; 10-19, another theme.
- A few / a small number of respondents; <10, a less commonly mentioned theme.
- Two/one respondents; a singular comment or a view identified in two responses.

Part 1: Empowering People

This chapter presents an analysis of responses to the first set of questions in the consultation, which focus on how individuals can have greater access to and control over their health and social care data. As noted in the consultation, this includes the ability to view and request updates to information in their records, and access information such as test results, letters and treatment and care plans.

While Part 1 focussed on individuals' own data, the consultation encouraged respondents to answer as many questions as they could, and organisations were encouraged to answer Part 1 by considering what empowering individuals would mean for their organisation. The analysis below therefore includes both individual and organisation responses, highlighting where any differences were evident.

1A. We all have different perceptions of what our health and social care data may be. When considering the term 'your health and social care data' what does this mean to you and what do you consider it to be?

A total of 105 respondents commented on the first consultation question. They answered in two ways; most reflected on the types of information they would consider as health and social care data, while others described who might hold the data.

Types of health and social care data

The most common perception of health and social care data, held by many respondents, was an individual's medical history. This was seen to comprise: clinical notes from GP and hospital visits; diagnosis history including treatments offered and their outcomes; test results; and medication, prescriptions and vaccination history.

"All paper and digital records held by any health or care team in primary care, community care, acute care, social care, dental, optometry. This could be written, verbal, photographic, recorded [and] include demographic information about me, consultations, appointment details, inpatient stays, outpatient attendances, investigations, test results (e.g. x-rays, blood results, endoscopies) diagnoses, treatment decisions, medications / prescribing history, maternity records and details of my children…" – Individual

"'Health data' as used here includes all information that could or should be included in every patient's health record (ideally held electronically) e.g., clinical examinations, signs, symptoms and diagnostic tests including scans and laboratory tests, treatments prescribed, records of vaccination, procedures undertaken and outcome measures, as well as similar information generated during the conduct of a clinical trial." – ABPI

Many respondents gave a general comment that the term encompasses any or all information held about someone's health and social care, but did not provide more detail.

Personal information was mentioned by some respondents, covering name, date of birth, contact details, next of kin or emergency contacts, ethnicity and preferred language, with a very small number including occupation and financial details. Some others felt health and social care data would include a history of interactions with health services throughout an individual's life e.g. emergency care, maternity, dentist, opticians, mental health services, physiotherapists, occupational therapists and osteopaths.

A few also considered including a record of past and future appointments, details of waiting times for treatment, a log of all communications e.g. letters from GPs, and equalities data. A small number suggested that it should include their wishes for current and future treatment, or any information which would be helpful to determining their care.

Very small numbers each suggested it could encompass: any data linked to an individual's CHI (Community Health Index) number; family health history and causes of death; any experiences of problematic substance use; sensitive personal data e.g. sexuality or continence; non-clinical data such as census data; housing support and social security; environmental monitoring data; or interactions with police and justice services.

Only some respondents specifically described what might be included in social care data. These comments varied and included: information about care needs; care plans, carer support plans and emergency plans for carers; a log of contact, appointments and interactions with social work, social services or social care including use of care homes and any private or third sector providers; information about relationships and family dynamics; and financial arrangements associated with social care provision.

Who holds health and social care data

Respondents were most likely to state that health and social care data is information held by the NHS. A few respondents each stated that the term could refer to: data collected or held by an individual, particularly from wearable or fitness devices; data held by a local authority, especially in relation to social work and social care; and data held by other public bodies, private or third sector organisations who deliver care and support.

Need for a clear definition

A few individuals and organisations such as Age Scotland highlighted the large amount of information that could be considered health and social care data, and how public understanding of the term can vary considerably. Consequently, there were calls from respondents for a clear definition to be developed, particularly for social care which organisations such as Key and Community Lifestyles and Coalition of Care and Support Providers in Scotland (CCPS) noted can be more challenging to define.

> "If a national, mutually agreed and understood definition of 'health and social care data' is to be arrived at, in order to further this strategy, Social Work Scotland believes greater precision is needed to avoid confusion among delivery and strategic partners and people getting support, to avoid inequity and potential rights infringement. Clarity and consistency of understanding is essential." – Social Work Scotland
>
> "Because we all have different perceptions of what our health and social care data may be it is critical that the Government's definition is clear and clearly communicated to the population. Without that clarity there can be no ethical, transparent and inclusive sharing of health and care data and, more critically, who actually owns it." – University of the Highlands and Islands

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?

Two types of comments were evident in the 95 open responses to Q2A. Most described a variety of types and levels of data they would like to access, while some made more general comments about access and control.

Types of data

By far the most prevalent theme in open comments was having access to and control over specific medical data, with individuals and organisations making similar suggestions. Most frequently mentioned was access to test results including an interpretation of what the results mean. A few individuals noted this would save GPs and patients time. Other data included: clinical notes; reports of consultations; diagnoses; prescriptions; allergies; and any correspondence about these issues.

“Quicker and direct access to my test results, for example direct notification where appropriate, rather than having to wait for the GP or other service to receive, process and then notify me of results by letter/telephone or face to face consultation.” – Individual

“Access to current, relevant information about an individual’s planned treatment – medication, test results, scans and x-rays, appointments and admissions/discharges. A personal health dashboard. This would allow greater transparency and control for individuals” – NHSS Records Management Forum and NHSS Health Records Forum

Some respondents stated they would like to see relevant information that could affect their treatment or care, or that would impact their ability to make decisions about their care or how they self-manage conditions. This included some of the data above, but also care plans and a log of ongoing symptoms or observations.

A broader response was given by some who stated they would like access to all data, all their medical records, or anything they might need to review or could need corrected.

“I expect to have access to all of my health records without having to request it… I cannot prioritise the health data I feel is most important – it should all be available.” – Individual

“Individuals should have full access to their own health and social care records with a mechanism for providing summary data for ease of access [and] be able to update their own records e.g. to add information about changes or increased needs.” – Carers Scotland

The potential to access and use data to keep people informed was raised by some respondents. They suggested that individuals should have access to: details about their previous and upcoming appointments, including the ability to book appointments; waiting time information; and schedules for treatment.

Several other types of data were each mentioned by a few respondents. These included:

- Personal details such as name and contact details, with respondents particularly keen to have a way to ensure contacts details are correct.
- A full vaccination record was requested by mostly individuals and one organisation.
- A history of service use including interactions with maternity, emergency care etc.
- Sensitive information such as sexuality, sexual health and mental health. This is examined more under the analysis of Q4A.

Only a few respondents cited social care data specifically. Singular requests included information about dependents or a trusted person, access to a person's history with social care services, access to personal records for people with care experience, and an option for carers to provide updated information.

A small number of respondents highlighted data they did not want to access. A few individuals stated they did not want access to test results because they would be unable to interpret them without professional advice; a few organisations made the same point, arguing that releasing test results without an opportunity for explanation could cause distress. One individual wanted access to current data but not historical diagnoses. Another stated they would not want to see inter-professional notes e.g. ward round notes.

Other themes

Some commented broadly on the importance of individuals having access and control over health and social care data, and of individuals being informed about and empowered to make decisions about how their data is used. A small number stressed the importance of ensuring data being accessed is clear and understandable i.e. it is in plain English, avoids medical jargon and is accessible for those with a disability or difficulties with literacy.

Another theme, mentioned by a few respondents, was the need to ensure a joined-up approach to data. This should allow individuals to access data from all parts of the system e.g. GPs, hospital, dentists etc, but also enable access to the same information by all practitioners across health and social care. Inclusion Scotland and the People Led Policy Panel suggested the use of a health and social care passport could help reduce the need for people to constantly retell their story and could be updated over time and as circumstances and needs change.

Legal considerations

It should also be noted that a small number of respondents gave conflicting views around the legalities of offering individuals access to and control of their data. Glasgow City Health and Social Care Partnership (HSCP) provided a detailed response where they expressed a view that the proposals outlined in the consultation paper are "*in contradiction to the basic principles of data protection law*". In particular, they highlighted the misconception that an individual – the data subject – has control over 'their' health and social care data, when it is the data controller who determines how and in what way their data is processed and used. The Information Commissioner's Office stated that allowing a patient access to their health data is in line with UK GDPR, and that it encourages data controllers to provide individuals with remote access and be more involved in their own care.

“Care will be needed around both the controllership situation and possible tension between a clinical record and a patient’s view and the responsibilities of the controller to control access” – Information Commissioner’s Office

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? If yes, what safeguards need to be in place?

Among those answering the closed question Q2B, 78% agreed that delegating access would be appropriate; 20% were unsure and 2% disagreed (representing two individuals). Organisations were marginally more likely to answer yes – 81% compared to 76% of individuals. Over four fifths of most sectors answered yes, including all HSCP, other public bodies and academia, but those in the third sector were least likely to answer yes (64%). A full breakdown by sector is available for this and all other closed questions in Appendix B.

The follow-up question was answered by 95 respondents, primarily those who agreed with delegated access but also some who were not sure or did not answer the closed question.

Use or mirror existing safeguards

The most common theme was that existing legal safeguards could or should be followed or used as examples to create new safeguards. Most prevalent was that access should only be delegated where there is Power of Attorney or Guardianship already in place. Others mentioned the potential to follow the Adults with Incapacity safeguards or made broad comments about legally defined roles being in place e.g. parent with parental rights.

Consent

A recurring theme, mentioned by several respondents, was that the individual delegating access would need to give their consent, if they had the capacity to do so. Recognising issues around capacity, a few suggested delegation would ideally be arranged in advance while a patient was fit and able; if not, suggestions for delegation included to a GP and a ‘break glass’ clause where access was granted for immediate care needs. A few called for consent and delegation rights to be regularly reviewed because an individual’s capacity to interact, and their relationship with their trusted individual, can change over time. A small number argued that more support should be given to those who find it challenging to interact with their data, rather than assuming control should be delegated in the first instance. Inclusion Scotland noted the need for greater supported decision-making to ensure disabled people can exercise their legal capacity. A very small number stated that the delegated individual should also consent to taking on that role.

Assessing the suitability of the trusted individual

Several respondents raised concerns about a trusted person’s suitability and competence and suggested safeguards to address this. Some stressed the need to verify the identity of the trusted person. A small number suggested that a nominated person needs to clearly understand the role of delegated access, with a very small number suggesting training on their responsibilities.

“Appropriate safeguards and privacy measures are essential to protect everyone’s personal data. There should be measures in place to validate the guardian/care/trusted individual and controls surrounding eligibility criteria. These measures should be directed towards validating the guardian/ carer/ trusted individuals’ identity, their relationship to the individual and ability to handle delegated data appropriately and safely.” – Cancer Research UK

“…Any agreement to delegate access needs to be properly identified using identification/validation and with the named individual’s consent, in the absence of a formal power of attorney/guardianship lodged with the office of the public guardian. Many utility companies use the term ‘authorised contact or alternative contact’ but have an enforced process to ensure the relationship and authority are legitimate and appropriate.” Renfrewshire HSCP

Mixed views were expressed on who should be a trusted individual. A few felt a family member would be appropriate; others disagreed. Opponents argued that next of kin may not have an individual’s best interests at heart or expressed concerns about exploitation. They called for acceptance in the sector that any anyone could be nominated as a trusted person, for example a few suggested sharing information with carers. Another safeguard, mentioned by a few, was delegating access to two individuals to reduce the risk of abuse.

“The individual’s preferences should be respected as much as possible, and certainly there should not be the assumption that a person should have access to someone else’s health and social care data by default because they are next of kin.” – Individual

“…Further clarification will be needed on exactly who can, and why, access data belonging to someone else – being a guardian or carer is insufficient of itself. Relationships are complex and the individual’s wishes must be obtained and respected; there are many reasons why someone might not want a parent or guardian to access their records on their behalf. The same applies to adult children of older people.” – Social Work Scotland

Less commonly mentioned themes

Other themes and suggested safeguards included:

- Ensuring the trusted person can only access relevant data was raised by some.
- A few respondents urged for delegation rights to be clearly defined and recorded so that all parties know who is involved in decision-making and in what way. Similarly, a small number called delegated access to follow all governance and sharing frameworks or for clear and straightforward frameworks and procedures to be used.
- Consideration of the rights and privacy of young people was raised by a small number. Singular comments ranged from enabling young people to make their own decisions, their right to keep their information confidential and worries about overly restrictive parents, and concerns about child protection e.g. in domestic abuse where both parents maintain parental rights and access to data could cause harm. Children in Scotland called for the strategy to consider children and young people’s views about data and welcomed the Scottish Government’s efforts to engage with young people when developing the strategy.

3A. 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 that must be maintained when gathering, storing, and using health and social care data, what information would you find most useful in providing clarity over how your data is used in a consistent and ethical manner?

What data is being used for

The most prevalent theme in the 96 responses to Q3A was the need for transparency about what individuals' data is being used for. While many simply stated they would like to know this, others provided more detailed comments. These included the need for privacy statements which clearly outline the intended use of data, and respondents who stated they would only be willing to share their data if it was being used for positive reasons. A few suggested the publication of reports or summaries to demonstrate how using the data has a positive impact. Related to this, a small number of mostly individuals reiterated they would not agree to their data being sold or used for commercial purposes.

> "A very clear privacy statement which is updated to reflect exactly how and what information is shared across services, and also how each service uses each specific data attribute for the purposes collected." – Renfrewshire HSCP

Who data is being shared with

Several respondents stated they would want to know who their data is being shared with. Some individuals and a few organisations from multiple sectors called for a clear record or log of who had been given access to data, when, and for what purpose.

