

Consultation on the National Data Strategy

Collated Responses Submitted by the All-Party Parliamentary Group for Longevity 9 December 2020

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Thank you for participating in the consultation on the framework National Data Strategy

This is the consultation on the [National Data Strategy](#), which was published on 9 September 2020.

Thank you for your participation. Your feedback and input is invaluable to the strategy's ongoing development.

This consultation is on a UK-wide basis and we welcome responses from organisations and individuals across the UK. The strategy covers both reserved and devolved areas; where the strategy covers reserved areas (and, in respect of Northern Ireland, excepted areas), it does so for the whole UK, and where it covers devolved or transferred areas, it applies to England only.

The survey begins with general questions on the overall strategy. These are followed by questions on each of the five missions; some are relatively broad, while others are quite technical. Please do not feel that you have to provide a response to every question. We welcome your feedback on as many or as few questions as you would like to answer.

You are able to save progress on your response and come back to it later. Simply click the 'save and continue later' button and you will be prompted to provide an email address to save your survey progress.

The deadline for responses is 11:45 pm on 2nd December 2020.

If you have any questions in the meantime, please do not hesitate to contact us at nationaldatastrategy@dcms.gov.uk.

The privacy notice for this consultation is available [here](#), on the National Data Strategy consultation gov.uk page.

Questions about you

The following questions will assist us in monitoring the range of users the consultation has reached. We will only be using the information provided in this section for the purposes of analysing consultation responses.

Please provide either your name, or the name of the organisation on behalf of which you are responding.

Your name:

Name of organisation:

[All-Party Parliamentary Group for Longevity](#)

What industry or sector best categorises the work of your organisation:

- Information and Communication
- Professional, Scientific and Technical Activities
- Financial and Insurance Activities
- Human Health and Social Work Activities
- Education
- Public Sector/Central or Local Government and Defence
- Charity or Non-Profit
- I'm responding in a personal capacity/no organisation
- Other (please specify):

[Other- All Party Parliamentary Group](#)

Please use this comment box to provide us with any additional information about you or your organisation.



The All Party Parliamentary Group (APPG) for Longevity was set up in March 2019 to address the scientific, technological and socio-economic issues relating to our ageing demographic and promote living healthier and longer lives. The APPG published the [The Health of the Nation Strategy](#) in February 2020 setting out key recommendations to meet the government goal of five more years of healthy life expectancy by 2035 ('HLE + 5') and at the same time to close the large social gap in healthy life expectancy. All details on the website <https://appg-longevity.org/>

One of the recommendations, the formation of an Open Life Data framework, is in motion with the APPG's 'Open Life Data Task Group', chaired by Lord O'Shaughnessy, to define what is needed to establish an open health system, drawing from other models like our Open Banking system and standards to harness data-intensive technologies to extend - and make more equal - the healthy longevity of British citizens across their life course. This was a key recommendation of [The Health of the Nation Strategy](#).

The overall goals of the task group are:

- explore how data-intensive technologies could make a positive contribution to the health, wellbeing and life chances of all people equitably
- propose solutions for innovating, scaling-up and leveraging these technologies across the private, public and academic sectors
- ensure that digital health infrastructure and innovation support is fairly distributed and resilient, reducing inequalities in co-creation, access and outcomes
- build public trust in the use of data for individual and collective health and social care purposes.

Two task groups took place, on 2 November and 27 November, with relevant findings informing our responses here in this National Data Strategy consultation form. The meeting minutes from Task Group One that took place on 2 November 2020 can be accessed [here](#). The meeting minutes from Task Group Two that took place on 27 November, which specifically explored ideas related to the five missions of the National Data Strategy Consultation, can be accessed [here](#).

The list of Task Group members include:

Task Group Chair

- Lord James O'Shaughnessy, Lord James O'Shaughnessy, House of Lords, APPG for Longevity Science Board Chair; Former Parliamentary Under Secretary for Health, former Director of Policy in No.10 Downing Street

