* use MY data

Consultation Paper: Data Strategy for health and social care, Scottish Government, August 2022

Summary response from use MY data

We note and support the three stated ambitions for the strategy:

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

Background to our response

To respond to the Scottish Government's draft **Data Strategy for health and social care**, we have used use MY data's position statements and principles and existing views from our Members (some of these views have been used in responses to other consultations, including in other nations of the UK.

The summary is presented here.

We have also flagged this consultation to our Members in Scotland and highlighted that they may wish to submit individual responses.

Key points from use MY data Members

Part 1: Empowering people

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

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

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

    We have discussed this question extensively with our Members. We outline the views of our Members in our Call to Action, "My Access to My Health Records", published in July 2021.

    Whilst access to (and patient understanding of) GP records has improved in recent years, there has been limited progress in gaining similar access to hospital records. We see this as a key point that needs to be addressed.

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?

    Currently if you are taken ill and go to a hospital away from home, that hospital may not be able to see your health records when making potentially life-saving decisions about the care you should receive. In many areas, even your local hospitals may not be able to see your GP record in an emergency. use MY data believes these data limitations can and should be overcome as a key step in delivering the best care or service wherever you need it.

    use MY data supports a move to ensure all parts of your health and social care record are available and accessible to you and your health professionals across the UK when you need treatment or advice.

We would draw your attention to our Position Statement, Realising the benefits of a truly National Health Record, which we would like to submit to the consultation. This is available here.

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

We have asked our Members to respond individually to this point. However, we would note that whilst clearly this must be optional, it makes no sense not to do this to allow for circumstances where a patient is incapacitated.

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?

We note that within ‘Data saves lives: reshaping health and social care with data’ the recently published strategy for England, there is a commitment to “work with the public to establish, for the first time, a data pact that will set out how we will use health and care data, and what the public has the right to expect”. Is this something that could be done in Scotland?

We would also highlight the Transparency Principles developed by our Members. These are available here.

We think that data release and usage registers should be mandated. Data release and usage registers are an essential element of increased transparency about the uses of health data. They are also an important starting point to be able to demonstrate the benefits that data can bring. There should also be consistency of style and content.

We would also highly recommend the wholesale adoption of the Patient Data Citation, which was developed by our Members. Whilst this is now rapidly becoming a standard across users of health data, we think it could be formally adopted as part of the Strategy.

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?

We are aware of surveys that have been undertaken to quantify the levels of trust in the way the NHS manages our health data. One survey about a person's likelihood to opt-out of their data being used for research, suggests a lower degree of trust in NHS staff than in the general public:

"After being told about the opt-out, 25% said they were likely to opt-out……. Among those working in health and care, likelihood to opt-out remains much higher – it was 46% in July 2020."

If this is true, do we need to think about doing something about why the NHS staff trust the NHS less than the public trust it?

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

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

We have asked our Members to respond individually to this point. However, we can foresee circumstances e.g. in the event of mental illness, a condition or lifestyle which, in the local population, may be socially less acceptable, where some people would be less comfortable sharing data.

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?

The conversation about 'value of data' needs to develop, to ensure good intentions in the Strategy are realised and that patients' expectations are met.

We think that a value sharing framework could help the health system to deliver good data partnerships. However, this framework needs to be developed alongside patients, and clearly communicated, if it is to provide the anticipated assurances.

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

> 5A. Do you gather your own health data for example measuring activity, sleep patterns or heart rate through a mobile phone or watch?
> Yes / no
>
> This is not something that we have asked our Members. They may choose to respond individually to this point.
>
> 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

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

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

These all focus on "doing something" with the data in the system, but there is no focus on the 'incoming' data and aligning that with why it's needed ("Good in, good out"). There should be a clear link to the issues and how the relevant data will be captured.

We also think a key element of improving trust in the use of health data is the need for a significant investment in communications and involvement skills.

The phrase "involved in delivering health and social care" is rather broad sweeping. There are likely to be different priorities for those DIRECTLY involved rather and those indirectly involved (e.g. planning & research).

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

We have seen several large national patient data policies across parts of the UK fail because of poor communication and involvement. We believe that large data programmes require a significant financial investment in communication, which should be designed, costed and built into any programme of work, with a clear delivery plan.

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?

Unsure why this question is in this section (skills and training), buta priority would be that means/method of access is easy to understand and use.

We would also emphasise the need to ensure those who hold data understand a patient's right to access and understand what each data item/value means in lay language.

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?

If this is to do with using data for healthcare delivery:

1. Letting patients see their data, and highlight problems for correction
2. Moving to a single coordinated health care record, used widely
3. Reducing duplication (as this inevitably leads to inconsistency and error).

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?

The vision of use MY data is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

We are a movement of patients, carers and relatives, endeavouring to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

We aim to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

We support and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

What we do

- We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.
- We work to bring a patient voice to all conversations about patient data.
- We have developed the Patient Data Citation, which acknowledges that patients are the source of the data.
- We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.

- We provide learning resources for patient advocates on patient data issues, including:
  - Hosting events for patients and the public, focussing on patient data topics
  - a library of resources of data security, consent
  - narratives from individuals about the value of collecting and using patient data.
- We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

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?

Our Members may respond individually to this point.

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?

We would encourage a strategic move to uncouple the application and data layers. This would reduce the need for duplicated data entry and storage and would simplify the move towards an integrated care record.

Similarly, we would encourage the use of common data standards, and interoperability, across primary, secondary and tertiary care. We would also like to see these used across the UK.

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?