> "A running list of who has accessed my records and when, whether it is a department, an individual or a company. I can see that with social media records, why not my health care? Who is in my 'friends' list for my records? But I do think that some should be default, like your GP." – Individual

Data storage and security

Another theme, mentioned by some, was the need for information and reassurance that data is being stored securely. Around half of those mentioning this theme made specific points about data security, suggesting they would need clarity over whether their data was anonymised, how they could request changes to incorrect data, and how long data is stored and when it is deleted or destroyed.

Consent and procedures for data sharing and use

Respondents described some of the processes they would like to see in place to ensure their data is being used ethically. Some focussed on consent, questioning whether their consent would be sought, or stressing that it should be. A small number suggested there should be easily accessible opportunities to regularly review, update and withdraw consent, and that there should be a process for complaints. A few respondents noted that all data use should adhere to existing data protection policies such as GDPR and to data storing and sharing frameworks, agreements and governance.

What data is being collected, stored and shared

A less commonly mentioned theme, raised by some, was to have information on what type and level of data is being collected and accessed. A few called for safeguards to be in place to ensure that only relevant data is shared, or for individuals to be able to opt out of sharing certain data, or sharing with certain people, on a case-by-case basis.

> "There has to be a transparency mechanism for safeguarding patients' interests that should only authorise the disclosure of information for the necessary 'medical or care purposes' of improving patient care or when disclosure is in the public interest: no less, no more, and not just because the data is merely useful." – University of Leeds School of Law

Clear and accessible information

A recurring theme was the need for clear, consistent and accessible information about all the above points to be readily available to individuals. This was raised by both individuals and organisations, but especially by third sector organisations. Suggestions ranged from privacy statements written in plain English to consent dashboards which people can access to have a clear overview who is using their data and why, and potentially switch their consent on or off. Related to this, a few argued that a meaningful discussion with the public about sharing their data, highlighting how it can be used to benefit health and social care more widely, would be beneficial.

> 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?

Among those who answered Q3B, 87% felt it is important to collect data to understand how health and social care services are serving those with protected characteristics; 74% stated it was very important and 13% fairly important. One in ten (11%) were neutral and 3 individuals felt it was not important.

There were some noticeable differences by sub-group. Organisations were more likely to state this was very important (91%) than individuals (61%). Sectors recording high levels of total importance included other public bodies (100%), the third sector (100%) and representative / membership bodies (100%). All HSCP considered this important, though this was split between 71% who felt it is very important and 29% fairly important. By contrast, 80% of other health public bodies considered this important (73% very, 7% fairly) and 20% were neutral.

Some respondents – primarily third sector organisations and a few health bodies, representative bodies and individuals – elaborated on their response to Q3B at Q3C. Most reiterated their view that collecting information about protected characteristics is vital to understanding inequalities and the met and unmet needs of those groups, particularly as they can have difficulty accessing health and social care or experience bias or discrimination in their treatment. A few including Age Scotland and Inclusion Scotland called for more opportunities to disaggregate data to get a better understanding of impacts and outcomes for older people, disabled people, and other protected characteristics.

“Very important – protected characteristics exist to prevent discrimination, whether active or passive. The only way to measure whether a given service is equitable is to understand the demographics of the people accessing that service, and by observing patterns of outcomes related to certain characteristics. This will be essential for service design in the future.” – Community Pharmacy Scotland

Challenges around protected characteristics data were raised by a small number. Voluntary Health Scotland noted importance of transparency and honesty as some marginalised groups have a deep distrust of public services due to past experiences of discrimination which can impact the collection and sharing of health data. For example, a fear of health data being shared with the Home Office deterring asylum seekers from engaging with health services. Key and Community Lifestyles called for consideration to be given to “*data which is wider than protected characteristics, for example legal status, communication needs, digital activity/inactivity, and personal situations which require sensitive handling such as domestic abuse/coercive relationships*”. Chest Heart and Stroke Scotland welcomed a proposed integrated health and social care record which would mean equalities information could be recorded once, in private, at an appropriate time, and making it more likely to be available to all services.

A few respondents called for greater training for health and social care staff in equalities issues, protected characteristics and human rights approaches more generally.

“And when it comes to equalities, better day to day evidence that the workforce understands and respects equality issues. If the person I see doesn’t get it, why would I trust them to keep my information and its sensitivities?” – Individual

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?

Q3C received 104 open comments. However, there was significant overlap in responses with the themes evident under Q3A covering transparency, consent and security. Other themes evident at Q3C included improved public understanding, information governance and data quality and staff training in data literacy. A small number noted that they already trust health and social care professionals with their data and had no concerns about this.

Transparency, consent and data security

A large proportion of comments at Q3C repeated themes described earlier, specifically:

- Many respondents reiterated the importance of transparency over how their data is being collected, stored, shared and used, with some recommending a clear record is kept of who accesses their date, when, and for what purpose. ABPI cited the steps the Estonian government has taken to allow patients to have access to their information and see who is using their data, alongside investing in cyber-security.
- Consent and being able to limit, restrict or revoke access to data on a case-by-case basis was mentioned by some respondents.

- Some noted that their trust would be improved if they could be reassured that their data was being stored securely with appropriate access rights and controls in place.

Improved public understanding

The most common theme at Q3C, not including the above, was the suggestion that an improved public understanding of how health and social care data is being used would increase trust. Respondents described how more work is needed to raise the public's awareness of what data is held about them, and how using the data benefits individuals and the wider population. A few suggested the public should be involved in developing systems handling health data. A common theme within this was the need to demonstrate the positive impact of sharing data, either through individuals seeing improvements in their own care as a result, or through the publication of reports and giving examples of where data has been used effectively or has driven change. A small number advocated public information campaigns to raise awareness, and others noted the need for clear and accessible communication.

"Prove that current data management is used efficiently across existing services where 'sharing' is not an issue e.g. across health boards and between primary and secondary health care" – Individual

"Trust could also be improved by providing individuals with examples of how data is used by those accessing it, both to improve care on an individual level and also to support improvements in the health and social care system" – The Innovative Healthcare Delivery Programme (IHDP)

Information governance

Some respondents stated that their trust would improve if there was clear evidence that all appropriate legislation and frameworks were being followed. This included adhering to GDPR, following governance frameworks with independent auditing, and publishing Data Processing Impact Assessments (DPIA). A few individuals, health bodies and HSCPs stated that it is important to see transparency and honesty when things go wrong, for example when a data breach occurs.

"Ensure staff are fully aware of consequences of accessing or sharing my data inappropriately, and that adequate action is taken when a breach occurs." – Individual

"The SSSC believes that ensuring the use of personal data is legally compliant is the most important thing that could be done to help to ensure a high level of trust." – The Scottish Social Services Council

Data quality and data literacy

Another theme was data quality, with two types of comments evident. Some respondents highlighted the importance of data quality, accuracy and completeness. They indicated that their trust would improve if they felt health and social care professionals understood the importance of, and were adequately trained in, the collection, recording and use of data, as well as data privacy and the handling of data. A few organisations including Microsoft, The Promise Scotland and the Health and Social Care Alliance Scotland provided detailed responses which stressed the importance of trusting relationships between individuals and professionals. They argued that trusting relationships can encourage individuals to feel empowered to share their information and to understand and make better decisions about data sharing, leading to better data collection and care. On a specific point, Aberdeen City HSCP noted the need for professionals to access secure equipment e.g. encrypted laptops and secure photocopiers.

The other strand of comments, from a small number of respondents, noted the importance of a means to review their data and correct any inaccuracies. A very small number argued a more integrated approach to data collection and sharing would improve trust.

“I don’t know what they access today but I think if they had the right information in one place and used it professionally then [I] would trust them more than the disparate, inconsistent records of today.” – Individual

4A. When considering sharing of your data across the health and social care sector, are there any health and social care situations where you might be uncomfortable with your data being shared?

A total of 95 respondents gave an open comment in response to Q4A. Respondents mostly took one of two approaches to answering the question, either citing types of data they would be uncomfortable sharing, or describing circumstances which would determine whether they were comfortable sharing. In addition, one quarter of those who answered stated there were no circumstances where they would be uncomfortable sharing.

Types of data

The most prevalent theme in responses to Q4A was the types of data which respondents would be uncomfortable sharing. A range of examples were cited by several individuals and a small number of organisations. Information about sexual health and sexual history was the most common, followed by information about mental health; both were raised by some respondents. All other examples were each mentioned by a few respondents, including: non-anonymised data or information which could identify an individual; historical information which is not relevant to current care needs; abortion history; information about disabilities; and one respondent mentioned problematic substance use. A small number elaborated by stating that this information could lead to them being unfairly judged.

“For the sharing of more sensitive information, it would be best practice to ask specifically for consent to share or restrictions over exactly what can be shared, e.g. mental health information, abortions, sexual health – these have a higher sensitivity.” – NHSS Records Management Forum and NHSS Health Records Forum

Four respondents made a distinction between health data and social care data. Three individuals stated they would not want their health data shared with social care. The Promise provided a detailed response outlining the best practice for respectfully sharing young people, parents and carers information.

Circumstances for sharing data

Consent was the second most prevalent theme in responses to Q4A, with all who raised this issue stating that information should not be shared without individual's consent. A small number stated that they would only be willing to share if the appropriate approvals and data protection controls were in place. One individual suggested that the level of client sensitivity should be part of a governance framework. The Innovative Healthcare Delivery Programme (IHDP) made a specific point calling for patients to be helped to understand how electronic images used for clinical assessment are stored and used.

Another theme, mentioned by some, was that their data should not be shared with organisations beyond health and social care, with private companies, or sold for profit. Some noted they would be uncomfortable sharing information if it led to prejudice or harm to them or others. For example, sharing health data with insurance companies or the Department for Work and Pensions could negatively impact the level of insurance or benefits an individual is offered. A few others noted that sharing protected characteristics, such as disability, sexual orientation or gender identity, or sharing a diagnosis such as HIV status, could increase stigma, particularly in some cultures or small communities. These points were also raised by small numbers at Q4B.

"A commonly cited area of concern was around care experience during childhood, and historical treatment for diseases such as HIV; both of which continue to carry stigma, with individuals facing discrimination. Another example was the location in which certain health and social care services were provided, the detail of which might reveal a history of incarceration, whether for criminal or mental health reasons. There may also be records which – under the Equality Act 2010 – are protected and sensitive; for example, gender assigned at birth, which is likely to be information that many professionals do not need or should not be privy to." – Social Work Scotland

Others felt that they would only be willing to share data that was relevant to the professional and their care setting. Similarly, a small number stated that sharing should only be considered on a case-by-case basis, once they could provide informed consent.

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?

Research and healthcare innovation

The most prevalent theme in the 87 open responses to Q4B was a willingness to share health and social care data for the purposes of research. Many respondents simply stated research would be a valid purpose for sharing but did not elaborate. However, some gave more detail, highlighting that research could result in improved interventions, new or more effective treatments, or create alternative ways to access services.

"To improve care for everyone (provided my privacy is protected) – both through service improvement by NHS but also research to work out better ways to improve health and care (treatments/ interventions)" – Individual

Performance management and planning

A recurring theme, mentioned by both individuals and organisations, was the sharing of data for service improvement. Some respondents noted the value of data in allowing health and social care services to audit and evaluate services, manage performance and improve the quality of service delivery. A few specifically highlighted the importance of data and data modelling in planning the distribution of funding and resources and forecasting future demand for services. Specifically, Inclusion Scotland noted that data on people's social care support needs will need to be collated in an unprecedented way to allow the new National Care Service to understand the need for services and plan at a local and national level.

Sharing data for use in developing wider public health policy was also mentioned by a few respondents, for example in developing public health initiatives and epidemiology.

"There is also an important distinction to be made between information shared about an individual to facilitate the delivery of a service, including protection, and information shared to evaluate and improve the quality of a service overall. The former requires detailed personal, identifying information to be shared, the latter does not. However, it is all "your health and social care data". The NHS has a framework for the safe use of individual's data for research and evaluation purposes, developed over decades. Any 'health and social care' data strategy should learn from, and where relevant replicate, this framework, The strategy must also make clear the distinction, described above, between purposes linked to the delivery of a service, and purposes linked to the administration / management / evaluation of a service." – Social Work Scotland

"The use of health data is crucial to the effective planning of services. Without data about how care is administered and the outcomes of this care, it is difficult to support the continuous quality improvement that is needed to improve patient care. The public must be consulted and informed about how their data is used to improve services and identify quickly where issues in care arise." **–** British Heart Foundation Scotland

Sharing data to administer care

Though the focus of the question was on the sharing of data for other purposes, some respondents reiterated the benefits of data sharing on administering care. Respondents argued that more data sharing was required within health and social care to ensure that services can provide the right care at the right time, without relying on the patient to provide necessary information. In their response, Microsoft described the example of the Dorset Intelligence Insight Service (DiiS). This was set up to link a patient's health, social care and socio-economic data from primary care, GPs, community and mental health, the police force, the fire service, and Dorset's three acute hospitals, and is now being used to make proactive decisions about individuals' care and in wider planning in the area.

Safeguards when sharing data

Around one in eight of those answering Q4B stated that they would not be comfortable sharing their data for other purposes within health and social care. Mydex CIC questioned whether the proposed sharing was feasible under existing data protection legislation.

Several other respondents outlined steps they would like to see in place to ensure they have control over how their data is shared, typically repeating actions or processes which have already been outlined in this chapter. In summary: several respondents noted that only anonymous data should be shared; some stressed that data should only be shared once consent had been given and this may need to be requested and granted on a case by case basis; and a small number reiterated that they would not be willing to share their data with private organisations.

