The National Data Strategy – a consultation

Response from use MY data

30 November 2020

Introductory Note

This response has been coordinated by the Secretariat of **use MY data**, on behalf of members.

As with all the responses we collate on behalf of **use MY data**, these may contain contrasting views from members. It is inevitable that we receive a range of views from members, and all these views are included in our response. We believe that there is strength in presenting a complete range of views.

We asked our members for their responses using our response@usemydata.org.uk address by the end of Friday 20 November 2020.

This document comprises the summarised responses from the members who provided a response.

Contact details and follow-up

Our members are happy for use MY data's response to be used or shared without restriction.

If you would like to follow-up with **use MY data**, or ask any questions about our response, please contact the Coordinator, Alison Stone - alison@useMYdata.org.uk

Our collated comments are shown below and include general points of feedback.
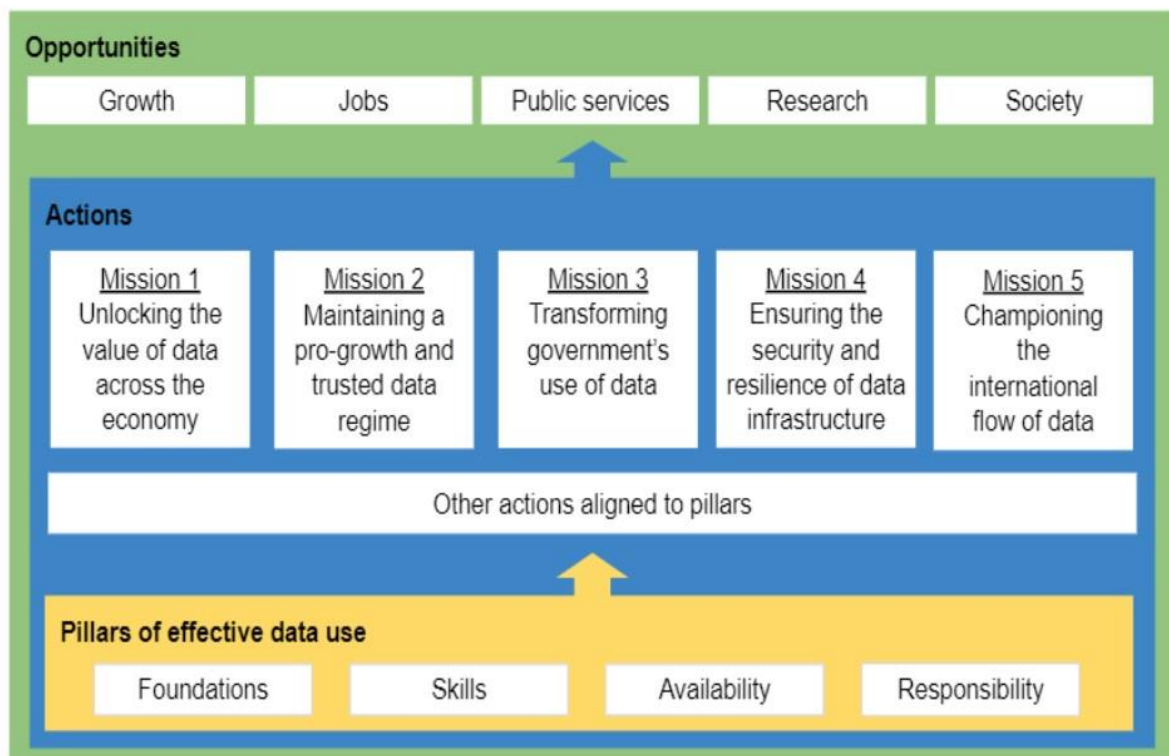
What we asked our members

We highlighted that the actual Strategy being consulted on is available at:

https://www.gov.uk/government/publications/uk-national-data-strategy/national-data-strategy

We submitted a response to an earlier consultation to the National Data Strategy back in July 2019, which is available here.

We used the text and the questions cut/pasted from the online response web-form and put into this Word document to make things easier for us to collate.

We provided a schematic from the consultation document, which is shown below:

Questions we are being asked to respond to, as written in the consultation document:

Q1. To what extent do you agree with the following statement: Taken as a whole, the missions and pillars of the National Data Strategy focus on the right priorities. Please explain your answer here, including any areas you think the government should explore in further depth.

The overall impression was that this was a good document and everything in it deserves saying.

It was not too difficult to read, but it was noted as being "very motherhood and apple pie and high level".

What will be important is when it goes down to the next level and says what is going to be done and, if anything, not going to be done. That will be when specific choices have to be taken and that's when it becomes interesting.