Task Group Members

1. Liz Ashall-Payne, Orcha, Founder & CEO

2. Professor Richard Barker, Chair, Health Innovation Network, Founder & CEO, Metadvice and New Medicine Partners
3. Professor Peter Bradley, Public Health England, Director of Health Intelligence/Chief Information Officer
4. Professor Iain E. Buchan, University of Liverpool, Executive Dean for Population Health; Chair of Public Health and Clinical Informatics; Director of Digital Strategy and Partnerships, Liverpool Health Partners; Executive Dean Elect, Institute of Population Health Sciences
5. Dame Fiona Caldicott, National Data Guardian
6. Dr Rupert Dunbar-Rees, Outcomes Based Healthcare, Founder & CEO
7. Lord Geoffrey Filkin, Strategic Advisory Board Chair, All-Party Parliamentary Group for Longevity
8. Mr Michael Geer, Humanity Inc, Co-Founder & CSO
9. Professor Carole Goble CBE, University of Manchester, Professor of Computer Science
10. Eleonora Harwich, Reform, Director of Research
11. Eric Kihlstrom, Aging2.0, UK Chapter Lead, Aging 2.0; Tech entrepreneur
12. James Kingston, Dataswift, VP Research Partnerships
13. Dr Amanda Lamb, Programme Director, Health Innovation Liverpool, #DataSavesLives
14. Dr Maxine Macintosh, Research Fellow, The Health Foundation & The Alan Turing Institute Co-founder, One HealthTech
15. Professor Joao Pedro Magalhaes, Institute for Ageing and Chronic Diseases, University of Liverpool
16. Dr Mahiben Maruthappu, Cera Care, Founder & CEO
17. Jess Montgomery, Executive Director for Data Governance Program and Accelerate Program/ University of Cambridge
18. Annemarie Naylor MBE, Future Care Capital, Director of Policy & Strategy
19. Dr Sukhmeet Panesar, NHS England & Improvement, Deputy National Director, Data and Analytics
20. Reema Patel, Ada Lovelace Institute, Head of Public Engagement
21. Professor Jill Pell, Institute of Health & Wellbeing; University of Glasgow, Director
22. Joe Rafferty, Mersey Care NHS Foundation Trust, Chief Executive
23. Professor Matt Reed, Materials Innovation Factory, University of Liverpool, Strategy Director
24. Dr Richard Siow, AI in Longevity Consortium, Kings College London, Director of Ageing Research
25. Richard Sloggett, Policy Exchange, Senior Policy Fellow
26. Gavin Starks, Dgen, Founder & CEO
27. Adam Steventon, Director of Data Analytics, Health Foundation
28. Svitlana Surodina, Skein.co, CEO
29. Ben Szymkow, Partners & Projects Lead, Openmined
30. Dr Michael Trenell, CEO, Changing Health
31. Ming Tang, NHS England & Improvement, National Director, Data and Analytics
32. Mr Peter Ward, Humanity, Co-Founder & CEO
33. Dr Adrian Weller, Turing Institute, Programme Director for Artificial Intelligence, and Turing Fellow
34. Joachim Werr, HN, Founder & Executive Chair
35. Professor John Wright, Bradford Institute for Health Research, Director
36. Tina Woods, Longevity International, CEO & Co-Founder
37. Dr Hakim Yadi OBE, Closed Loop Medicine Ltd, Co-Founder & CEO

If you are happy for DCMS to contact you for further discussions about your response, please provide us with an email address here. Leave this box blank if you do not want to be contacted.

tina.woods@longevityinternational.org

Please click 'yes' if you are happy for your name/the name of your organisation, and/or quotes from your response to be used publicly. Otherwise leave blank.

If you select this option by mistake, please double-click to deselect.

- Yes, I am happy for this response to be mentioned in the published summary of the findings to this consultation

Yes

1. 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.

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Please explain your answer here and, if applicable, identify any areas you think the government should explore in further depth.

The consultation is very focussed on government and public sector data.

We believe there needs to be more focus on the potential of private sector datasets and 'non-health' data to leverage the potential of multimodal AI in understanding wider determinants of health and devising solutions for social impact at scale for wider societal benefit. This will drive social and business model innovation, unearth new models on how data can grow economies in a fairer, more equitable way and offer alternatives to US market-led approaches and Chinese state-driven ambitions to lead in AI.

The UK has rich and diverse data sets in the NHS, and these have the potential to bring significant societal and economic benefits by enhancing and maintaining the nation's health. Presently, however, there is too much focus on sickness data (i.e., NHS data) when healthcare comprises only 10-15% of the overall determinants of health. We need to broaden the data view to encompass the wider determinants of health (Donkin et al., 2019): 60% behavioural, social and psychological, 30% biological / genomic, and leverage insights and solutions from data science across the life course to deliver HLE+ 5 while minimising health inequalities, as illustrated from the government Foresight report, Future of an Ageing Population (Government Office for Science, 2016).

With approximately 30% of our health determined by our genes, more attention and funding are needed on the role of genomics and epigenetics in reducing premature ill-health rather than treating diseases. The recently published National Genomic Healthcare Strategy focusses on how genomics can aid diagnosis and personalised medicine and in particular exploring the potential of genomics in prevention. Central to this is the Accelerating Detection of Disease programme, the platform for developing effective diagnostics for early, asymptomatic chronic disease, carrying out up to 5 million polygenic risk score assessments on volunteers.

To leverage the true potential of these initiatives in health prevention and to achieve HLE+5, however, will require harnessing insights using multimodal AI from multiple datasets outside healthcare, and

including social care, within an open data ecosystem geared to identifying solutions to keep people healthy and well across the life course.

The potential of machine learning and multimodal AI to develop predictive and preventative health strategies is colossal. Insights from genetics, biological, behavioural, environmental, and financial data are currently under-utilised and there are significant opportunities to use AI and multimodal learning to predict disease and incentivise healthier living through harnessing such “life” data.

The big opportunity for AI is finding patterns in very large datasets in ‘healthy’ domains- the most important data to look at if you are interested in keeping people well and healthy. Finding solutions that minimise our risk for disease, delay ageing and extend our healthspans all rely on this.

Leveraging data outside health will enable us to assess new ideas about the “exposome” that represents the complex environmental exposures we are subjected to throughout our lives, including our diet, lifestyle factors, and social influences, and our body’s response to these challenges. The exposome consists of three overlapping domains:

- A general external environment, including the urban environment, education, climate factors, social capital, and stress
- A specific external environment with specific contaminants, radiation, infections, and lifestyle factors e.g. tobacco, alcohol, diet, physical activity, etc.
- An internal environment to include internal biological factors such as metabolic factors, hormones, gut microflora, inflammation, and oxidative stress

The exposome catalogues and integrates the complex factors that can also help us understand the effects of the environment on healthy longevity.