5A. More people are using wearable devices to track their own health including sleep activity, mindfulness, heart rate, blood pressure and physical activity. Do you gather your own health data for example measuring activity, sleep patterns or heart rate through a mobile phone or watch?

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?

Of those who answered Q5A, 65% stated they gather their own health data. Among the individuals who answered, 63% collected their own data. Given the more personal nature of the question, only 23 organisations responded, but of this group 70% answered yes.

Open comments were given by 73 respondents; slightly over half were individuals. The most common theme was agreement from several respondents, mostly individuals, that they would be happy to share their wearable data to improve services. A few gave examples of how they already collect or share data e.g. a Fitbit. Conversely, a very small number explicitly stated they would not share this information.

Uses of wearable data

The second most prevalent theme was that people's own health data, collected from wearables or from equipment such as personal alarms, could be useful for monitoring conditions such as diabetes or heart disease, or in highlighting a change in measurements which could mean there is a need for early intervention. A mix of individuals and organisations felt that as well as being useful for self-management, sharing this information could support ongoing care and reduce unnecessary appointments.

Some respondents argued that data collected by individuals should only be shared if it was linked to a specific purpose which was clinically relevant to the individual's care. A small number stated that they would be happy to share their data if the specific purpose was to help improve health outcomes and services more widely.

Consent and control

Some respondents highlighted the importance of individuals having control over sharing their wearable data, that it is only shared with consent, and ensuring individuals have sufficient information when deciding whether to share. A few stated they would only be willing to share their data if it could be stored securely or called for more clarity on how shared data would be stored and accessed. A small number stressed that they would not be willing to share wearable data with third parties for commercial purposes.

“I might be willing to use remote health monitoring devices and share that data with healthcare professionals, but I’d be concerned that it was also being shared with 3rd parties e.g. the equipment suppliers. Hence, I would want to have a more detailed understanding of who would have access to my data throughout the entire data lifecycle, including data gathering, processing, analysis, and storage.” – Individual

Reliability of wearable data

Another theme, raised primarily by some health bodies and HSCPs, questioned the reliability and usefulness of data collected by individuals. Respondents argued that data collected by personal devices is not as accurate as that recorded by medical equipment. Views were mixed; some felt wearable data should not be used, while others felt it could but with a degree of caution. A few respondents highlighted that the data might only be useful if it could be added to or synced with NHS systems and records, for example by using NHS built or approved apps for data collection. A small number raised compatibility and security challenges around transferring data.

Less commonly mentioned themes

Other themes, each mentioned by very small numbers, included:

- Ensuring that individuals who do not use, or cannot afford, wearable devices are not disadvantaged in the care they receive as a result, particularly as there may already be differences in health between users and non-users of wearables.
- Concerns that data collected by individuals, for example weight or physical activity data, could be used against them by biased professionals who shame their choices or offer inadequate treatment.
- One respondent suggested a system should be in place if the shared data requires an action e.g. there should be a process that triggers an appointment.

Part 2 – Empowering Those Delivering Health and Social Care Services

Part 2 of the consultation examined how people involved in delivering health and social care services can be empowered to use data. Questions included the need to develop data skills, and the technology, infrastructure and frameworks required to ensure high quality data can be collected, stored, accessed and used effectively to deliver services.

Data skills and training

6A. Considering skills and training opportunities for those delivering health and social care services, what are the top skills and training gaps relating to data in Scotland's health and social care sector?

At Q6A, respondents were presented with a list of six data skills and asked which were most in need of additional skills and training in the sector. Respondents ranked the skills from the most to least in need of additional training. An 'other' option was also available with respondents asked to elaborate on their answer.

The table below presents the outcome of the ranking exercise. In this instance, the data is presented among all respondents i.e. it includes those who did not answer the question.

Skill	Top 3	1st	2nd	3rd	4th	5th	6th	7th
Understanding of what data exists and where to find it	46%	25%	14%	7%	6%	6%	3%	1%
Knowledge of how to access data	38%	4%	15%	19%	11%	9%	3%	2%
Understanding of governance	30%	9%	10%	11%	10%	10%	8%	4%
Confidence in using data	30%	8%	9%	13%	12%	10%	9%	0%
Understanding / use of management information by managers	18%	6%	6%	6%	11%	14%	14%	4%
Data visualisation	16%	4%	7%	5%	8%	12%	19%	6%
Other	10%	6%	2%	2%	2%	1%	2%	22%
Not answered	-	38%	36%	37%	39%	39%	42%	60%

Respondents identified the understanding of what data exists and where to find it as the key skill and training gap. One quarter (25%) of all respondents selected this as the top skill gap, with almost half (46%) ranking it as one of the top three areas in need of additional training. While knowledge of how to access data was only selected by 4% as the top priority, over one third (38%) placed this in the top three.

Understanding of governance and confidence in using data were similarly ranked; just under one in ten selected each of these as the top skills gap, with three in ten including each area in their top three. The remaining skills of understanding and using management information and data visualisation were noted by some, but only featured in the top three of around one in six respondents.

Free text comments were invited from respondents who indicated there were ‘other’ skills and training gaps. The most common response focused on a need for training in digital literacy to help health and social care workers analyse data and use it to benefit their service and service users. This theme is related to the ‘confidence in using data’ option in the list of data skills presented in this question.

> “After consultation with our members, the RCOT believes that there is a training gap regarding being able to understand and analyse data. Some members are unsure on what conclusions can be drawn from data and how this may help health and social care practices.” – Royal College of Occupational Therapists

Some respondents provided comments connected with the ‘understanding governance’ option. The importance of ensuring that data is collected, processed and stored securely and in line with relevant legislation was highlighted in these responses. A few referred to issues around sharing data with other organisations and ensuring that members of the public can access data held about them.

Another theme was training in skills for collecting data in an accurate and standardised way. A few made comments about the importance of understanding equalities issues when collecting and analysing data. Other suggestions for training, each made by one respondent, included: systems thinking; process science; using data for service evaluation; data science; and the use of artificial intelligence and wearable devices in data collection.

6B. How do you believe skills and training gaps about data should be addressed?

Many respondents to Q6B noted that training in the categories mentioned in Q6A would be the best way to address the skills gap. In order from most respondents to least, these included: training in data literacy and analytics, specifically understanding the value of data collection and the benefits it would bring to health and social care work; governance; training for managers; and training in systems and platforms.

Resourcing

The need for further resources to address skills and training opportunities was mentioned by several respondents. Paid training time was mentioned by some, while others highlighted the need to invest in updated technology and more trained staff.

“Support and investment in skills, workers and infrastructure are needed to make this strategy a reality. It is imperative that staff are supported to feel comfortable handling data and using new practices. For example, one factor for improving data in Scotland is the standardisation of data across health boards that will allow for its more effective use. Health professionals must be engaged in the need for this standardisation and how it can best support patient care, whilst not creating excessive burden on health professionals.” – British Heart Foundation Scotland

Standardisation

Several respondents mentioned a standard, national approach to training to ensure there was a uniform approach to data collection, coding, analysis, access and use. This is examined in more detail in the analysis of Q8A and Q8B.

“A combination of in house and consistent regional/national training programmes (e.g. Scottish Digital Academy) are essential to build capacity and capability and would support public organisations to utilise data effectively for drawing insight, trend analysis and modelling. – Renfrewshire HSCP

Include in curriculum

It was noted by some respondents that data science should be a requisite part of medical training and education courses. One health board noted that data standards will soon be a core competency of many positions and should therefore be reflected in the curriculum.

Accessible training

Continued professional development (CPD) was mentioned by some as needed to keep the current workforce up-to-date with technological advancement. Others argued that training and assessment should be part of job descriptions to ensure staff are undertaking mandatory training modules. A few mentioned using accreditation or accredited programmes, such as a master’s degree, to encourage staff participation. Some mentioned tailored training for different positions. For example, one organisation recommended The Data Lab[2] as a resource to facilitate programmes.

Some respondents highlighted the importance of creating training packages that encourage participation through ease of access. Others emphasised the need for training to be online, mobile-friendly, and free. Recommended educational materials also included leaflets, manuals, glossaries, dictionaries, and course catalogues. In contrast, a few suggested that courses be held face-to-face.

The response from Skills Development Scotland provided detail around the data skills training provision available in Scotland, but noted the demand for data skills across all sectors and that health and social care will be competing with the private sector for talent.

---

[2] The Data Lab is a part of the University of Edinburgh, and they work with companies to foster technological innovation through collaboration.

Less commonly mentioned themes

Other suggestions mentioned by small numbers of respondents included the following:

- Define career pathways for those with data training and experience to enter the health and care services.
- Create clear expectations and guidance regarding data standards.
- Assess the training needs for staff already in the sector.
- Engage in knowledge exchange with academia, private and third sector organisations, specifically regarding successful training programmes.
- Use innovative new technology, particularly developments in artificial intelligence.
- Adjust job descriptions to include necessary technological and data qualifications.
- Hire staff with protected characteristics to lead training sessions.
- Ensure that collection of protected characteristic data is central to new training and focus on how the lack of data can negatively impact treatment practices. For instance, the Coalition for Racial Equality and Rights (CRER) highlighted that "*a lack of adequate data to monitor the health outcomes of BME groups impacts the ability of health services to provide for minority ethnic needs*."

A few respondents suggested training tools that are already available, including Turas and LearnPro training software. Others recommended tools such as Microsoft Teams to create drop-in sessions. Scottish Care recommended using the Digital, Data and Technology (DdaT) Capability Framework to support the planning of any training programmes.

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?

Create practical and simple pathways

The most common theme in the 115 responses to Q6C was that health and social care data, whether that was personal, related to NHS systems or general medical information, was easy to find using intuitive interfaces. For example, respondents suggested platforms that provided data visualisation tools. Others noted the importance of simple, jargon-free language and a few mentioned digital banking apps as an example of how to share complex data with the public in an easily accessible and comprehensible manner.

Public consultation

The second most prevalent theme, mostly raised by organisations, focused on the importance of getting input from service users about their wants and needs regarding data access. Some recommended a patient-centred approach including user research that attempts to understand what types of information users want and how they plan on using it, before designing a platform. A few recommended using a co-design approach.

> "A pilot programme could identify what support and education people need to understand their healthcare record and what would be required to support this." – ENRICH Scotland

Other respondents focused on data management on potential platforms, noting that data should be co-produced or co-managed between service providers and service users, allowing the public to add and edit their own information.

> "We need to move beyond the 'access' paradigm into a 'co-manage' one. This question supposes the main value is in reading and reuse of data, when in many scenarios citizens or their trusted people need to be able to write into the record as well. Some of the Digital Health & Care Innovation Centre's most successful recent service transformations are based on citizens writing directly into clinical systems / records." – The Digital Health & Care Innovation Centre

Clear communication and Guidance

Several respondents mentioned the need for clear communication and guidance with the public throughout the process of researching, creating and launching any new data access interfaces. This included making presentations – covering the planned tools, safety and security measures and uses of data – available in multiple formats, such as digital communication and print pamphlets, and through public health channels. In line with responses at Q3C, some suggested that raising public awareness about the diverse uses of data and the resulting benefits would be essential to establish support for the project.

Standardisation and Interoperability

Confusion about terminology and measurements, inconsistent data capture and repeating medical histories were highlighted by several individuals and organisations as barriers to accessible and comprehensible health and social care data. Respondents noted support for interoperable systems and national standards which they felt would simplify the system for service users and improve care, specifically for instances of geographical relocation.

> "Consistently capturing, managing and sharing the same sets of data regardless of geographical location. This will help with portability across locations where service users/patients move between different HSCPs/Health Boards and also aids us to compare services across locations." – Renfrewshire HSCP

Digital exclusion and data literacy

Concerns about digital exclusion were mentioned by some respondents, who stressed that those without digital access to their data should not be further disadvantaged as a result. They recommended providing access to any necessary equipment and to training and support for those who need help using technology. While digital exclusion was considered important, a few noted access to data will only be effective if service users also have a level of health literacy. They argued individuals should be helped to understand their health and social care data as well as access it.

“Enabling individuals to have “control” of their data must ensure that inequalities in control are not inadvertently created. It will be important to ensure that there are other access methods available to citizens who are not fully digitally enabled or not digitally enabled at all. There remain fundamental issues with regard to internet access and the capacity to speedily access electronic records particularly in some rural areas and this must be addressed for benefits to be gained across all of Scotland.” – NHS Scotland Board Chief Executives’ Group

Investment in infrastructure

Some respondents mentioned investment in infrastructure as the first step in improving access for service users. This included investment in hardware that allowed for standard and easy data collection as well as tools to allow people without necessary devices to access their data. Other respondents mentioned investment in platforms and interfaces as necessary to provide clear access pathways for service users. Infrastructure is also explored in more detail under the analysis of Q13A

Concerns

Respondents raised a few concerns that did directly answer the question but highlighted some issues they saw as important to service user accessibility:

- Clear data protection and storage procedures were mentioned by some as necessary before granting public access. This included concerns about transparent communication, data ownership, and ensuring anonymity of service users.
- Respondents noted that data had to be a certain quality before it warranted sharing with the public.
- Staffing resources i.e., hiring trained staff or upskilling current staff was considered necessary to create accessible systems and programmes.
- A very small number of respondents said they did not believe any change to user accessibility regarding data was necessary.

Technology and infrastructure

7A. Thinking about improving the quality of data that is used by health and social care services, what three things are needed to improve quality and accessibility?

