

# DATA STRATEGY FOR HEALTH AND SOCIAL CARE

**Closes 12<sup>th</sup> August 2022**

More information can be found [here](#).

## Questions

### Part 1: Empowering people

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

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

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

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

The difference between individual level and organisational Hospital Trust level data is an important distinction to make when thinking about the use of general health and social care data, as is the difference between patient reported data and clinical data. All data that comes under these areas could be considered an individual's health and social care data, in that it relates to their wellbeing. It is a priority for patients to have access to their individual data and the clinical data that is relevant to them and their condition.

The Brain Tumour Charity ran a Data Sharing Survey in 2017 prior to the establishment of the BRIAN app, in order to understand how brain tumour patients felt about their data being used. The results provided a useful understanding of what data patients feel is a priority to have access to.

270 people from the UK responded to this survey. In terms of the control patients have over their data, the results of this survey showed that patients are generally very willing to share their data in order to improve treatment and care. Most respondents were happy to do this in order to improve future outcomes rather than due to purely potential individual benefits.

- 97% of respondents agreed they would be happy to give their medical and health data to the data bank to help improve brain tumour treatment and care.
  - 87.7% agreed because they want to improve outcomes and help others with the disease now and in the future, even if they themselves get no benefit.
  - 8% agreed because of the benefits it could give them as individuals in terms of their treatment, care and quality of life.
  - 4.2% provided other reasons for agreeing.
- 94.7% of respondents agreed they would be happy to share information even if, due to the specific nature of the data shared (e.g. very rare tumour type), they could potentially be identified from it.

Whilst not exhaustive, The Brain Tumour Charity's 2017 Data Sharing Survey also asked questions to respondents around specific aspects of their health and social care data that they would be willing to share, the results showed that:

- 92% of respondents would want to share information about any **non-prescription drugs or methods used during treatment and care.**
- 40.8% of respondents would be willing to share information on **non-prescribed or even illegal drugs**, even if this could potentially expose themselves to legal proceedings.
- 21% said they would share information that **could expose themselves**, but not someone else.

Over 5,000 people affected by brain tumours have signed up to The Brain Tumour Charity's BRIAN app<sup>1</sup> which allows them to record their symptoms, treatments, side effects, and appointments. The app also allows patients to also share their data with anyone they trust – such as family, carers and their healthcare team – enabling them to better understand their situation. Having autonomy and control over what patient reported data is shared can be an empowering way for patients to contribute to their own care and wellbeing, through keeping up to date with their symptoms, appointments and medication, which acts as a supportive tool when meeting and sharing information with healthcare professionals.

**In a similar way to the BRIAN app enables, patients should have autonomy and control over their health and social care data, to provide autonomy over their own condition.**

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?

It is essential to ensure there is duty of care when utilising patients' data, and when a guardian is delegated to make decisions over how that data is used.

The Brain Tumour Charity's 2017 Data Sharing Survey showed that:

- 92.7% of respondents agreed with the statement: *"I would want my family to donate my data even if I have passed away."*

Whilst the 2017 survey shows that the majority of brain tumour patients are willing for data to be donated when they are able to make no active choice in the matter, it is key that informed consent is made by the individual where possible. The safeguarding of data needs to be protected by layered legislation, where there are multiple touchpoints that ensure informed consent and patients who have decisions delegated have protections so that the decisions made on their behalf are interrogated appropriately. Power of Attorney or a court appointed guardian should also be used where necessary in order to protect vulnerable patients.

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 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?

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<sup>1</sup> <https://www.thebraintumourcharity.org/living-with-a-brain-tumour/brian/>

It is important that all patients are informed about what data will be used (patient reported, clinical, etc.), who will have access to this data (healthcare professionals, researchers, commercial entities), and at what level the data is being provided (individual, organisational, regional, etc.).

It is also important to think of the consent implications when the data donated by individuals and organisations is repurposed in any way materially from the original explicit consent parameters. For example, when that data might have been given on a free to access basis and then reappears behind a for profit paywall.

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?

It is necessary that all uses of data abide by the Caldicott Principles. It is particularly important to consider Caldicott Principle 7 (the duty to share information can be as important as the duty to protect patient confidentiality) when considering the use of patients' data. Transparency around these principles and guidelines (such as the Health Data Research (HDR) UK network guidelines) and any associated processes is important, alongside an easy access method for patients to request to know what health and social care data is being used about themselves, and for what purpose.

The Brain Tumour Charity is a member of the Health Data Research (HDR) UK network and has therefore signed up to abide by the guidelines, principles and framework laid out in order to use patient data in a trustworthy manner.

**The Scottish Government should ensure there is explicit, clear and thorough guidelines for health and social care professionals to abide by when using patient data.**

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?