Not particularly applicable, as we are a movement of patents, relatives and carers. However, from a patient perspective, we would like the clinicians to have an understanding of the patient's needs, views and concerns of our safety.

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?

This is difficult to comment on from a patient perspective.

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

No response

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?

Currently if you are taken ill and go to a hospital away from home, that hospital may not be able to see your health records when making potentially life-saving decisions about the care you should receive. In many areas, even your local hospitals may not be able to see your GP record in an emergency.

use MY data believes these data limitations can and should be overcome as a key step in delivering the best care or service wherever you need it.

use MY data supports a move to ensure all parts of your health and social care record are available and accessible to you and your health professionals across the UK when you need treatment or advice.

We support this because, in making the best decisions about what advice or treatment to give you, clinicians need to know your full health background - your health history, your current health problems, treatments, medications and your allergies. In fact, they should be able to access all the data held by your GP, hospitals and mental health and social care providers that have previously treated you.

Clinicians, throughout the UK, need to know your full health background. We have people from Scotland receiving treatment in England as it's not available more locally (specialist centres & clinical trials).

This use of your data, to provide you with the most appropriate healthcare, is the key reason why use MY data supports this change but there are two other important benefits that this access to health records will enable.

- Personal access to your own health record. Through full security controls, you should be able to access your health records to better understand the trends in your health and potentially to add health data such as daily blood pressure readings, to enable professional monitoring of your progress. Also, to check if any health incidents are missing and if there are any errors on your health record which you can then ensure are corrected.

- Once this data is available nationally it could enable a separate, freestanding anonymised version of the data to allow approved researchers to carry out strictly controlled research in order to identify better approaches to prevention and diagnosis, to support smarter and more personalised treatments and to promote well-being and good health.

Part 3 - Empowering Industry, Innovators and Researchers

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

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?

A key point is that data uses should primarily be for the benefit of patients, rather than the focus being only on the type of user. However, it is very unclear how industry is going to be able to use a Trusted Research Environment (TRE). Primarily the tensions about the access rules by which industry users gain approvals for access, and secondarily, about the ways that industry users can operate in an environment where code and algorithms are shared. It is unclear whether industry users will have an exemption from code-sharing, and if so, how that will be undertaken in a transparent manner, and audited. This will be an essential element of operating in a trustworthy manner and being transparent.

We can understand concerns from industry about protecting their commercial interests, but this cannot be at the expense of transparency and trust.

We think it is important that the strategy is clear how it will address difficulties faced with a rare disease, especially as 55% of UK cancer deaths are from rare and less common cancers (Cancer52). We can't accept a universal approach when tackling this issue as resources need to focus for the 'benefit' to be worthwhile.

TREs offer a unique opportunity to address the data requirements of rare diseases, which need national and international data, though TRE links to international data are unclear. Patient registries do not exist for every disease type, and there is no national approach to collecting this data. If we were to identify the research that should be prioritised for each disease area, TREs could be the place to collate this data for researchers to work with. Crucially, this needs a national approach.

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?

See our response above

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

Exclusive, non-transparent deals must not be allowed.

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

To ensure openness and transparency about how patient data is used, and to build trust in the uses of patient data, we expect any organisation that uses patient data to explain their data uses, including how they use data to deliver benefits for patients: **Say what you do, do what you say and how you will do it**.

We expect organisations to be clear and open about how they respect any choices which patients have made about their data use.

Principles which we would expect organisations to publicly adopt (when communicating via website, press releases, reports, contacts, etc.):

Individual Choice
1. Describe clearly how you have respected the wishes and preferences of patients regarding use of their data
2. Respect the wishes of patients who choose to opt out

Societal benefit
3. Be explicit that the primary focus must always be on benefit to patients, relatives and carers
4. Demonstrate the benefits of what you do, and what you have done, and publish this openly

Patient Voice
5. Embed patient voices in all parts of the organisation and be responsive and accountable to them
6. Recognise the use of patent data by adopting the Patient Data Citation
7. Be open to questions, and answer these questions openly, clearly and fully

Transparency
8. Be clear about how you are delivering fair value to the NHS in what you do with patient data, and how you do it, and publish your assessment of fair value
9. Be proactive - say what you do, how you do it, and publish this for transparency in plain language suitable for its intended audience -see our Transparency principles

Security
10. Ensure the security of patient data held in digital and other formats

This information is also contained in our Position Statement: "Our expectations of organisations which use our patient 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?

We welcome the move towards the default use of Secure Data Environments. But we have a concern that there is a lack of detail on common access processes/committees to speed access. This is an area which needs high quality, patient involvement in decision making.

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?

No response

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?

We think it is reasonable to state that there is a degree of mistrust around use of AI fuelled by media and little positive information from those that develop or use AI. More needs to be done in this area to engender public trust.

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

No response. AI can enhance the human interaction, but not replace it

* use MY data

The only independent UK movement of patients, relatives and carers focussed on the use of patient data to save lives and improve outcomes

---

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

Our mission statement

- **use MY data** is a movement of patients, carers and relatives.
- **use MY data** endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.
- **use MY data** aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.
- **use MY data** supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

What we do

  - We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.
  - We work to bring a patient voice to all conversations about patient data.
- We have developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are available here.
  - We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.

❖ We provide learning resources for patient advocates on patient data issues, including:
  - Hosting events for patients and the public, focussing on patient data topics
  - a library of resources of data security, consent
  - narratives from individuals about the value of collecting and using patient data.

❖ We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

---

www.useMYdata.org.uk
join@useMYdata.org.uk
@useMYdata