Interoperability

The most common theme in response to Q7A was the importance of interoperability, shared systems, and linked data to improving data quality and accessibility. Respondents highlighted the benefits of an interoperable system, such as a ‘tell-it-once’ or a ‘once for Scotland’ approach to data collection which allows data shared by users to be included in a Scottish-wide system, reducing the repetition of work by both service users and providers. Others highlighted how data silos or safe havens can be a barrier to creating a unified system for health and social care data.

“Interoperability – a great deal of research and statistical work involves lengthy and imperfect data linkage work to connect health records of individuals across pathways of care and measure outcomes. Therefore silos in health data systems not only affect joined up patient care but can also hamper research and innovation.” – Research Data Scotland

Standardisation

The second most prevalent theme focused on standardising data collection. Respondents recommended reducing duplication, using standard data collection methods, terminology, and coding practices, and requested standardising the types of data gathered and the forms used for data collection. A few noted the importance of agencies and bodies using the same programmes, software or platforms so they work together seamlessly. A few suggested using open-source software to connect different systems to one user platform.

“If the NDP [National Data Platform] was allowed access to structured records across the NHS today, they would find inconsistent, variably coded and duplicated data for many of the high impact data items that systems and citizens want access to… the structured data needed by systems and citizens will only be routinely collected at any kind of scale and efficiency through root and branch redesign of clinical workflows at all levels and tiers.” – The Digital Health & Care Innovation Centre

Training and support

Training, targeted recruiting and technical support was mentioned by many. This included training staff in data literacy and data security including GDPR, including an improved understanding of the importance of collecting accurate and timely data. Others recommended hiring and training specific teams, for example, IT teams to create new platforms, frameworks and programmes, or data management teams with medical knowledge to maintain health and social care records.

User-friendly platforms

The necessity of an easy-to-use platform was raised by many respondents, often giving the example of a ‘digital front door’ where health and social care data from different agencies and bodies is collated into one accessible place. There were suggestions for an interface where service users could ask questions, clean and clarify their personal data, and access information about their conditions or healthcare plans. Several also highlighted the importance of a user-friendly platform for service providers, noting that gathering quality data would only be possible if practitioners found it easy to use the designated platforms. Respondents recommended including mechanisms to capture digital copies of paper notes and investing in hardware that could immediately capture data electronically.

"Practitioners need to ensure accurate entry of data and completion of all fields etc. They need to see systems as an enabler rather than something that gets in their way." – Aberdeen HSCP

"It is therefore crucial that any new data strategy does not add yet more administrative burdens and pressures on social workers. The system needs to be intuitive and simple to use. Social workers should be able to see the positive impact that the system is having on their work. It should be time saving for them and make their work easier to do. For example, have easy-to-use templates that can be used to record and analyse data across departments and professions." – Scottish Association of Social Work

Infrastructure improvements

Many respondents noted that infrastructure improvements, both hardware and software, would be needed to improve the quality of data collection and accessibility. Suggestions for improvements included methods for efficient data entry including hardware for easy data capturing, or tools, forms or platforms that enable the easy sharing of data. Some called for a mechanism that enables real-time data sharing. A few called for tools that enabled clear data visualisation, both for service providers and service users.

Guidance and standards

Stressing that data quality cannot be improved through technology alone, several suggested clear guidance and expectations for data collection for staff. They suggested that as well as governance and legal frameworks, guidance should provide clarity about the data being collected and shared and who will have access. One respondent felt clear guidance would allow organisations to feel more confident about correctly sharing user information. Some respondents highlighted a need to audit and validate data regularly.

"There is a need for ongoing, centralised, routine maintenance and enhancement of quality conducted on data sets. Currently, there is a tendency to leave data accumulating and only assess its quality as and when it is required. A cultural shift is required to move away from spending long periods of time cleaning data towards proactively monitoring datasets before they become out of control. This would require investment but would be worthwhile by improving the overall quality of data" – Royal Society of Edinburgh

Less commonly mentioned themes

A few respondents each noted the need for the following: further research, including pilot programmes and user research; inclusion of private and third sector service providers in data collecting and sharing; a person-centred approach to data collection; and standards that mandate the collection of equalities data which is useful in analysing differential impacts. One felt it was important to distinguish between health data and social care data so that social care models are not overshadowed by medical models. Another mentioned the need to consider accessibility for people who may be less technologically literate.

A few respondents provided examples or recommendations for improved programmes. These included the use of natural language processing, using new data sets like Patient Reported Outcome Measures or patient activity data, and compliance with WCAG 2.1 AA+ accessibility standards as a minimum. The Digital Health & Care Innovation Centre recommended starting with small-scale projects, such as centralised vaccine records data, which could build momentum towards larger-scale change. Mydex CIC noted that the Digital Identity Scotland project is already working toward this goal.

Concerns were raised by small numbers. ABPI noted that existing data would need to be decluttered and cleaned to fix incorrect and incomplete information, and that the timescales needed to implement change may impact Scotland's competitiveness compared to other countries. Another noted legal barriers to data sharing and one highlighted that staff often do not have the time to collect and collate high quality data.

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?

Implementing standards

Of the 78 respondents who answered Q7B, the most common theme was the role organisations could take in complying with standards themselves, or assisting members, providers or service users in complying with new standards. Others highlighted the success of their own standards or codes, specifically regarding governance, confidentiality, and data protection, which highlighted their experience in supporting and implementing standards. For example, the Office for Statistics Regulation mentioned their Code of Practice for Statistics, the sharing of which could help those producing and analysing data.

Management of data

Several respondents described their data management experience, outlining the type and volume of data they store, how they collect, store and access that data, and their governance strategies. While not all these respondents spoke explicitly about what they would do with this data under a new data strategy, a few noted their interest in data sharing to benefit their members, patients or service users, and others mentioned an openness to sharing their data. This data ranged from health and social care details gathered from patients to public health sources, as well as the knowledge and experience of their service providers. As an example, Research Data Scotland Ltd mentioned they could assist by bringing together multiple datasets and facilitate the creation of new data catalogues with metadata which describes or gives information about the data itself.

> "We need to facilitate the sharing of data but also sharing of our knowledge and expertise of methodologies for collecting, coding, analysing, and interpreting data internally and with colleagues in other local and national organisations." – NHS Fife

Strategy implementation

While some generally expressed support for partnership working, some others specifically suggested how their organisation could help implement the new strategy. This included coordinating and communicating with stakeholders and colleagues across sectors, undertaking user research, working with individuals and professionals to co-design strategies, integrating impact assessments, advocating for members, leveraging clinical leadership to improve data quality, policy campaigning, and advising on ethics.

“Since the introduction of the Public Bodies Joint Working (Scotland) Act 2014 there has been considerable discussion across Health and Social Care Partnerships (HSCPs) on sharing information but unfortunately to date there has been limited progress. COSLA’s hope is that the development of a data strategy for health and social care will enable better collaborative working across health and social care services, in turn improving service delivery and satisfaction” – COSLA

Innovation

Developing technology, systems or platform architecture was mentioned by some respondents as a way their organisation could contribute to improved accessibility and quality. This included a few private organisations providing technological services, as well as public bodies or third sector organisations who have already adopted successful platforms and frameworks. Scottish Care mentioned that they had experience with practice-based innovation that improved data accessibility and quality.

Training

Some respondents suggested their role would be in staff training and promoting digital and data literacy with their workforce or members. A few mentioned the need for a commitment to resources, technological tools and time to facilitate training in accurate data collection and coding. A small number mentioned the importance of including data literacy and competency in curricula or national skills development programmes.

Review of current systems

Auditing and analysis of data gaps was highlighted by some respondents as the way in which their organisation could improve data quality, whether that was lobbying for research or conducting the research themselves.

“Our audit programme for 2022/23 includes a roundtable initiative on data gaps. This will engage leaders from across the public sector in what needs to be done in getting the basics rights with data so that its value can be realised. Data is an area that we will continue to monitor and consider as we plan our audit work programme.” – Audit Scotland

Less commonly mentioned themes

Other roles mentioned by small numbers included: promoting the utility of data, communicating how data is collected, stored and used to service users, and data analysis. A few respondents highlighted concerns about existing accessibility barriers and suggested that national guidance was needed to ensure all partners are working to the same principles and creating consistent and cohesive data sets.

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?

Types of data

Among the 109 respondents who answered Q7C, there was support for using a range of externally sourced data sets. Respondents noted the value this data could provide in building a fuller profile of service users and improving patient outcomes.

> "In Scotland, health is defined and influenced by more than clinical data; developing a health data ecosystem that can receive, link and allow health boards and researchers to access a diverse range of data sets beyond the health sphere would add richness and extend opportunities for quality improvement and research." – British Heart Foundation Scotland

Many respondents highlighted the value of sharing housing data and information to improve health and social care outcomes. Housing data – defined broadly as relating to housing tenure, quality of housing, and care homes, but also including health and social care data related to care in the home such as telecare and ambient assisted living[3] - was mentioned as a key way to track poverty and inequality by some respondents.

Several respondents each mentioned the following types of data, listed from most to least frequently mentioned. These included both data about an individual, and about their wider circumstances, environment or community:

- Information from apps or wearable technology, tracking data such as exercise, regular heartrate and sleeping patterns.
- Other biopsychosocial indicators of heath and health behaviours, such as educational attainment, socio-economic level, and HMRC information.
- Interactions with other services, including social services, counselling and therapy, private health services, dental, pharmacy, optometry, third sector organisations, community services and social prescribing, and emergency services.
- Demographic data, including employment status.
- Population indicators such as geographic information including poverty and deprivation levels and environmental information, including adverse climate, water quality and pollution levels.

Some respondents each mentioned the following types of data:

- Public health and health research[4].
- Equalities and protected characteristics.
- Transport, travel, and tourism.

---

[3] Ambient Assisted Living (AAL) involves the use of devices and ways to ensure that older people in the home stay safe and can age in place. It includes smart devices, wireless networks, software application, computer, and medical sensors.

[4] Contrary to the focus of the question on data from outside the sector, some respondents gave examples of types of data which might typically be thought of as being generated within the health and social care, such as public health data or clinical research data.

A small number of respondents each mentioned the following data categories:

- Immigration status.
- Search engine data.

A few respondents suggested that certain data be made available to service providers and users for reference, such as data from A Local Information System for Scotland (ALISS)[5].

Concerns

While the question concerned the use of data from outside the sector, some respondents opted to raise concerns about privacy and the excessive sharing of health and social care data outside the sector. The Royal College of Physicians and Surgeons of Glasgow and Turning Point Scotland cited concerns about sharing some medical information with organisations or departments without a health remit, who could misuse or misinterpret the information. However, Social Work Scotland noted there are existing protocols for sharing information with service providers outside health and social care. Others approved of wider sharing in theory but highlighted the importance of a clear plan covering what data could be shared and the safeguards in place to protect individuals. A few called for no additional sharing of data beyond what is already shared, stating a fear that an all-seeing state may misuse the data.

A small number raised concerns about the practicality of data collection and quality control. Community Pharmacy Scotland noted that there are gaps in accessibility within health and social care that need to be addressed, for instance local pharmacies are not able to access information about prescriptions histories, such as those filled in hospitals, that could help in ensuring patient safety.

> “We need to recognise that ‘social care data’ will be held not just by 32 Local Authorities, but by several thousand social care service providers across the third, private and public sector. The strategy should recognise that the level of complexity is an order of magnitude greater in the Social Care sector than Health. Quality, consistency and access are all major issues created by the complexity of the landscape and the strategy needs to articulate how these fundamental issues will be addressed.” – NHS Education for Scotland (NES)

Data standards and interoperability

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

8B. What data standards should we introduce?

---

[5] ALISS is a digital programme that enables people and professional to use and share resources, support, groups and services, and is supported by the Scottish Government.

Support for standards

There was widespread support for mandating standards among those who answered Q8A – 88% agreed, 2% disagreed and 9% were unsure. Though high among both, agreement was higher among organisations (94% agreed, 6% unsure) than individuals (83% agreed, 5% disagreed, 12% unsure). While organisations all recorded high agreement with mandating standards, there was some variation. Nine out of ten (91%) public bodies agreed, but this ranged from 100% among HSCP to 90% among other health public bodies and 80% of other public bodies. The third sector (93% agreed), representative / membership bodies (88%) and academia (83%) were also in support.

Many of the 118 respondents who answered Q8B either reiterated their support for mandating standards or expressed their support for the standards outlined in the consultation paper. This included general comments in support of consistent data collection and storage, which would provide a foundation for interoperability and ensure high quality data capture. Respondents supported standards for coding, governance and data protection, and for access and transparency about data usage.

> “Common data standards are important in maximising the value of data and joining up of services. They can help foster collaborative working across services and sectors.” – Audit Scotland

> “We agree for mandated national standards, but this is not the same as mandating the actual data sharing activity itself. These standards should allow for a range of privacy protecting methods to be used, and encode citizen ownership, control and choice at their heart.” – The Digital Health & Care Innovation Centre

Existing standards, strategies, and frameworks

Existing standards, codes and guidance were suggested by several respondents. Some recommended general frameworks, such as the Health and Social Care Alliance’s Core Principles from the ‘My World, My Health’[6] project, and others mentioned general standards set out by the UK Records Standards Body (PRSB), the Office for National Statistics (ONS) and Scotland’s Artificial Intelligence Strategy. Others provided very specific examples, including:

- Standards such as Fast Healthcare Interoperability Resources (FHIR), OpenEHR, and Observational Medical Outcomes Partnership (OMOP) Common Data Model.
- Coding systems, such as Systemised Nomenclature of Medical Clinical Terms (SNOMED), the Dictionary of Medicines and Devices (dm+d), Classification of Everyday Living (COEL), and International Classification of Disease, particularly the ICD10 and ICD11 codes.