There are a number of situations in which brain tumour patients have told us they feel comfortable sharing their data, including with researchers. However sharing data with industry seemed to be a bit more complex. The Brain Tumour Charity's 2017 Data Sharing Survey showed that:

- 56.9% of respondents felt commercial users such as pharmaceutical companies or researchers wishing to access data from the BRIAN app should pay a fair commercial fee to The Brain Tumour Charity.
- 43.1% agreed that commercial users, such as pharmaceutical companies or researchers, should not have to pay a fee so all users, regardless of ability to pay, can access and use the information to accelerate the development of new treatments.

It is important that data is made available for research, in a secure and consented way. However, the sharing of data with commercial users should only occur when explicit consent has been given and full information is shared about the use of, and implications of sharing, a patients' health and social care data.

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

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

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

- Yes
- No
- N/A

(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?)

N/A

## 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? Please rank the following list in order from 1 to 7, with 1 being the most important.

1. Confidence in using data
2. Data visualisation
3. Knowledge of how to access data
4. Understanding of what data exists and where to find it
5. Understanding/use of management information by managers
6. Understanding of governance
7. Other

6B. How do you believe skills and training gaps 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?

It is important that a way of providing data is agreed to even when the numbers of patients are very small, such as in rare disease types, without compromising the quality and accessibility of the data. For example this could be brought about by using more longitudinal data. Data from fewer people over a longer time period can often be more informative than data from more people over a short timeframe.

Even before actions are taken so that the public have access to data they can understand and use, it is important to be mindful that rarer conditions, such as brain tumours, will need to have greater sensitivity to the higher potential for the loss of anonymity, due to the smaller numbers. This needs to be balanced against the potential benefit of accessing that data.

There is also a need to provide more data, that is accessible, on patients' quality of life in order to achieve the goal of reducing the harm of brain tumours, as this is just as important as understanding patients' survival outcomes. This is particularly pertinent for brain cancer patients, as only 12% of adults diagnosed with the disease survive for five years or more.

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?

Good quality and accessible patient data is crucial in providing insights to advance medical research, as well as health and social care services, and holds significant potential to deliver benefit to patients, as well as measure progress. We need an increase in good-quality research and data in order to further the knowledge and understanding of brain tumours, accelerate new treatments, and enhance quality of life through evidence-based supportive care. This data needs to be granular to be meaningful, as the impact of brain tumours is so varied depending on type and location in the brain.

Firstly, it would be beneficial for Trusted Research Environments (TRE) that hold NHS data in Scotland to allow for federation with other datasets. Having a federated identity service, along with standardised

terms in government and NHS contracts, would drive forward standards for federation of TREs and allow easier access of data while still maintaining safety and confidentiality. This would improve the accessibility of data to researchers.

**The Scottish Government should work to federate Trusted Research Environments that hold NHS data in Scotland and work with The Brain Tumour Charity to allow NHS Scotland data to be used within BRIAN.**

Secondly, it is also important that data does not become stuck in siloes and can be easily aggregated in order to draw insights. Being able to understand the various impacts of different treatment and care areas on both outcomes and quality of life is important in achieving overall progress on improving the experience of a specific rare disease, such as brain tumours.

Being able to access comprehensive and consistent data will provide crucial insights to both move towards and measure progress on the Scottish Government's goals on health and social care services. The integration of data would help improve the quality of the overall dataset, making it more usable.

Thirdly, the cost of accessing data for charities can also be a significant barrier, preventing charities and patient organisations from gaining (and contributing to) a more detailed understanding of where potential gaps in treatment and care exist and therefore supporting patients in addressing potential unmet needs. Accessing national healthcare datasets is currently costly for charities and researchers and can be time-consuming. There are often errors, poor coverage of certain information and inconsistencies in clinical coding and reporting practices between trusts, which makes trends harder to understand. Access to data and assurance of data quality are key, alongside ensuring accurate linkage of complimentary datasets and making it easier to request additional aspects of data. Greater transparency over the outcomes of every clinical encounter as well as over the technology and services employed in different hospitals would enhance the research value of the data, improving both the data's 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?

Our role as an organisation is to be a facilitator, particularly through the data in our BRIAN app, in order to make the data accessible to the relevant parties. The data insights from BRIAN need to be comprehensive and organised clearly enough to be used in research and create the greatest impact, for which a high quality level of data is essential. In making data from BRIAN accessible, it must be ensured that patients' data can be accessed in a secure manner (such as a Trusted Research Environment).

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?

It is important that as much data as possible is shared to help inform clinical practice, whether that comes from industry, research or charities. This data needs to be integrated and joined up, so that the data isn't provided in siloes and therefore able to have a greater impact on informing clinical practice. Data should also be collected and provided around quality of life, as reducing the harm and understanding a patients' experience is just as important as understanding their outcomes. This is particularly pertinent for brain cancer patients, as only 12% survive for five years or more.

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?

### **Overall Reflections**

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