We are seeing fascinating developments with ageing biomarkers, which could lead to the development of strategies to minimise the risk of the diseases of ageing, including chronic diseases like dementia. Aided by AI, scientists are working out which biomarkers will be most useful to track the ageing process but most importantly, practically assess which interventions, whether lifestyle, food (microbiome and supplements) fitness, social, economic or pharmaceutical interventions, work best at a personalised health level but also at a wider population health level- important for health prevention and building up innate resilience to Covid-19 (and other pandemic threats too).

The opportunity for Britain to lead in this space, perhaps in a new moonshot initiative, is getting these devices to learn, think, and work together to produce novel insights. There are billions of petabytes of data flowing through AI devices every day and the volume will only increase in the years to come, especially with 5G, edge and quantum computing on the horizon which will help to manage the proliferation of data that will only increase in years to come.

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2. We are interested in examples of how data was or should have been used to deliver public benefits during the coronavirus (COVID-19) crisis, 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.

Please note that we are 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.

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There are a number of examples to consider:

Civic Data Models

There are emerging models that show the significant potential of civic data models operating within a tight diameter of trust in regions like Liverpool that leverage data outside health, mobilise local communities, and deliver wider social and economic benefits.

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

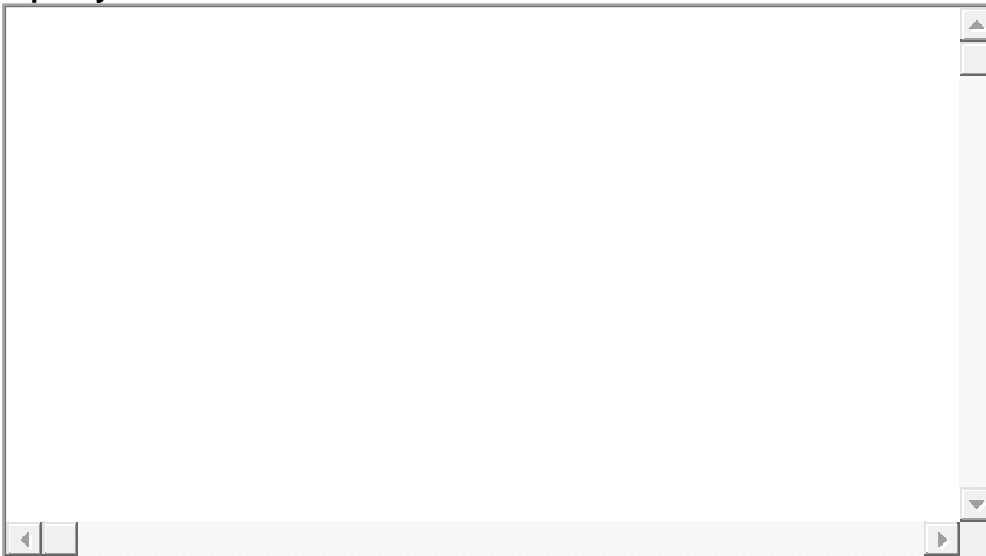
[Liverpool Civic Data Cooperative Model](#) (also included as case study in [Lessons and legacy from the COVID-19 pandemic in health and care](#))

<https://www.connectedhealthcities.org/> and <https://www.connectedhealthcities.org/chc-hub/public-engagement/datasaveslives/>

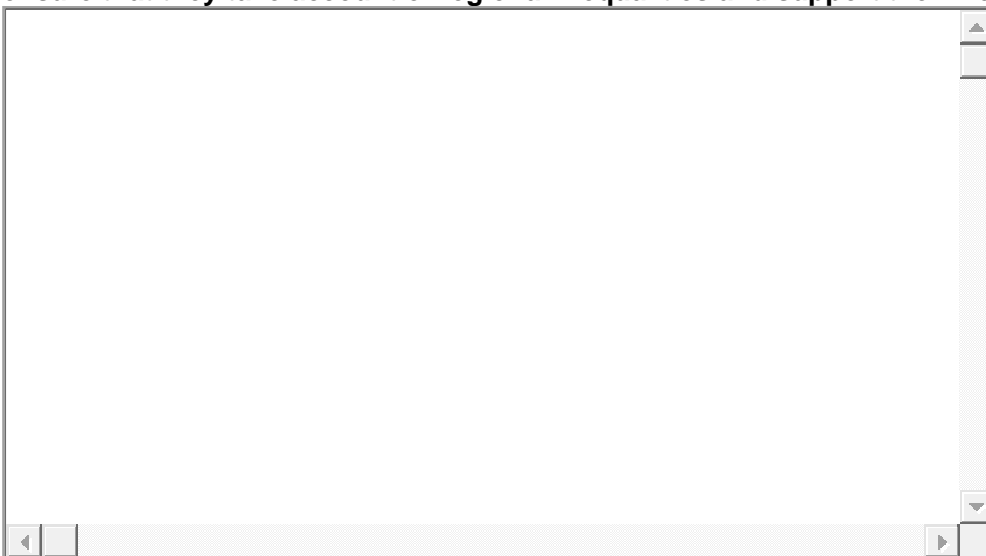
Non-Health Data to drive behaviour change

There are also emerging start-ups that focus on leveraging data outside health, for example, [Sweatcoin](#) (Fitness data) and [Spoon.Guru](#) (supermarket data) to incentivise and nudge people towards healthier behaviours.