---

[6] This project was delivered by the ALLIANCE Scotland and the Digital Health & Care Innovation Centre between November 2020 and March 2021, highlighting wellness solutions that are not necessarily medical.

- Other tools, such as AHP Operational Measures Project, the Caldicott principles, NHS research governance frameworks, European Data Format, use of HDR UK's metadata specification and the Data Utility Framework, and FAIR Principles.
- A few noted the importance of aligning new standards with legislation in existence, such as GDPR, Data Protection Act, and Public Records Act.

"Standards should be agreed on what data should be collected, agreeing a minimum core data that everyone has committed to, to ensure a core quality across Scotland. For example, across health boards male/female is currently recorded differently. There needs to be consistency across boards. Core fields that are mandatory regardless of the condition and then condition specific fields should be agreed. These should not be set by the strategy but should be agreed and endorsed by all health boards. Standardised data fields reduce the admin burden and allow for greater interoperability. Fragmented and disconnected data is a barrier to research as well as clinical practice, it would be helpful if data standards were also included for modernising data architecture for interoperability that could incorporate research readiness e.g., structured data store using common data model. Simplifying existing processes and structures should be front of mind (rather than creating new ones) at all times." – ABPI

Concerns

Several respondents did not suggest specific standards but raised concerns about the implementation of standards on a national level. These included a few each mentioning:

- Resourcing challenges, specifically training and staffing capabilities. A few argued that forcing data collection tasks onto an already burdened workforce could negatively impact care and data quality.
- Fears about use of data and access. Cancer Medicines Outcomes Programme (CMOP) specifically mentioned limiting access to for-profit firms unless appropriate scrutiny is in place.
- Innovation and the possibility that national standards could exclude suppliers and third-party tools that meet global standards and integrate with legacy systems.
- Failures of past attempts, for example eCARE7 and the National Clinical Datasets Development Programme.
- Concerns about adopting high-level or ideological standards rather than standards that focus on practical application.
- Cost of national data sharing standards, which may outpace the potential benefits.
- Responsiveness to local practice as national standards may remove autonomy from health boards.

---

[7] A European project to deliver solutions for the prevention and comprehensive management of frailty.

Other recommendations

A few respondents each mentioned suggested that standards should:

- Ensure a user-friendly output.
- Consider equalities and protected characteristics for data collection purposes.
- Create a human-rights or person-centred approach to data collection, especially regarding the types of data important to service users.
- Ensure the data standards are auditable and are being adhered to through enforcement or punitive policies.

While not directly related to types of data standards, a small number provided recommendations for implementation, such as:

- Improve infrastructure to ensure that all necessary hardware and software is available to all service providers participating in data collection and management.
- Use a meta-layer of infrastructure to solve interoperability problems.
- A few respondents including Aberdeen HSCP, Coalition of Care and Support Providers in Scotland saw the creation of the National Care Service as an opportunity to embed digital in social care, improve data collection quality and address existing information governance and data sharing barriers.

Management information

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

Three quarters (76%) of those answering Q9A agreed that greater sharing of data in the sector will lead to better quality services; 7% (all individuals) disagreed, and 17% were unsure. Organisations were more likely to agree than individuals (85% compared to 67% respectively). Agreement varied by sector. Nine in ten (91%) of all public bodies agreed, including 89% of HSCP and other health public bodies. Agreement fell from 83% of academic respondents to 71% of representative / membership bodies and 64% of those from the third sector.

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

The 80 respondents who answered question 9B interpreted it in two ways. Many described positive outcomes which could result from better sharing of data, building on their response to Q9A. Several others, however, provided technical solutions and implementation strategies that they deemed necessary to improve safety through data sharing. It should also be noted that a few respondents highlighted that the question wording referred only to health setting rather than care, suggesting 'practitioner' should have been used instead of 'clinician' and 'person' instead of 'patient'.

Improved safety and services

In line with Q9A, many respondents described ways in which sharing data and information would improve service user safety and lead to better quality services.

> "Ensuring that primary, secondary, and social care information can be seen across the different agencies should in itself (assuming the system actually works, and can be easily viewed) reduce patient harm, both directly and indirectly." – NHS Tayside Directorate of Public Health

Several respondents believed data sharing would enable health and care practitioners to meet the needs of service users more fully. These needs included not repeating histories, timely referrals to appropriate services, and earlier intervention for those nearing crisis points. One organisation noted the value of shared data in alerting primary care providers of potential problems, for example monitoring collection of regular prescriptions. Others mentioned the need for medical and social care records to be available across health board boundaries for complete care to be provided to those who may be more mobile, such as university students. The importance of sharing information to smooth the transition of young people from children to adult services was also noted.

A few suggested shared data would provide enhanced analysis of patient experience and treatment successes, such as Patient Reported Outcome Measurements, and could allow researchers to spot trends and target prevention programmes at a population level.

The challenge of primary care providers getting data from social care and vice versa was mentioned by a few, as was the slow process of sharing data between primary and secondary care providers. Other care providers, such as the ambulance service, do not have access to full patient records that would allow them to help service users at home.

Implementation recommendations

Several respondents suggested changes to data processes that are needed for patient safety to be improved. A few respondents suggested that efficient collection of data was needed, including rapidly updating systems with complete information.

> "Timing and completeness are key to improving clinical safety. Having immediate access to the most up to date data on a service user is an imperative to ensuring frontline staff can make the best decisions with confidence. And as an extension they need all the available information relevant to their role and the service they are providing. All relevant information should be accessible at the point and time of demand." – NHS Education for Scotland (NES)

A few respondents noted this could be accomplished through aggregated systems, such as a single patient platform or a single electronic health and care record. Community Pharmacy Scotland mentioned it should include secondary care provider records, such as pharmacy records and prescription histories. However, a few others highlighted the importance of data sharing guidance, security and governance, noting that linking data could cause harm if data is shared without consent. Respondents mentioned different guidance currently in use, such as the Caldicott Principles or Role Based Access Controls

(RBAC), that could be integrated into larger security protocols. It was noted by a few respondents that the data would need to be of better quality and regularly updated or it would not be useful on a shared platform.

Concerns about misinterpretation and misuse

Some of the respondents who disagreed with or were unsure of Q9A were concerned about the misuse, misunderstanding or misinterpretation of data, whether by patient or other medical and care professionals.

10A. Thinking about the actions needed to improve the quality of management information and internal reporting data across health and social care, what are the priority pieces of management information needed (that are not currently available) to provide better health and social care services?

Operational insight data

Of the 75 respondents to Q10A, the most common theme was a recommendation to collect operational data. Suggestions included Demand, Capacity, Activity and Queue (DCAQ) information, dynamic risk assessments, workforce size data and future service plans. A few mentioned an interest in collating this across health boards for comparison.

A few respondents also mentioned financial data including cost effectiveness to support commissioning decisions. NHS Education for Scotland (NES) also suggested gathering data on the channels of associated funding and resources.

> “Relevant management information would include staffing levels, service need, patient and client numbers, individual measures of patient/client dependency and details of any additional services involved in delivering care. Many of the pieces of management information needed to improve health and social care services are available but can be limited to a particular service or system and may not be available in a timely manner to allow services to respond to current need. Aligning systems across organisations and consistent coding of information would support use of data across sectors to inform service provision.” – The Innovative Healthcare Delivery Programme (IHDP)

Service user outcomes

Service user outcomes, either reported by the user or the measured by the provider, were mentioned by several as an important piece of management information. These included monitoring effectiveness, service user experiences and consistency of care. This was not seen as limited to primary care, but included outcomes from secondary, social, community and intermediate care.

“The single health care record for the patient should also be single record of all the citizen’s interactions with health and social care – that is a record of the care provided by whom, what, where and when. Ensuring this is recorded consistently, accurately and in real time (or as close to real time as is practical) will substantially improve the quality of management information and internal reporting data. If we ensure we get the clinical coding correct upfront and the input of it is of a consistently high standard, then the management information should be able to flow easily from this.” – Royal Pharmaceutical Society

Impact on inequalities

A few respondents mentioned the importance of gathering data on protected characteristics, particularly how they intersect with poverty data, to track the impact of social inequalities. This is examined more under the analysis of Q3A and Q3B.

Less frequently mentioned types of data

Other improvements to management information mentioned by small numbers included the needed to define and track Key Performance Indicators, and to include metadata which tracks who created the data and who has shared or seen the data.

Implementation

While many mentioned the management information above, several respondents used this question to reiterate best practices for implementation. This included noting the importance of integrated systems for sharing data between service providers, and a few who mentioned data governance and privacy, and efficient systems that improve visualisation and interpretation of data while reducing duplication.

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

Removing barriers to data sharing

Of the 81 responses to Q10B, many respondents highlighted that removing barriers to data sharing was necessary to develop an end-to-end system. Respondents suggested the system should be a national, interoperable, central hub with a single access point or a digital front door. A few respondents suggested it needs to integrate old legacy systems as well as use interfaces between applications. The importance of using a single identifier for service users, such as the CHI number, to enable information to be linked across organisations was raised by a small number. A few others also noted that anxiety around information governance remains a barrier to sharing data between services.

“A key barrier to this is that data and systems to support planning and performance are not joined up and organisations are not always willing to share data. For an end-to-end system of business intelligence to exist there is a need to: address those parts of the system where there is a lack of data and intelligence – primary and community care and social care; make improvements to data sharing; use common data standards across the system; and address any legacy systems that exist.” – Audit Scotland

“Data should be freely shared within the NHS (including GP-controlled data) and Local Authority care services to allow them to be used to improve the delivery of integrated care. Concerns around information governance can prevent effective sharing of information between different parts of NHS and HSCPs, and it would be helpful to address this.” – Healthcare Improvement Scotland.

Trained staff

Several respondents mentioned trained staff were needed to develop a new system, i.e., upskilling current workers or hiring those with expertise in delivering end-to-end systems, health and social care data, hardware and software infrastructures and governance and data ethics. Others recommended creating specific employment pathways for employees, such as clinical practitioner informatics roles to work alongside data analysts, or pathways for clinicians with an interest in data collection or IT.

“There is a need and opportunity to invest in digital maturity for the health and social care sector. This should build skills at every level, establish infrastructure that enables real time analysis, and be informed by an understanding about how data reflects people’s lived experience.” – East Ayrshire HSCP

Consistency and standardisation

Standardising collection, coding and storage procedures was raised by several respondents as an issue that must be addressed before an end-to-end business intelligence system can be considered. Respondents noted that disparate workflows and systems across Scotland create different types of data that may not currently be compatible into one system.

Comments about guidance on governance were made by some. A few mentioned that understanding what guidance and standards is needed requires an audit and analysis of the data gaps in the current system to provide more detailed recommendations and a thorough understanding of each sectors’ needs. This is examined more under Q13B.

Collaborations

Some respondents suggested collaboration to assist in the creation of an end-to-end system. These included collaborations with both larger-scale consulting experts as well as organisations with local business intelligence who could provide strategic direction. Others noted the importance of seeking input from key stakeholders in health and social care. A few, including Audit Scotland, recommended research among service users and service providers to understand the most relevant types or fields of data. Two others stressed the importance of collecting and analysing Patient Reported Outcome Measures (PROMs).

Infrastructure improvements

Investment in updated tools, both systems and hardware, were mentioned as necessary by some respondents. When considering the new technological needs, a few respondents noted the importance of scalability to allow for growth, and of flexibility that allows local systems to be easily migrated and integrated. Other recommendations included using artificial intelligence, agile working overcome challenges in integrating disparate systems, and utilising public computing.

"This ambition requires transformative solutions, likely only to be realised by fully leveraging the power of digital technology, public computing, and the extensive growing data infrastructure underpinning them." – Microsoft

The Coalition of Care and Support Providers in Scotland called for the strategy to recognise the role of commissioning and procurement in shaping the system. They argued that providers should be supported and enabled to deliver the strategy, partly by ensuring social care contracts include funding for digital to deliver safe, reliable infrastructure, future development costs and staff training.

Population health data

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

Medical or clinical records

Many of the 99 responses to Q11A suggested data from medical or clinical records which could be routinely reused. These included: full Emergency Medical Records, key diagnoses, allergies, vaccinations, medication lists, previous admissions, outpatient care records, and imaging records. One respondent advocated open access between NHS GP records and private healthcare providers.

"We believe that information on diagnosis, treatment (what, where and when and by whom) and outcome is a key data set for each citizen that can be reused not only to ensure patients only have to tell their story once but also for innovation and research with appropriate data control and consideration of ethics." – Royal Pharmaceutical Society

"The GP record needs to be the anchor dataset that is then linked to a variety of other datasets e.g. SMR01[8], HEPMA and PIS. There is considerable movement of people across UK borders so the ability to share comparable data across UK nations would be advantageous." – University of Edinburgh

As described throughout Part 1 of this report, not all respondents believed all medical data should be shared. A few specifically noted there should be variable access to medical records, only making them available to service providers who need to see them.

---

[8] SMR01 is the General / Acute and Inpatient Day Case dataset which collects episode level data on hospital inpatient and day case discharges from acute specialities from hospitals in Scotland. HEPMA (Hospital Electronic Prescribing and Medicines Administration) is a single digital solution for prescribing and managing medicines within hospital environments for the North of Scotland region. The Prescribing Information System (PIS) is the definitive data source for all prescribing relating to all medicines and their costs that are prescribed and dispensed in the community in Scotland.