There is a fear is that it portends the government infrastructure being involved across the whole picture and at all stages.   This could create an overarching standardisation, conservatism, bureaucracy and state interference mentality which could stifle innovation and drive the real non-conformist innovators to seek a more open environment in which to build their mould-breakers.

Perhaps the key to avoiding this will be allowing the next stages to be designed outside the existing decision-making structures with wider non-civil service input leaving the civil service as subsequent implementors where appropriate.

There has been little public involvement so far and that will clearly need to change as it moves forward - there is nothing about citizen inclusion. This is clearly a strategy aimed primarily at government benefits rather than those to the individual.

You referenced a document with a list of who was consulted, and it was commented that "real people" are notable for their absence.   We consider it essential that proper engagement comes in the next phase as the document moves from the abstract wish list to a set of concrete proposal.

One of our members commented that the ways that they judge documents of this nature is 'are there things I disagree with?'. If there aren't, I tend to feel it is an abstract motherhood and apple pie statement". To this end, they commented "I feel this doc falls into that trap. It's critical that the next iteration become more specific with clear statements of what will and will not be done".

The overall comment was that the document does not define priorities – it wants to do everything.

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree ✓

Strongly agree

Q2. We are interested in examples of how data was or should have been used to deliver public benefits during the coronavirus (COVID-19) pandemic, beyond its use directly in health and social care. Please give any examples that you can, including what, if anything, central government could do to build or develop them further.

We noted that for question two, the consultation is only looking for examples outside health and social care data. Health and social care data will be covered in the upcoming Data Strategy for Health and Social Care.

Noting that they are after examples outside of health and care, this is moving beyond our normal scope.

However, we did not see sufficient economic impact modelling to balance against the health impact modelling.

Q3. If applicable, please provide any comments about the potential impact of the proposals outlined in this consultation may have on individuals with a protected characteristic under the Equality Act 2010?

No response

Q4. We welcome any comments about the potential impact of the proposals outlined in this consultation on the UK across all areas, and any steps the government should take to ensure that they take account of regional inequalities and support the whole of the UK?

No response

Mission one: Unlocking the value of data across the economy

Data is an incredibly valuable resource for businesses and other organisations, helping them to deliver better services and operations for their users and beneficiaries. However, there is increasing evidence to suggest that the full value of data is not being realised because vital information is not getting to where it needs to be.

Our first mission is to create an environment where data is appropriately usable, accessible and available across the economy – fuelling growth in organisations large and small. We will create a clearer policy framework to identify where greater data access and availability across and with the economy can and should support growth and innovation, in what form, and what government's role should be, in the UK and globally.

Data availability: For data to have the most effective impact, it needs to be appropriately accessible, mobile and re-usable. That means encouraging better coordination, access to and sharing of data of appropriate quality between organisations in the public sector, private sector and third sector, and ensuring appropriate protections for the flow of data internationally.

Q5. Which sectors have the most to gain from better data availability? Please select all relevant options listed below, which are drawn from the Standardised Industry Classification (SIC) codes.

- Accommodation and Food Service Activities
- Administrative and Support Service Activities
- Agriculture, Forestry and Fishing
- Arts, Entertainment and Recreation
- Central/Local Government inc. Defence
- Charity or Non-Profit
- Construction
- Education
- Electricity, Gas, Steam and Air Conditioning Supply
- Financial and Insurance Activities
- Human Health and Social Work Activities
- Information and Communication
- Manufacturing
- Mining and Quarrying
- Transportation and Storage
- Water Supply; Sewerage, Waste Management and Remediation Activities
- Wholesale and Retail Trade; Repair of Motor Vehicles and Motorcycles
- Professional, Scientific and Technical Activities
- Real Estate Activities

- Other

Q6. What role do you think central government should have in enabling better availability of data across the wider economy?

No response.

Q6a. How should this role vary across sectors and applications?

No response.

Data foundations: The true value of data can only be fully realised when it is fit for purpose, recorded in standardised formats on modern, future-proof systems and held in a condition that means it is findable, accessible, interoperable and reusable. By improving the quality of the data we are using, we can use it more effectively, and drive better insights and outcomes from its use.

Q7. To what extent do you agree with the following statement: The government has a role in supporting data foundations in the wider economy. Please explain your answer. If applicable, please indicate what you think the government's enhanced role should be.

The government has a key role in using data to promote innovation and competition. For example, the work on portability of bank accounts via enforced data sharing at the time of transfer has been critical.

A key role of government going forward is to ensure new, disruptive entrants to markets are not inhibited by "cosy data sharing clubs" of existing players.