3. If applicable, please provide any comments about the potential impact of the proposals outlined in this consultation on individuals with a [protected characteristic](#) under the Equality Act 2010.

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4. 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.

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The pandemic has shown how the nation's health is our greatest asset and is far bigger than the NHS.

'Our Unhealthy Nation' was published in Lancet Healthy Longevity on 8 December (see [here](#)) on behalf of the All-Party Parliamentary Group and spells out the critical need to address regional inequalities. Localities, local government, and communities are essential partners to improve our health and to develop a community-based commitment to improve local health. They will need the resources to do so and be involved in shaping the national plan with central government.

Specific considerations are below, as detailed in recent AHSN Network report, [Lessons and legacy from the COVID-19 pandemic in health and care](#).

We need to effectively mobilise local networks and community data intelligence. Feedback loops between central and local command centres need to improve. The COVID-19 Test and Trace system is an example of where these strengthened national-local relationships need attention.

Moving forward, the right balance between centralised information governance, including data sharing agreements and data standards to facilitate interoperability, and decentralised decision-making will be important to leverage the value of data and potential of artificial intelligence (AI) in disruptive innovation and sustainable health improvement.

The lessons from COVID-19 have highlighted the need for a robust national data infrastructure, information governance, and common standards to support better and quicker data sharing, in both public and private domains and in a way to make available datasets for multimodal AI and federated learning. This must be a focus of government and industry attention and investment ahead.

Data sharing agreements agreed centrally will facilitate data interpretation and data impact assessments. This will facilitate health and care integration, enable local networks to mobilise their communities and harness data intelligence more effectively, and support preventative health measures at both an individual and population health level. We need ethical governance frameworks that will promote data sharing for wider public benefit and the social good.

A 'decentralised national health resilience model' could reduce health inequalities, empower communities, build public trust and overall national health and economic resilience. Central to making this happen is ensuring health literacy, underpinned by digital literacy at all levels of society, to promote better decision-making while minimising the risk of digital exclusion.

Questions on 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 that is of appropriate quality between organisations in the public, private and third sectors, and ensuring appropriate protections for the flow of data internationally.

5. Which sectors have the most to gain from better data availability? Please choose all relevant options, below.

This list is based on the [Standardised Industry Classification \(SIC\)](#) framework for categorising work of organisations.

- Charity or Non-Profit
- Public Sector/Central or Local Government, including Defence
- Financial and Insurance Activities
- Information and Communication
- Professional, Scientific and Technical Activities
- Accommodation and Food Service Activities
- Administrative and Support Service Activities
- Agriculture, Forestry and Fishing
- Arts, Entertainment and Recreation
- Construction
- Education
- Electricity and Gas supply
- Human Health and Social Work Activities
- Manufacturing
- Mining and Quarrying
- Real Estate Activities
- Transportation and Storage
- Water Supply and Waste Management
- Wholesale and Retail Trade
- Other (please specify):

Please give any further details about your selections here:

Although all sectors would undoubtedly benefit from better data availability, the health sector would make the biggest impact. There is nothing more valuable than saving and improving the lives of people by increasing their health, so we feel the first major amount of effort needs to be concentrated in this sector. Also because of the higher privacy needs of the sector, all methods developed for the health sector would be quite likely to work in all other sectors.

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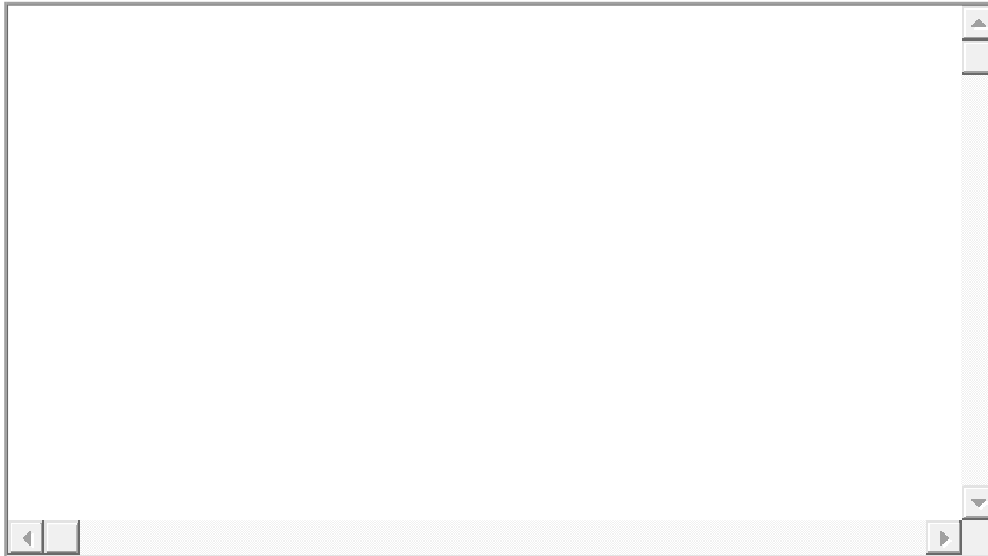
6. What role do you think central government should have in enabling better availability of data across the wider economy?

There are two central roles the government can play. The first is by leading by example and opening up health datasets (ie those associated with the NHS services) in a privacy preserving manner and showing best practice to do so. The second is to create more clarity around how to legally open up datasets and what approvals are needed from data owners.