Personal data

Personal demographic data was mentioned by several respondents. This included date of birth, address, employment status, marital status, dependents, and how service users prefer to be addressed. Often respondents considered this to be the bare minimum of the types of data that should be available for use across health and social care.

Treatment choices

Some respondents noted the importance of treatment choices, such as the Recommended Summary Plan for Emergency Care and Treatment or the Anticipatory Care Plans. They also highlighted the importance of including next of kin details or information about any guardianship or Power of Attorney in place; this is covered in more detail at Q2B.

Less frequently mentioned data sets or records

A few respondents each mentioned the following types of data: Social care notes and pathways; functional abilities, such as communication, walking, cooking and personal care needs; protected characteristic data as defined by the Equality Act; Patient Reported Outcome Measures (PROMs); and self-generated personal data, such as data gathered from wearable technology.

Other themes

Some did not explicitly answer the question, but instead noted specific benefits of reusing data and reducing duplication. These included assisting service users whose clinical or personal histories evoke trauma, or those who move and change primary care providers. Others noted the benefit to service providers, especially those who work across health and social care, such as occupational therapists or pharmacists.

Some respondents highlighted concerns. These included worries about data privacy and the extent to which medical information can be shared under GDPR. A few mentioned the importance of attaching personal identifiers, such as CHI, to health and social care data. While this is not a data set, respondents pointed out that it is needed to make the sharing of data practical. Mydex CIC and The Health and Social Care Alliance Scotland suggested the best next step would be to focus on personal data stores that individuals could share with their care providers, rather than building government platforms.

Part 3 – Empowering Industry, Innovators and Researchers

The final part of the consultation explored opportunities to use high quality data for innovation, industry and research, which can support the delivery of health and social care services. Questions covered access to data for research and innovation, the infrastructure needed to ensure timely and secure access to data, and Artificial Intelligence (AI).

Access to data for research and innovation

12A. When considering the ethics of accessing health and social care data for commercial, development and research purposes, how do you think health and social care data should be used by industry and innovators to improve health and social care outcomes?

Q12A received 109 open responses where respondents set out ways in which data could be used to improve health and social care outcomes. Suggestions included using health and social care data to: aid research into new and innovative healthcare solutions; evaluate the impact of health and social care interventions; and monitor population health trends to inform future policy and planning. These broad themes align with the reasons respondents said they would be willing to share their data at Q4B.

Many responses to Q12A related to other sections of the consultation paper. For example, several respondents emphasised the need for strict data protection protocols, and others argued that health and social care data should not be used by industry solely for commercial purposes e.g. advertising, developing and selling products and services, or insurance, or for any activities which promote harmful behaviours e.g. smoking. Some noted they were not wholly opposed to commercial bodies profiting from the use of population data if there were demonstratable benefits for the public or patients. Such comments have been included within the analysis of other more relevant questions.

Advancements and innovation in healthcare

The most prevalent theme was support for using health and social care data to drive medical innovation and advancements through research. Respondents felt that access to large, aggregated datasets could aid the development of new medical technologies, interventions and treatments, which could lead to improvements in the public's health and quality of life. Some noted specific examples of advancements in disease diagnostics and treatment which could be realised through the utilisation of health data. A few noted that health and social care data could be used by industry to improve the efficiency and speed of clinical trials, by aiding the identification and recruitment of candidates.

> "Data collected by the [health and social care] system is fundamental for progressing medical research. It is essential that innovators have access to [health and social care] data to drive insights into fundamental biology and natural history of disease; identify of risk factors associated with disease; uncover potential opportunities and targets for intervention; and ensure that services and interventions are as efficient and effective as possible." – Cancer Research UK

“From a [research and development] perspective, exemplar projects such as Artificial Intelligence Assisted Capsule Endoscopy building on SCOTCAP will potentially be a game changer for how to optimise use of [Artificial Intelligence] for Colon Capsule Endoscopy Images as a part of future bowel cancer diagnostics.” – The Digital Health & Care Innovation Centre

Evaluating the impact of health and social care interventions

Many respondents suggested that health and social care data should be used to evaluate the long-term impact of health interventions. Findings of such analysis could lead to the optimisation of services and treatments and be used to improve patient care in the future. A few described access to data as being critical for assessing the performance and cost effectiveness of medicines, interventions and technologies in clinical practice. The Office for Statistics Regulation also called for the strategy to include using data to hold governments and service providers to account.

“The wealth and scale of clinical and administrative data that is collected from patients provides ‘real world evidence’ of how medicines, devices and interventions that patients receive actually have the desired outcomes amongst the populations they are intended for… This is a major benefit stemming from having population level clinical and administrative health and care data available in a timely and safe way for research, with the ability for efficient data linkage to track patient pathways through the heath and care system.” – Research Data Scotland

Shaping policy and planning

Using health and social care data to monitor population trends such as disease prevalence, social care demands, and use of services was suggested by several respondents. It was noted that analysis of such trends could be used to forecast future need and demand and inform government policy, investment and service planning.

“The RCOT believe that health and social care data is vital for future planning. It’s particularly important to gain a better understanding of the needs of our workforce and communities and the workforce planning and training which will be required to meet those needs.” – Royal College of Occupational Therapists

Importance of collaboration

Some respondents stressed that optimising the application of health and social care data will require effective collaboration between Government, the NHS, social care and industry. A few cited examples of existing models which have successfully allowed health and social care data to be used to support innovation and industry collaboration, including OpenSAFELY, Early Access to Medicines Schemes (EAMS), ChemoCare and DataLoch.

Other themes

Some supported granting industry access to health and social care data as they felt it could lead to the creation of jobs in the medical research sector. A few suggested that health and social care data could be utilised to address inequality but did not set out any specific actions or applications of data which could be used to achieve this.

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?

Q12B received 106 responses. The most common suggestion for how industry and innovators can gain the trust and confidence of the public when using their health and social care data was through being open and transparent about how their data will be processed. These comments have been included in the analysis of Q12D, which focussed specifically on transparency. Other suggestions for how trust can be built and maintained between industry and the public are set out below.

Anonymity

Many respondents suggested that trust could be built by ensuring that researchers only have access to aggregated and non-identifiable data. They reasoned that this is the best way for researchers to guarantee the confidentiality and privacy of patients.

“Data should be anonymised wherever possible to protect the confidentiality of citizens.” – East Renfrewshire HSCP

Compliance with data protection legislation and ethical approval protocols

Another prominent suggestion for how industry can improve trust and confidence was through strict compliance with data protection legislation and ethical codes of conduct. Examples of regulations, schemes and ethical protocols cited by respondents included: GDPR, the Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP), Disclosure Scotland and independent ethical approval panels or academic ethics boards.

“The ability to access data by applying to an independent, expert ethics body would be a good way to maintain trust for the public that their data is being used properly, and in a way that will serve the public good.” – Individual

“While it is accepted that the government relies on the private sector to innovate, a new legal framework needs to be developed by considering a cross-section of laws which includes data protection law, the law of confidentiality, IP, competition and company laws.” – School of Law, University of Leeds

Emphasise benefits of using data

Some felt that trust could be built through innovators and industry making greater efforts to communicate the benefits of using the public’s health and social care data. For example, industry bodies could demonstrate how their research aligns with public health priorities, or its contribution to medical breakthroughs and advancements in technology and treatments. Some called for greater collaboration between industry, NHS, government and academia in communicating the benefits of industry access to population health and social care data.

"Demonstration of the benefits of accessing data and how innovation has driven service improvement will improve public trust in how their data can be used for a good purpose." – The Innovative Healthcare Delivery Programme

Choice and consent

Informed consent was stressed as an important factor in building trust between the public and industry. Respondents suggested that industry access to public health and social care data should be based on individuals' choice of whether to opt in to a particular study or not, allowing the public to feel more in control of how their data is used.

Less commonly mentioned themes

A few other suggestions for building trust between industry and the public included:

- Establishing a centralised, national approach to information governance.
- Improving public knowledge of data subject rights through education and public awareness campaigns.
- More consultation with the public to understand concerns relating to the use of health and social care data in research, and how these can be addressed.
- Audits of industry bodies processing population level health data.
- Industry bodies increasing investment in cyber security.
- Introducing greater financial penalties for misuse of data or data breaches.

Some respondents emphasised the critical importance of building trust between the public and industry in order to make medical advances through research.

"Public trust is vital if we are to fully harness the unique potential of our health and care data." – Scottish Industry Life Sciences Group's subgroup on Digital & Data

A few individuals expressed a view that there was nothing that could be done to increase their trust in industry bodies.

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

Using data for commercial gain

Among the 104 responses to Q12C the most common objection to the use of health and social care data by industry was where the data would be used solely for commercial purposes or financial gain. Specific examples included using data for: market research and targeted advertising; developing and selling products and services; and predictive technologies such as insurance. Some noted that they were not wholly opposed to commercial bodies profiting from the use of population data if there were demonstratable benefits for the public or patients.

“Anything that is purely commercial (e.g. wanting to understand their market share of a medicine, rather than measuring the benefits and harms of different medicines in a class). The driving principle is that there should/could be benefit for the Scottish population from the analysis. Not just benefit to the commercial operation funding it.” – Institute of Genomics and Cancer, University of Edinburgh, Western General Hospital, Edinburgh

Personally identifiable data

Many respondents felt strongly that industry should not be given access to people’s health and social care data if it has not been aggregated or anonymised, or if it can be used to identify individual patients or service users. A few added that it was essential to ensure data is not used for any purpose that could lead to individuals being negatively impacted, for example, sharing medical history with government departments or insurance providers.

“Sharing or transmission of any personally identifiable information must never happen.” – Individual

Activities not in the public interest

Several respondents felt it would be unacceptable to grant access to population health and social care data for any research that is not in the public interest or does not have the support of NHS or the government. Some felt data should only be shared with industry bodies and researchers who can demonstrate clear benefits to the public and have appropriate safeguards in place. Some emphasised that data should not be used for any research that promotes harmful behaviours such as smoking or alcohol consumption.

Other unacceptable uses

A few other unacceptable applications of data included:

- Any research that has not been through a robust ethical approval process.
- Any research that does not fully adhere to all legal, regulatory, privacy and security obligations.
- For any purpose outwith what the data subject has explicitly consented to.
- Purposely manipulating or misinterpreting data which leads to misleading findings.

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

Make clear how data will be used

The most common suggestion across the 101 responses to Q12D and the relevant comments from Q12A for how industry, innovators and researchers can be transparent about their use of health and social care data was through making clear to data subjects the aims of their work and the intended use of data. Respondents suggested that researchers do this through direct communications with data subjects or by publishing the relevant information online. A few urged researchers to be transparent about conflicts of interest and commercial interests when accessing the public’s health and social care data.

> “Relevant researchers, innovators etc should be required to set out a clear scope which describes the purpose, breadth and intended outcomes of their use of health and social data.” – Renfrewshire HSCP

Publish information about data security and ethics

Several respondents suggested that researchers should publish information about their data security protocols and the ethical approval processes they have navigated. Respondents called on researchers to clearly articulate how data will be kept safe and secure, and evidence how they are meeting the key principles of GDPR.

Publish results or findings

Some respondents felt that researchers accessing health and social care data should be required to publish their findings. A few felt this should be required regardless of whether the intended outcomes had been met or the study has been a success. A small number suggested case studies would be a good way to communicate findings to the public.

Accessible information

Respondents discussed the importance of researchers providing accessible information about their use of health and social care data. For example, some stressed that research findings should be free to access and not hidden behind paywalls and should have content that is easily understood by the public, i.e. not overly technical or jargonistic. A few added that such information should be available in a range of accessible and tailored formats, including hard copies, large print, Braille and BSL.

> “It is important that industry, innovators and researchers are able to clearly articulate – using accessible language – their purposes in accessing health and social care data and the subsequent benefits to patients and the public at large.” – The Cloud Consulting and Technology Association

Other themes

Some other themes were present among responses to Q12D:

- Many stressed the importance of transparency, sharing concerns about low public awareness of how health and social care data is used.
- There were calls to introduce channels for the public to ask research bodies questions about their use of health and social care data.
- A few suggested resources and frameworks which researchers could use for guidance on transparency including: the Association of the British Pharmaceutical Industry’s principles for analysis and use of health data, the ‘Five Safes’ framework and Microsoft Responsible AI principles.

Infrastructure

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

Infrastructure considerations

Reflections on the value and role of safe havens or trusted research environments was the most prevalent theme across the 99 open responses to Q13A. As well as straightforward endorsements of the use of safe havens to store and share data, some described how safe havens should be resourced, managed and structured. Suggestions included greater investment, for safe havens to work together or with other partners, access to the latest technology, to learn from the private sector or be led by Research Data Scotland. The benefits of using safe havens were also stressed, including improved data security, scope to provide approved researchers with access to linked, unidentified data, and building public trust in the use of their data for research.

"Build on and invest more in what we already have and works well. The usage and expansion of the current national and regional Safe Havens infrastructure to provide a more comprehensive approach to the collation and effective curation of health and care data in Scotland seems a sensible way forward. This may require a mandate from Government for public sector bodies to capture and effectively share local and regional information." – The Digital Health & Care Innovation Centre

Ensuring infrastructure complies with international standards was raised by several respondents who noted this would enable collaboration. Specifically, one advocated an approach which ensures data sets are scalable across countries, noting that commercial partners will gravitate to data sets which are pan-country scalable. Another mentioned a need to share data across the UK to generate large data sets on rare diseases. One suggested the Scottish Government considers becoming a participant in the European Health Data Space, as this could present opportunities to access additional health data.