In healthcare this should be used to facilitate enhanced data sharing between providers – it needs to be achieved both within the NHS and between the NHS and other providers.

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree ✓

Q8. What could central government do beyond existing schemes to tackle the particular barriers that small and medium-sized enterprises (SMEs) face in using data effectively?

Ensure steps are taken to reduce barriers when cosy data cartels are identified.

The Smart Data Review in 2019 consulted on ways to make evolving schemes more coordinated across banking, finance, telecoms and energy. The focus of Smart Data is citizens asking their providers to share information about them with third parties.

A good idea in principle but we must ensure that these permissions are not buried within reams of terms and conditions and so, in practice, just get nodded through by users.

Q9. Beyond existing Smart Data plans, what, if any, further work do you think should be done to ensure that consumers' data is put to work for them?

Where there are gatekeepers for release of data they must be identified, their roles and rules must be transparent, their decisions and rationales must be clear and it should be considered for which of them subjects must have the right to opt out of their control and thus allow their data to be more widely used for their (or society's benefit).

Mission two: Maintaining a pro-growth and trusted data regime

Building on our status as a world leader in technological innovation and our robust data protection standards, we will maintain a data regime that supports the future objectives of the UK outside of the EU and promotes growth and innovation while maintaining public trust. This regime will not be overly burdensome for the average company, nor will it be unnecessarily complex or vague; it will help innovators and entrepreneurs use data legitimately to build and expand their businesses, without undue regulatory uncertainty or risk at both the domestic and international levels.

To encourage the widespread uptake of digital technologies, we will also work with regulators to provide advice and support to small- and medium-sized businesses to help them expand online, and develop sector specific guidance and co-regulatory tools to accelerate digitisation across the UK economy.

Q10. How can the UK's data protection framework remain fit for purpose in an increasingly digital and data driven age?

From a data perspective we may want to highlight the increasing need for international standards on data interoperability.

A key point for use my data would be the adoption of the principles of Transparency, which could be adopted across all areas of Government and across different countries.

One response commented "They say 'This regime will not be overly burdensome for the average company, nor will it be unnecessarily complex or vague; it will help innovators and entrepreneurs use data legitimately to build and expand their businesses, without undue regulatory uncertainty or risk at both the domestic and international levels.'"

The responder followed by saying "Seeing is believing!   I do not have full confidence that civil servants view of what is not 'overly burdensome' will match the view of others". Whilst this was the wording from one individual, it is reflected in views of others too.

In section 7.1.2 we lay out the functions of the Centre for Data Ethics and Innovation (CDEI), set up in 2018 to advise the Government on the use of data-driven technologies and AI.

Q11. To what extent do you agree with the functions set out for the Centre for Data Ethics and Innovation (CDEI) - AI monitoring, partnership working and piloting and testing potential interventions in the tech landscape? Please explain your answer.

It is worth noting that we submitted a response previously on the role of the Centre for Data Ethics and Innovation.

Our key view is that so long as what it comes out with is not overly burdensome, time delaying or bureaucratic it is essential. But there is "a fear it will have all of those characteristics and thus stifle innovation in the UK and cause it to shift to more independence valuing countries which are better able to foster innovation."

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Q11a. How would a change to statutory status support the CDEI to deliver its remit?

No response

Mission three: Transforming government's use of data to drive efficiency and improve public services

There is massive untapped potential in the way the government uses data. We will implement major and radical changes in the way that the government uses data to drive innovation and productivity across the UK. In doing so, we will improve the delivery of public services, as well as our ability to measure the impact of policies and programmes, and to ensure resources are used effectively.

To succeed, we need a whole-government approach led by a Government Chief Data Officer from the centre in strong partnership with organisations. We need to transform the way data is collected, managed, used and shared across government, including with the wider public sector, and create joined-up and interoperable data infrastructure. We need the right skills and leadership to understand and unlock the potential of data – and we need to do so in a way that both incentivises organisations to do the right thing, as well as build in the right controls to drive standardisation, consistency and appropriate data use.

The government is going to set an ambitious package of work in this space and wants to understand where we can have the biggest impact.

Q12. We have identified five broad areas of work as part of our mission for enabling better use of data across government:

1. Quality, availability and access
2. Standards and assurance
3. Capability, leadership and culture
4. Accountability and productivity
5. Ethics and public trust

We want to hear your views on any actions you think will have the biggest impact for transforming government's use of data.