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6a. How should this role vary across sectors and applications?

We believe these two central roles are applicable across all sectors and will lead to greatly increased value being produced from all current data in all sectors.



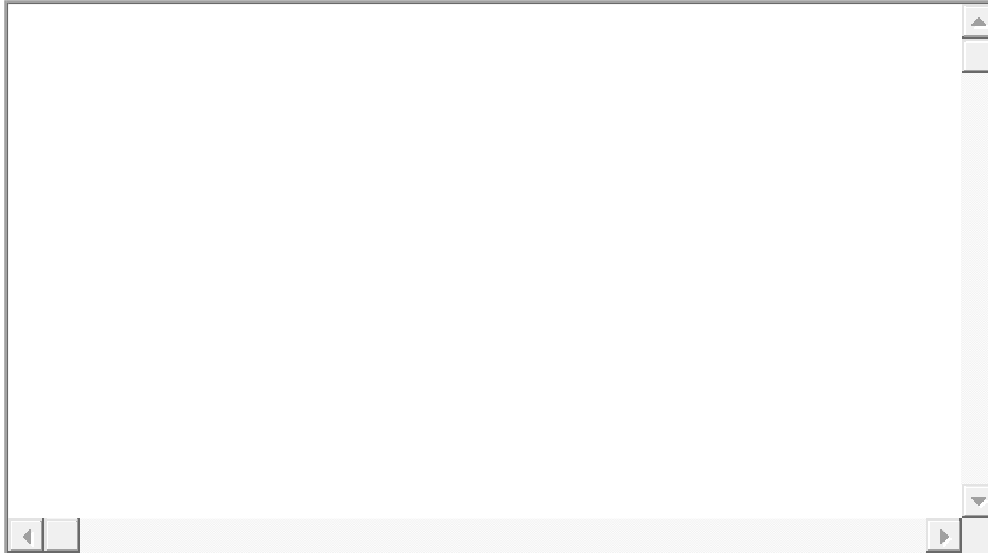
Data foundations: The true value of data can only be fully realised when it is fit for purpose, recorded in standardised formats on modern, future-proof systems and held in a condition that means it is findable, accessible, interoperable and reusable. By improving the quality of the data, we can use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

7. To what extent do you agree with the following statement: The government has a role in supporting data foundations in the wider economy.

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

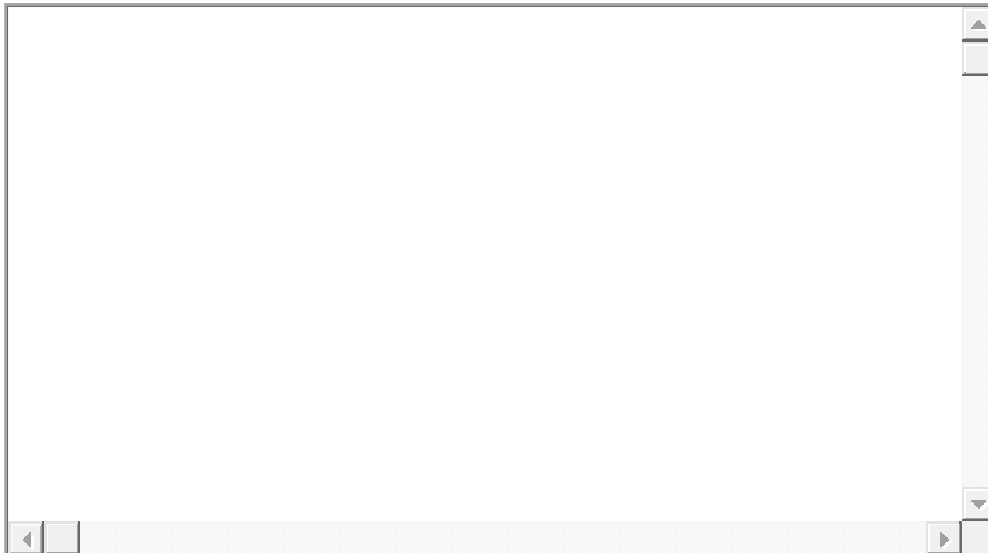
Please explain your answer here. If applicable, please indicate what you think this role should be.

We strongly agree that data standardization is a vital part of leveraging data properly. We, however, want to highlight that we don't think centralizing the data itself is the best answer. We must have increased standardization but done in a decentralized manner where all the data stays in local databases where it was originally collected. This allows for better data privacy and ownership, as datasets are not transferred between multiple parties. With standardized datasets, we gain the ability to do federated learning across local datasets without the need for data transfer.



8. 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?