Interoperability was mentioned by some respondents, mostly stressing the need for this to be a key feature of the infrastructure. A few noted that use of international standards would ensure interoperability. A need for stakeholders to play a role in the infrastructure design was highlighted by some respondents; some also advocated patient involvement while others more broadly stressed the need for a partnership approach across sectors.

Some respondents reflected on data storage, typically noting that data would be stored on a cloud, and that this could create timely and effective access to data, security, control over access, computational power, and opportunities for researcher collaboration. A small number commented on open platforms, calling for open data which is accessible and, for example, can be used by small organisations and independent researchers. A few stressed the need to stay aware of evolving technology.

A less commonly mentioned theme was the importance of independently auditing Scotland's infrastructure, for example to test security and vulnerability and the timely access to data and approval processes.

Small numbers commented on risks and challenges of developing data infrastructure. One stressed the data infrastructure could not cover all relevant information, noting the importance of genetic, lifestyle and environmental factors. A few described delays and frustrations with current data systems and their hope that a new infrastructure could remove existing barriers.

Data access and usage considerations

The second most prevalent theme across comments was discussion of access to data. Different views were evident in comments on ease of access to data – some argued that processes should be clear and simple to engage with, others stressed that security should override ease of access. Respondents emphasised the need for a secure system which minimises the risk of breaches or data misuse, suggesting registered users or regulated access, access and usage tracking, the protection of identities within the data set and robust firewalls, encryption and sophisticated approaches to security. Some suggested that data sets should be available at national, health board or hospital level.

While calls for the use of aggregated or anonymous data was another prevalent theme, a small number called for pragmatism, suggesting data sets could be linked while maintaining confidentiality. Some comments on anonymity included discussion of need to use technology and governance standards to enhance security and trust.

Different aspects of transparency were identified in some responses. This included: calls for transparent language, processes and data sharing agreements; transparency on what data is held, who is accessing it and why; for results to be published; and clarity about the role of any commercial partners. Small numbers stated that data sharing agreements should be transparent, but not so laborious that they impede engagement with data.

The role of the Scottish Government and others

The role of the Scottish Government in establishing the infrastructure was the third most common theme. Respondents called on the Scottish Government to: provide clarity on key issues such as responsibilities, governance and security; allocate resources to build the framework or expand existing resources; and establish or allocate responsibility to a national body to manage and govern the infrastructure.

On the latter point, very small numbers suggested a recognised national information governance office and a single set of standards that all Health Boards comply with for research, or one accountable organisation to store health and social care data which has a national, statutory, and legal responsibility. Some talked generally about the role of a dedicated service, noting this would allow access and provision of data to be managed and scrutinised, and referenced the resourcing, training and standards that such a service would require. A small number, including Public Health Scotland, mentioned Research Data Scotland and described the value of its work; another called for further investment to expand the reach of its work and engagement with networks.

"There should be a designated body which has responsibility for managing all aspects of the access to health and social care data such as ensuring the necessary procedures and safeguards are in place e.g. relevant policy and legislation, criteria for gaining access, management of onboarding and offboarding and regulation of participants. Any infrastructure should not be replicating the storage of large amounts of data but ensuring that the infrastructure in place intelligently manages access in an efficient manner." – Aberdeen City HSCP

Other less commonly mentioned themes

- On governance, GDPR and standards, a few respondents stressed the need for data storage to comply with GDRP, for Data Protection Impact Assessments (DPIAs) to be publicly accessible, and to consider how data governance frameworks may evolve across the UK, EU and wider world.
- Comments on a single person identifier highlighted that this would allow different systems to connect and make data linkage robust and comprehensive, highlighting the potential to get greater value from the CHI number through which researchers can follow patients from birth to death.
- Benefits stemming from greater control through a single point of access, such as accountability and oversight, standard access processes, and high levels of security.

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?

Of the 85 responses to Q13B, most comments related to challenges that industry, innovators and researchers have in accessing data in the health and social care sector. These responses explored issues such as the disparate datasets held by different organisations, data linkage, complex procedures to request data access, and concerns around data quality. There were also some specific data gaps identified in responses.

Challenges

The most common theme was the disparate datasets held by different organisations in the health and social care sector. Many respondents described a lack of integration and interoperability among different organisations' systems, causing difficulties in accessing, sharing and collating data between organisations.

"A key data need and current gap is the ability for real time data sharing and the reality of fragmented data. We do not know much is presently being missed – in terms of intelligence and opportunity – by not having right information in the right place at the right time." – Scottish Care

"ABPI members highlight a lack of interoperability between datasets (stifling potentially valuable analysis and insight), inconsistent access arrangements and a generally fractured data environment as the key barriers holding back data driven innovation in the UK." – ABPI

Some respondents emphasised the importance of data linkage and that more needs to be done to improve data linkage in health and social care. Comments focused on the value of data linkage in tracking data held about individuals in different datasets; this enables analysis of a patient's journey through health and social care, the outcomes achieved and the factors that determine health outcomes.

> "Linkage of data for individuals across a period of time is critical for many industry, innovation and research projects. However, this is currently very challenging to do with truly anonymised datasets." – Community Pharmacy Scotland

Procedures for requesting access to data were another challenge highlighted by some respondents. Comments focused on a need for easier and quicker processes to allow researchers, industry and innovators to request access to data, as well as difficulties caused by variations in procedures across different Health Boards.

> "Simpler and timelier processes are required for requesting, accessing and gaining permission and approvals for access to data." – Cancer Medicines Outcomes Programme (CMOP)

Some respondents cast doubt on the quality, accuracy and completeness of health of social care data. This has been examined in detail across Part 2 of this report.

> "Poor quality of data, poor integration and communication between systems, poor allocation of the necessary technology. This creates an unnecessary burden on researchers and health and social care professionals who require additional time to access and use data that could be used more productively." – ENRICH Scotland

Other challenges, each identified by a few respondents, included: gaining timely access to data; public understanding of health and social care data; issues around governance, security and anonymity; organisational culture, leadership and resistance to change; gaps in digital literacy skills including data analysis; lack of awareness of what data is available; and resources to collect and analyse data. Two mentioned challenges associated with bureaucracy, and one said there was a lack of data available in digital format.

Data gaps

Respondents identified a wide range of data gaps, but there was little consensus. The most identified gap related to protected characteristics and other information about inequalities such as socio-economic data. Some felt there should be more of a focus on collecting and analysing data about these characteristics.

> "Currently data on ethnicity, gender, sexuality, socio-economic status, caring responsibilities and disability are not routinely collected as part of health and social care data. To fully understand the extent of health inequalities in Scotland the collection of data on inequalities and marginalised groups needs to be significantly stronger." – Voluntary Health Scotland

A few noted a need to improve data in the social care sector specifically. For example, COSLA noted gaps in social care workforce data, data around unmet needs in communities, and about choices and support being provided under Self-Directed Support. SCLD (Scottish Commission for People with Learning Disabilities) cited the 2020 Office for Statistics Regulation's review of adult social care statistics in Scotland, which identified gaps in data collection, resources weighted towards health data, inconsistencies in data definitions, poor data quality, delays in reporting and inaccessible data.

Gaps in data about primary care and patient outcomes were mentioned by a small number of respondents. GMC Scotland (General Medical Council) identified a gap in their understanding of the risks and challenges of clinical practice resulting from limited data availability. Other themes where respondents felt more data should be collected included: secondary care services; data on long-term conditions including cancer and kidney disease; patient experiences; the scale of the health and social care workforce; and drug safety and clinical trials.

Further suggestions, each made by one respondent, included: waiting times; disabilities; rare conditions; medical imaging data to support diagnosis; health and social care services provided by charities or religious organisations; research related to the work of Allied Health Professions (AHPs); and product usage.

Innovative technologies

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

Three types of comments were evident in the 103 responses to Q14A. Many respondents expressed an overall view for or against the use of Artificial Intelligence (AI) or elaborated on the perceived benefits. Further detail on these comments is provided below. Many other respondents highlighted concerns about the use of AI and commented on safeguards around its use; these responses are included in the analysis of Q14B.

Overall views on AI

Mixed views were expressed on using AI, though on balance the majority of respondents were in favour. Many individuals and organisations expressed a generally positive view, encouraging the use of AI. Several caveated their agreement with an assumption that AI would be used safely and alongside some of the safeguards outlined at Q14B.

> "There's no question that we've reached a point that AI is not only useful but that denying its use for the population of Scotland would be unfair." – Scottish Clinical Imaging Network
>
> "The potential for AI's role in improving health and social care services is vast, and we are fully supportive of this to continue." – Advance Care Research Centre (ACRC)

Several respondents expressed some support but stressed that AI is only appropriate in certain circumstances and that the introduction and use of AI should be carefully considered. They typically argued that clear parameters should be set out for its use which consider what is of most value to services and services users, and an assessment of any potential risks or unintended consequences. A few respondents argued that AI should only be seen as a tool to assist humans in decision making and should not be relied on.

"It is critical that the narrative and framing around AI use in healthcare is set firmly from the outset – that it is a very promising supportive tool, but no replacement for complex clinical decision-making." – Community Pharmacy Scotland

Some argued that the effectiveness of AI still needs to be proven, and a few expressed clear opposition to AI, arguing that there is unjustified hype around what it can achieve.

Benefits of using AI

The most mentioned benefit, particularly by health bodies and HSCPs, was the use of AI in diagnostics. Respondents highlighted how AI could result in earlier diagnosis and better treatment. Some specifically noted the use of AI in image analysis in cancer detection and dermatology, for example. Others described how AI could detect exceptions or anomalies in health data, which could lead to conditions being identified and preventative measures being put in place. A few noted that AI could be used as a triage tool, or stressed that it should be used to complement, rather than replace, decisions made by clinical professionals. Related to this, a small number noted the potential to use AI to predict future risk. While most comments related to diagnosis focussed on healthcare, Scottish Care cited their 2020 TechRights report which details some examples where AI is already supporting citizen independence and preventative care approaches in Scotland.

"AI can be particularly useful in recognising anomalies in images that are hard or impossible for the human eye and this can flag to a human radiologist for example cases that should be followed up during screening services. Given the massive learning capacity of deep learning algorithms, it qualifies them to handle such variance and detect characteristics well beyond those considered by humans. Moreover, the use of AI in digital pathology setting to make predictions regarding treatment response can enable the selection of more effective treatments for patients" – Cancer Research UK

Another prevalent benefit was that AI could enable more efficient use of resources within health and social care, allowing staff to provide enhanced clinical care rather than routine tasks. This could result from automation of some processes and using AI in diagnostics as above, or from the ability to better predict the need for resources as below. This was again commonly mentioned by health bodies and HSCPs.

"Speech and text recognition are already employed for tasks like patient communication and capture of clinical notes, and their usage will increase. It also seems increasingly clear that AI systems will not replace human clinicians on a large scale, but rather will augment their efforts to care for patients. Over time, human clinicians may move toward tasks and job designs that draw on uniquely human skills like empathy, persuasion and big-picture integration." – NHS 24

Some respondents described the potential for AI to detect relationships and patterns in data, particularly large data sets, and to derive additional insight from that analysis. Respondents noted that it would be impossible for people or traditional IT to analyse and draw conclusions from the same volume of data, or do so quickly.

Using AI for planning, forecasting and decision making was another theme mentioned by some respondents. The analysis of large data sets or population data could be used to predict future demand, plan and target service provision, and manage public health.

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

Governance, regulation and ethical approval

The most common safeguard mentioned across Q14A/B was the need to ensure AI is used in line with all relevant governance, regulation and codes of conduct to mitigate risk and avoid harm. Others noted the need to have appropriate legal and ethical frameworks in place and regularly reviewed, while a few specifically suggested that some AI could or should be classed as a medical device and be subject to regulatory approval. Some reiterated the need to comply with appropriate data security and privacy regulations, and for the transparent use of data and presentation of any outcomes or results from using AI.

> “The Scottish Government’s AI strategy nicely sets out the safeguards about using AI well, with data ethics and transparency at its heart.” – Research Data Scotland
>
> “For the full benefits of AI technology to be realised, they need to be supported by trustworthy and cybersecure data, combined with responsible use. Appropriate data governance and people consent are key to fully seize this opportunity in a sustainable way.” – Microsoft

Human oversight

Another prevalent theme was the need for human oversight of AI. This would involve a ‘human in the loop’ to review of algorithms and testing for bias, peer review of decisions resulting from AI and the potential to intervene should AI go wrong. A few respondents called for clinical staff and expert input into the design of AI models and algorithms, and in the review of results. This could be from epidemiologists, radiologists, statisticians etc. A few called for training but did not elaborate on what is required.

> “Use of AI should be informed by a suitable trained health care professional to intervene if something may harm a patient. However, AI requires clinical input to interpret correctly and findings / outputs. AI can only empower health workers if the health workers have a say in what is planned or implemented, how the technology will be used and how the outputs may affect care.” – Cancer Medicines Outcomes Programme (CMOP)

Bias

Several respondents highlighted the importance of recognising and addressing any bias built into AI which could skew the results. Respondents described how bias could result from unconscious bias held by programmers, or from incomplete data being used. Some respondents, including the University of Edinburgh and Health Data Research UK, specifically highlighted the potential for bias against marginalised groups, in particular ethnic minorities, who may be less represented in data. The Health and Social Care Alliance Scotland recommended carrying out Equality and Human Rights Impact Assessments to fully consider the impacts of AI on different population groups.