Transparency should underpin everything and is essential if the trust and support of patients and the public is to be maintained and developed. Transparency means operating in such a way that it is easy for others to see what actions are performed. In a nutshell – **Say what you do, do what you say.**

We would highlight our principles of Transparency which have been developed by use MY data members:

- Accessible – easy access to information
- Understandable – the right language for the audience
- Relevant – addresses audience concerns
- Useable – in a form that meets the audience needs
- Assessable – is checkable/provides sufficient detail
- Being as pro-active with 'bad news' as with 'good news'
- Being timely with communication

We would add that the mindset should be how can we use data to improve the UK and its people (whilst respecting the law and privacy) rather than how can we ensure that no data is released unless "a million hurdles" have been jumped.

Q13. The Data Standards Authority is working with a range of public sector and external organisations to create a pipeline of data standards and standard practices that should be adopted. We welcome your views on standards that should be prioritised, building on the standards which have already been recommended.

Our only comment would be to suggest that the emphasis on standards that "should be adopted" needs to change to "must be adopted".

Mission four: Ensuring the security and resilience of the infrastructure on which data relies

In the UK, the government already imposes safeguards and enforcement regimes to ensure that our data is handled responsibly. But we will also take a greater responsibility for ensuring that data is sufficiently protected when in transit, or when stored in external data centres.

The government will determine the scale and nature of risks and the appropriate response, accounting for emerging trends in the market landscape. We will also determine whether current arrangements for managing data security risks are sufficient to protect the UK from threats that counter our missions for data to be a force for good. And we will consider the sustainability of data use, exploring inefficiencies in stored and processed data, and other carbon-inefficient processes.

The infrastructure on which data relies is the virtual or physical data infrastructure, systems and services that store, process and transfer data. This includes data centres (that provide the physical space to store data), peering and transit infrastructure (that enable the exchange of data), and cloud computing that provides virtualised computing resources (for example servers, software, databases, data analytics) that are accessed remotely.

Q14. What responsibilities and requirements should be placed on virtual or physical data infrastructure service providers to provide data security, continuity and resilience of service supply?

One member made a significant comment here:

"Good question.   This comes down to how we keep Huawei and similar out of controlling core elements of this infrastructure and thus give them the opportunity to exploit the data or gain power by withholding service.   I think we need to do it. But how? A simple blacklist of suppliers will always be circumvented.   It's about the innards of the technology being transparent (to coin a word) but how do you balance with upholding IP?   A key area for further analysis in the next iteration of the strategy."

Q14a. How do clients assess the robustness of security protocols when choosing data infrastructure services? How do they ensure that providers are keeping up with those protocols during their contract?

How do we ensure that providers are doing just what they say? Critical questions

Q15. Demand for external data storage and processing services is growing. In order to maintain high standards of security and resilience for the infrastructure on which data use relies, what should be the respective roles of government, data service providers, their supply chain and their clients?

No response

Q16. What are the most important risk factors in managing the security and resilience of the infrastructure on which data use relies? For example, the physical security of sites, the geographic location where data is stored, the diversity and actors in the market and supply chains, or other factors.

No response

Q17. Do you agree that the government should play a greater role in ensuring that data does not negatively contribute to carbon usage? Please explain your answer. If applicable, please indicate how the government can effectively ensure that data does not negatively contribute to carbon usage.

No response

Strongly disagree

Somewhat disagree

Neither agree nor disagree

Somewhat agree

Strongly agree

Mission five: Championing the international flow of data

In our hyper-connected world, the ability to exchange data securely across borders is essential.

As the UK leaves the EU, we have the opportunity to develop a new UK capability that delivers new and innovative mechanisms for international data transfers.

Using our reputation as a world leader in digital, a champion of free trade and the rules-based international system, and an engaged, rule-abiding member of the global community, we will build trust in data's use, creating the regimes, approaches and tools to ensure personal data is appropriately safeguarded as it moves across borders. We will also facilitate cross-border data flows by removing unnecessary barriers to international data transfers that promote growth and innovation. And we will seek to promote data standards, data interoperability, and UK values internationally.

Q18. How can the UK improve on current international transfer mechanisms, while ensuring that the personal data of UK citizens is appropriately safeguarded?

No response

We will seek EU 'data adequacy' to maintain the free flow of personal data from the EEA and we will pursue UK 'data adequacy' with global partners to promote the free flow of data to and from the UK and ensure it will be properly protected.

Q19. What are your views on future UK data adequacy arrangements (e.g. which countries are priorities) and how can the UK work with stakeholders to ensure the best possible outcome for the UK?

No response

About use MY data

use MY data is a movement of patients, carers and relatives

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.

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.

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.

What we do

❖ We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.

❖ 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 workshops for patients and the public, focussing on topics related to patient data
- a library of resources of data security, consent
- narratives from individuals about how collecting, storing and using data can help patients.

❖ 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.

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