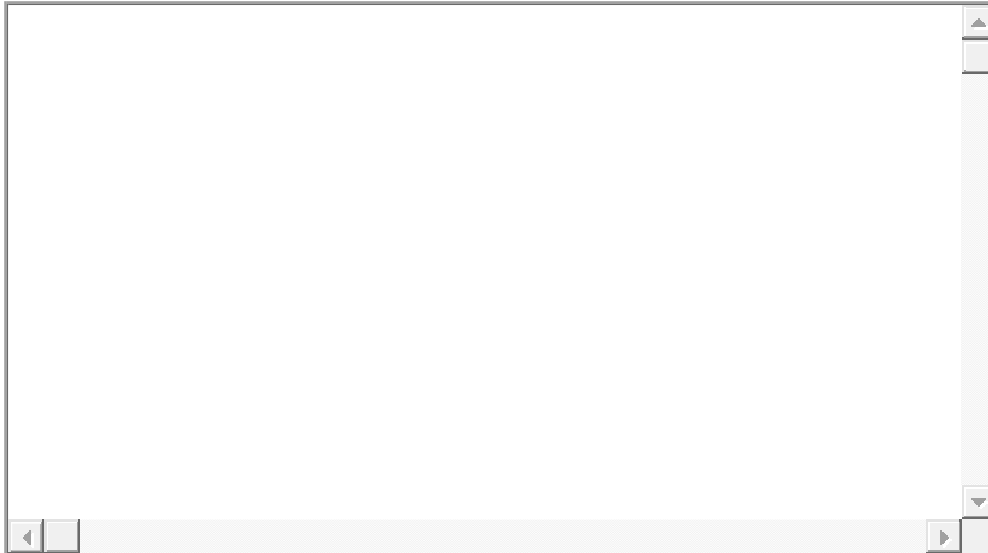
Setting a clear example of best practice in moving towards a system where data stays in local databases, but model training enabled across these databases in a privacy preserving manner. At the moment only large corporations have the ability to purchase centralized databases which gives undue advantage keeping SMEs out of the market. By opening up databases in a privacy preserving manner (using federated learning and possibly differential privacy methods) and greatly lowering barriers and timelines to access (even current databases with open application systems like UK Biobank can take months to access data), SMEs will be playing on a much more level field of play and thus innovation and market growth will increase.



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.

9. 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?

We now have the technology to keep consumers' data private AND allow for model training and learning from that data. Consumers want their data to be put to work for them and for their data to be kept private. Consumers do not actually want to give permission to every single different type of use for their data. We recommend that we start to use methods like federated learning and differential privacy to allow for consumers to keep their data private but also at the same time to start getting unfettered value from their data from the ingenuity of everyone in the UK and beyond.



Questions on 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.

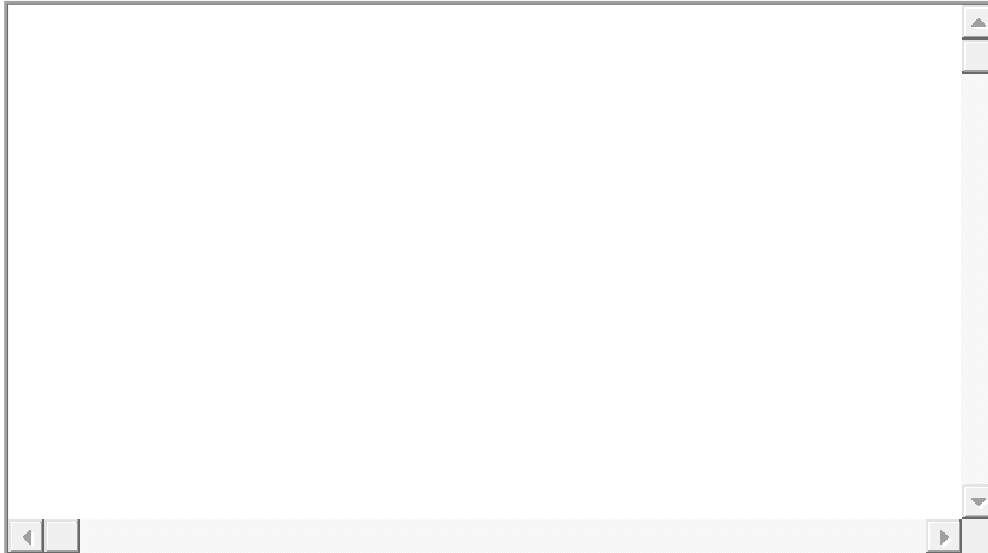
To encourage the widespread uptake of digital technologies, we will also work with regulators to provide advice and support to small- and medium-sized businesses to help them expand online, and develop sector specific guidance and co-regulatory tools to accelerate digitisation across the UK economy.

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

To maintain a pro growth and trusted data regime the following points need to be considered:

1. Know what trusted looks like (standards, regulations, best practice)
2. Have a clear process to assure which meet no 1

3. Have a clear distribution with transparency about the outcome of 2 to people
4. Have a clear distribution with transparency about the outcome of 2 to professionals (particularly in H&C)
5. Have a process to continuously monitor and assure oneself of this