> “As highlighted by a breadth of literature, traditional artificial intelligence development and training methods can often entrench bias and prejudice within AI systems, negatively impacting Black and minority ethnic groups and, in particular, BME women. If AI is to be incorporated into health and social care decision making processes, every precaution must be taken to ensure that biases within the training, deployment and evaluation process are identified and eliminated.” – Coalition for Racial Equality and Rights (CRER)

Testing and evaluation

Another recurring safeguard, raised by several respondents, was to regularly trial, monitor and evaluate the effectiveness of AI to ensure they continue to be fit for purpose.

Other considerations

While not specifically safeguards, many respondents outlined themes which they felt ought to be considered for AI to function effectively. Most commonly, several noted that AI will only be effective if it uses high quality, complete, accurate, representative and linked data.

> “In order to benefit the most from machine learning and other more complex statistical models (aka AI), health data needs to be big, of good quality and linked effectively. Linking health data across all services will allow models to identify risk factors and build up a picture of how data points interact at a much deeper level. The more data it is given the richer this picture will be.” – Office for Statistics Regulation

Engaging the public was mentioned by some respondents. They suggested that patients should be informed when AI has been used to make decisions about them, and that greater public awareness of AI and its benefits is needed to improve trust and confidence.

A few respondents – including Public Health Scotland, The Innovative Healthcare Delivery Programme, University of Edinburgh and Scottish Cancer Patient Reported Outcome Measures (PROMs) Advisory Group – called for investment in data infrastructure, so that Scotland has the technological capabilities to use AI effectively. This includes a better network of safe havens or trusted research environments for data sharing.

> “There is a need to utilise significant data sets to ensure that AI applications are accurate and inclusive. The proposed approach to modernising Scotland’s health and social care infrastructure and data curation will be crucial, if we are to unlock the benefits of AI and attract further research and innovation activity in this space.” – Scottish Industry Life Sciences Group’s subgroup on Digital & Data

Two respondents raised the importance of being aware of unintended consequences of AI; that AI does not drive inequalities because data is not available across the population, and that funding for AI is not diverted from other work or improvements.

Additional information

The consultation ended with Q15 which allowed respondents to provide further information they felt could be useful. Most comments aligned with themes already outlined in this report, highlighting the value of health and social care data and the importance of information governance. This chapter summarises other themes evident at Q15.

Further actions or considerations

A variety of actions were suggested by a few respondents, mostly individuals, to ensure Scotland remains at the forefront of data enabled innovation in health and social care. These included: investing in data infrastructure and the standardisation of data collection; addressing governance issues which create barriers to sharing data within the NHS; using policy levers to encourage Scotland's business, research and public sector to play a role; encouraging greater engagement and data sharing with the third sector and the independent social care sector; piloting data sharing to get feedback from the public as service users; and opening Scotland's data landscape to clinical trials. Two individuals stated money should not be spent on data initiatives.

> "We also feel there is opportunity to go further in the strategy to develop a globally leading environment that will support collaboration between Scotland's health and care system and the Life Science industry… We would also like to see further recognition of the international aspect of data and the need to collaborate internationally as we did in our response to the Covid-19 pandemic. Scotland has much to learn and contribute to on an international stage–" - Scottish Industry Life Sciences Group's subgroup on Digital & Data

Equality and human rights considerations

A small number called for an equalities and human-rights based approach. This included gathering equalities data, co-designing with marginalised groups or people with protected characteristics, aligning with Human Rights conventions, and producing Impact Assessments. These respondents argued that, without these steps, there was a danger that investment in digital infrastructure could widen inequalities. One anonymous organisation noted the need to include those who do not have digital records e.g. refugees, and South Ayrshire HSCP noted challenges around data access in rural areas.

Comments on the consultation and strategy

Some respondents shared mixed views on the strategy. Most were positive, stating it addressed the right issues and described it as a strong vision and a welcome and timely step. Conversely singular critical comments included; that the strategy is too heavy on ethics and governance; that it fails to take account of past failures; and a detailed response from Mydex CIC on why the proposals are not well thought through.

> "Scottish Care commends the approach taken by those engaged in the development of the Strategy, which has prioritised meaningful and regular engagement with the independent social care sector as well as other stakeholders. We hope this approach will be maintained and built upon as the Strategy develops and implementation gets underway, and we look forward to further contributing positively." – Scottish Care

Conclusions

Many individuals and stakeholders with detailed knowledge took part in the consultation, sharing their views on how health and social care data could be gathered, stored and used. Their views will provide a useful evidence base to draw on when shaping Scotland's first Data Strategy for health and social care. This report provides a high-level summary of the consultation responses; for more detail, readers are encouraged to look to individual responses where permission was given for publication[9].

Health and social care data was perceived to cover a wide range of information, including data collected by individuals themselves. There were calls for the strategy to include a clear definition, and for steps to be taken to improve public awareness of how health and social care data is being used effectively and how this benefits individuals and the public.

There was broad agreement that individuals should be made aware of what data is collected from and about them, how it is stored, what their data is used for, and by whom. Transparency and consent were recurring themes and respondents stressed the importance of providing this information in clear and accessible formats, and of compliance with data protection regulations and ethical codes of conduct. Ensuring only relevant data is shared or being able to consent to sharing on a case-by-case basis was also requested.

To empower practitioners, respondents supported investment in training to give them a better understanding of data processing, the value of data in health and social care, and of governance and ethics. Respondents highlighted the need for user-friendly platforms, interoperable systems, linked data and data standards to improve the accuracy, completeness, consistency and accessibility of data. These would allow for a joined-up approach that is scalable and flexible across services and lead to better quality services. The value of operational data and data about protected characteristics was also noted.

Many suggested collaboration with staff in health and social care, service users, academia, third sector service providers, and private sector experts to create an effective end-to-end system, but there were concerns about the quality of existing data and the barriers created by data silos and staff anxiety over data sharing.

Respondents largely supported industry, innovators and researchers accessing anonymised population data to help drive medical advancements, evaluate the impact of health and social care interventions and shape future policy and planning. There was, however, repeated opposition from some to data being shared or sold to private organisations for commercial gain or for activities which are not in the public interest.

The use of safe havens and trusted research environments, international standards and interoperability were seen as vital to sharing data for research purposes. Respondents highlighted challenges around the disparate nature of existing data sets and expressed mixed views on how easily data should be accessible. Many reflected on how Artificial Intelligence could improve diagnostics and efficiency but stressed it must be used in line with all relevant regulations, with human oversight, and that any bias is addressed.

---

[9] Responses are published on the Scottish Government's consultation website: https://consult.gov.scot/

Appendix A: Respondent Profile

In total, 162 consultation responses were received. Individuals provided 62 responses to the consultation; the remaining 100 were from organisations.

Organisations were asked to select from a list which sector their organisation belonged to. In addition, 14 individuals also indicated the sector they worked in. The analyst team reviewed respondents' classification to ensure this was consistent and reclassified a few organisations where necessary. The option for Public Body was split into three sub-categories, and a new category for Representative / Membership Body was added.

The table below provides a full breakdown of the final sectoral classification.

Table 1: Sectoral classification

Sector	Number of responses	% of all responses
Public Body (total)	53	33%
- Public Body - Health	28	17%
- Public Body - HSCP	13	8%
- Public Body - Other	12	7%
Third sector	20	12%
Representative / membership body	16	10%
Academia	10	6%
Other	10	6%
Private organisation	5	3%
Not answered (individual)	48	30%

It should also be noted that over four fifths of those responding as individuals (44%, 28 out of 63) responded from an NHS, Government or Academic email address, indicating some level of engagement with the topic, as opposed to being a lay member of the public.

Appendix B: Quantitative analysis

The following tables outlines the results for each of the five of the closed questions in the consultation – the results for Q6A are included in the main report.

As not all respondents gave an answer to these questions, the quantitative analysis in the main report is based on those who answered each question.

For each question the following tables show:

- The number of respondents from the **total sample** of 162 who selected each response, and the corresponding percentage.
- The number and percentage response **among those who answered each question,** broken down by:
- Individual and organisation responses.
- By sector[10].

---

[10] The 'Other' category comprises five private organisations and 10 organisations who classified themselves as Other.

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?					
Base	**n=**	**Yes**	**No**	**Unsure**	**Not answered**
All respondents	162	78	2	20	62
All respondents (%)	162	48%	1%	12%	38%
All answering	**100**	**78**	**2**	**20**	**-**
All answering (%)	**100**	**78%**	**2%**	**20%**	**-**
- All individuals answering (%)	58	76%	3%	21%	-
- All organisations answering (%)	42	81%	0%	19%	-
All answering by sector (%)					-
Public Body (all)	25	88%	0%	12%	-
- Public Body - Health	15	80%	0%	20%	-
- Public Body - HSCP	8	100%	0%	0%	-
- Public Body - Other	2	100%	0%	0%	-
Third Sector	11	64%	0%	36%	-
Representative / Membership Body	6	83%	0%	17%	-
Academia	5	100%	0%	0%	-
Other	8	88%	0%	13%	-
Not answered (Individual)	45	71%	4%	24%	-

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?

Base	n=	Very important	Fairly important	Neutral	Not important	Not answered
All respondents	162	76	13	11	3	59
All respondents (%)	162	47%	8%	7%	2%	36%
All answering	**103**	**76**	**13**	**11**	**3**	**-**
All answering (%)	**103**	**74%**	**13%**	**11%**	**3%**	**-**
- All individuals answering (%)	59	61%	19%	15%	5%	-
- All organisations answering (%)	44	91%	5%	5%	0%	-
All answering by sector (%)						-
Public Body (all)	25	76%	12%	12%	0%	-
- Public Body - Health	15	73%	7%	20%	0%	-
- Public Body - HSCP	7	71%	29%	0%	0%	-
- Public Body - Other	3	100%	0%	0%	0%	-
Third Sector	12	92%	8%	0%	0%	-
Representative / Membership Body	6	100%	0%	0%	0%	-
Academia	5	80%	0%	20%	0%	-
Other	9	67%	33%	0%	0%	-
Not answered (Individual)	46	65%	13%	15%	7%	-

5A. Do you gather your own health data for example measuring activity, sleep patterns or heart rate through a mobile phone or watch?				
Base	**n=**	**Yes**	**No**	**Not answered**
All respondents	162	53	29	80
All respondents (%)	162	33%	18%	49%
All answering	**82**	**53**	**29**	**-**
All answering (%)	**82**	**65%**	**35%**	**-**
- All individuals answering (%)	59	63%	37%	-
- All organisations answering (%)	23	70%	30%	-
All answering by sector (%)				-
Public Body (all)	17	76%	24%	-
- Public Body - Health	11	82%	18%	-
- Public Body - HSCP	4	75%	25%	-
- Public Body - Other	2	50%	50%	-
Third Sector	5	60%	40%	-
Representative / Membership Body	2	50%	50%	-
Academia	5	80%	20%	-
Other	7	71%	29%	-
Not answered (Individual)	46	59%	41%	-

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?					
Base	**n=**	**Agree**	**Disagree**	**Unsure**	**Not answered**
All respondents	162	107	3	11	41
All respondents (%)	162	66%	2%	7%	25%
All answering	**121**	**107**	**2**	**11**	**-**
All answering (%)	**121**	**88%**	**2%**	**9%**	**-**
- All individuals answering (%)	58	83%	5%	12%	-
- All organisations answering (%)	63	94%	0%	6%	-
All answering by sector (%)					-
Public Body (all)	34	91%	0%	9%	-
- Public Body - Health	20	90%	0%	10%	-
- Public Body - HSCP	9	100%	0%	0%	-
- Public Body - Other	5	80%	0%	20%	-
Third Sector	15	93%	0%	7%	-
Representative / Membership Body	8	88%	0%	13%	-
Academia	6	83%	0%	17%	-
Other	13	77%	8%	15%	-
Not answered (Individual)	45	89%	4%	7%	-

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?

Base	n=	Agree	Disagree	Unsure	Not answered
All respondents	162	89	8	20	45
All respondents (%)	162	55%	5%	12%	28%
All answering	**117**	**89**	**8**	**20**	**-**
All answering (%)	**117**	**76%**	**7%**	**17%**	**-**
- All individuals answering (%)	58	67%	14%	19%	-
- All organisations answering (%)	59	85%	0%	15%	-
All answering by sector (%)					-
Public Body (all)	33	91%	0%	9%	-
- Public Body - Health	19	89%	0%	11%	-
- Public Body - HSCP	9	89%	0%	11%	-
- Public Body - Other	5	100%	0%	0%	-
Third Sector	14	64%	0%	36%	-
Representative / Membership Body	7	71%	0%	29%	-
Academia	6	83%	0%	17%	-
Other	12	92%	0%	8%	-
Not answered (Individual)	45	64%	18%	18%	-

Appendix C: Consultation questions

Part 1 - Empowering People

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

4A. When considering sharing of your data across the health and social care sector, 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?

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

Part 2 - Empowering Those Delivering Health and Social Care Services

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?

Part 3 - Empowering Industry, Innovators and Researchers

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?

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?

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

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

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?

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?

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?

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

15. Please use this box to provide any further information that you think would be useful, which is not already covered in your response.

Appendix D: 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.

Scottish Government
Riaghaltas na h-Alba

This publication is available at **www.gov.scot**

Any enquiries regarding this publication should be sent to us at

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-80525-081-4 (web only)

Published by The Scottish Government, November 2022

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS1176362 (11/22)