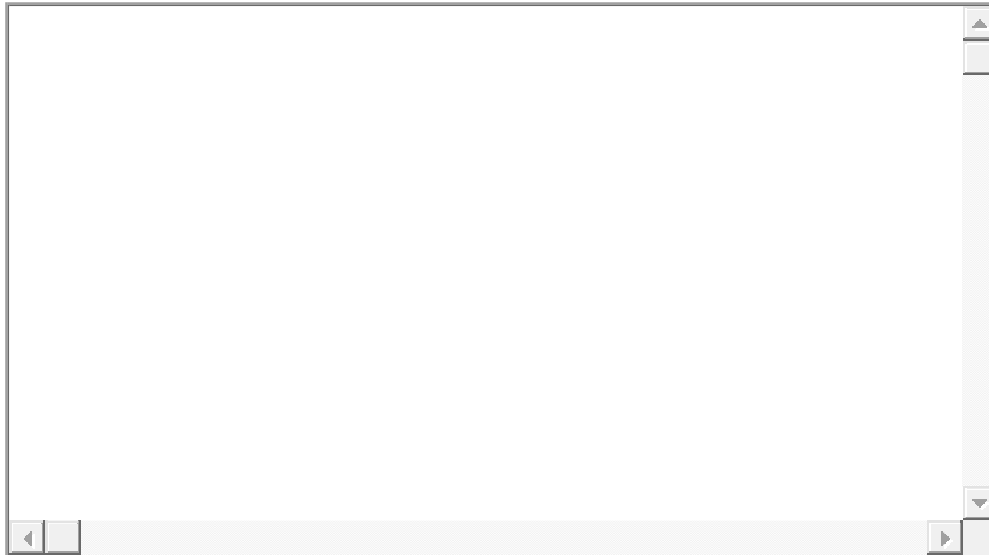
In section 7.1.2 of the framework National Data Strategy we lay out the functions of the [Centre for Data Ethics and Innovation \(CDEI\)](#), set up in 2018 to advise the Government on the use of data-driven technologies and Artificial Intelligence (AI).

11. To what extent do you agree with the following statement: the functions for the Centre for Data Ethics and Innovation (CDEI) should be Artificial Intelligence (AI) monitoring, partnership working and piloting and testing potential interventions in the tech landscape?

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

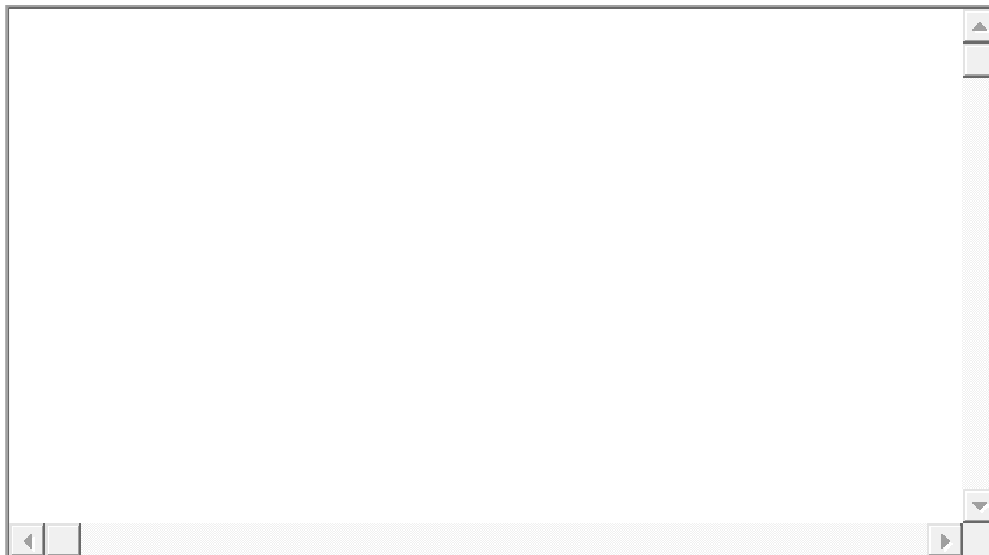
Please explain your answer here:

It appears that there is a growing list of responsibilities the CDEI is being tasked with. It could do these things, but it's going to need a lot of funding and expertise and some serious commitment. But if they are tasked with, say, 'modelling and testing intervention', what does that mean? What does 'monitoring AI' mean? What does that do and what kind of interventions? And then how is it empowered to do anything on what it finds? In summary, the CDEI could have a much broader scope, but as the scope becomes broader it needs to be much more tightly defined.



11a. **How would a change to statutory status support the CDEI to deliver its remit?**

[It may give it more power to enact what it finds.](#)



Questions on 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.

12. 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.

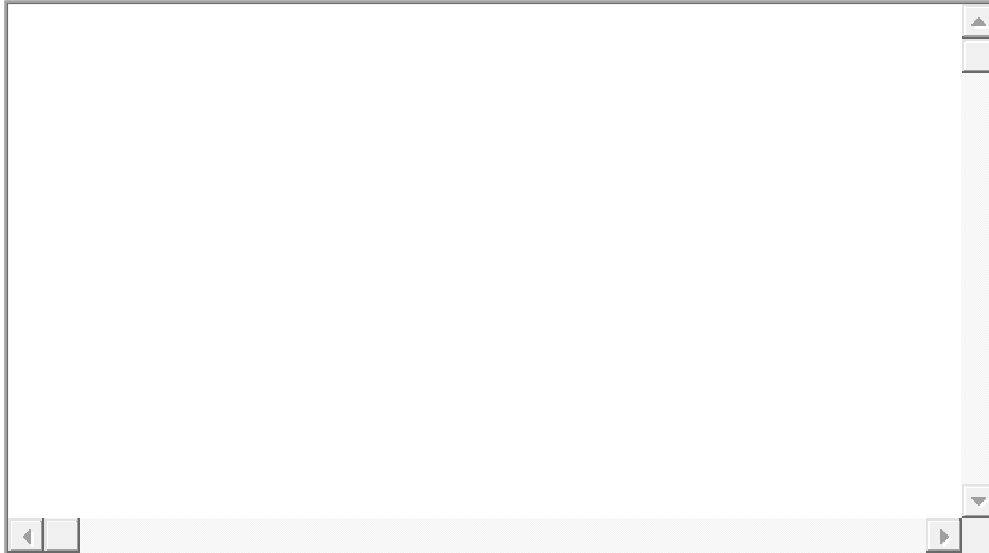
The data strategy needs a clear objective to support improving health and wellbeing. It should be looking to measure and support the 'HLE+5' goal of 5 extra years of healthy life expectancy while minimising health inequalities.

Healthcare data is much broader than NHS data and any data strategy needs to look beyond the NHS and connect into wider population health and wellbeing data.

From a Government perspective there is a need to ensure that centrally there is a dashboard of these key metrics being used to assess progress towards the healthy longevity goal. The Treasury and Cabinet Office could be the owners of this dashboard and convenors for cross government action.

Investment in healthcare data needs to invest in public health data and analytics as well as NHS data. This is particularly important with the forthcoming abolition of Public Health England.

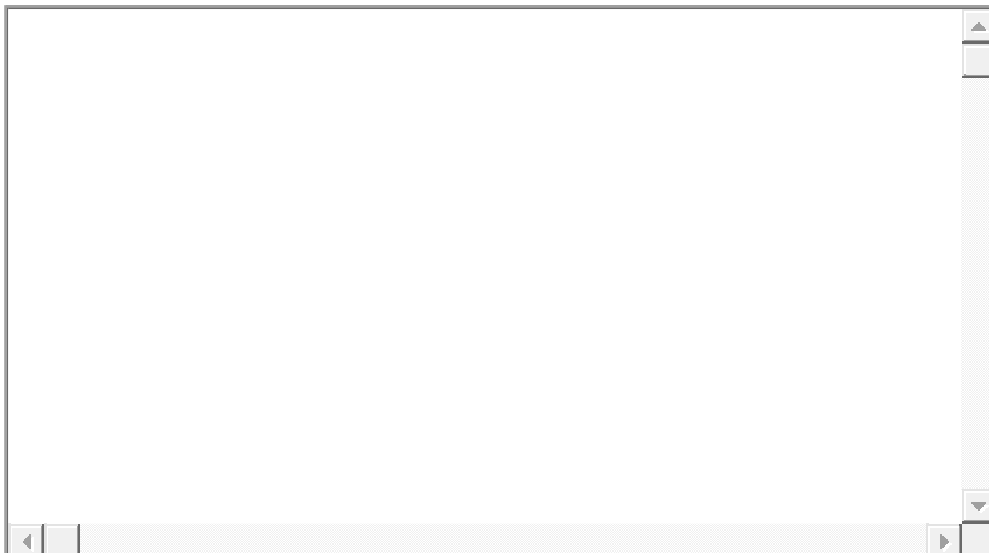
Any data strategy needs to ensure it is 'bottom up' as well as 'top down', empowering users with greater information about their health and wellbeing.



13. 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.

[Procurement frameworks and contracts need to have a standard clause in for data sharing](#)



Questions on 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.

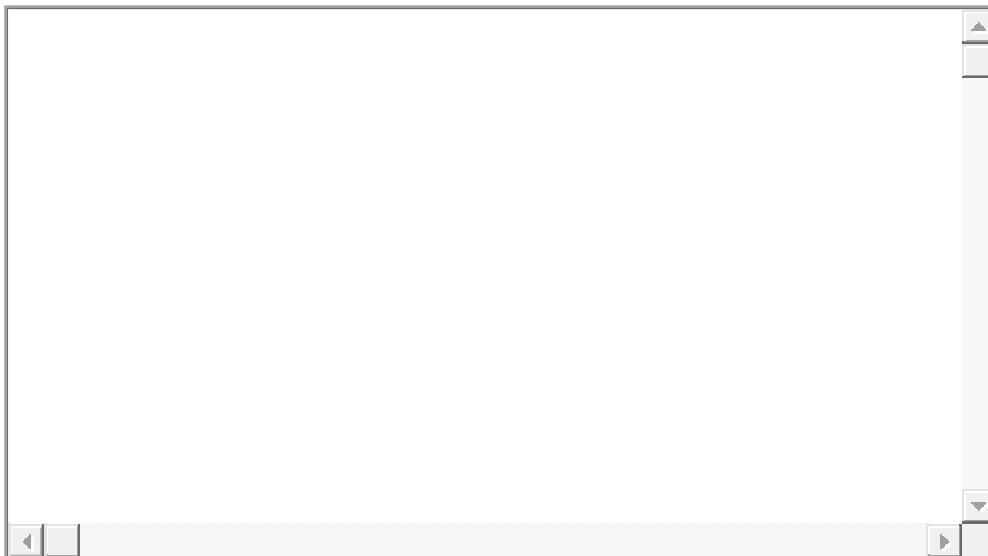
The government will determine the scale and nature of risks and the appropriate response, accounting for emerging trends in the market landscape. We will also determine whether current arrangements for managing data security risks are sufficient to protect the UK from threats that counter our missions 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 virtualised 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.

14. 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?

The infrastructure of security and privacy may need to be reconsidered with more focus on local hubs (for example, the Liverpool Civic Data Cooperative model), in line with the principles of empowerment of local organisations and individuals.

The participatory principle that gives control and ownership to the data owners need to be reinforced by policies that incentivise and provide infrastructure for consent management, transport layer protection and so on, as well as by regulations of data exchange marketplaces.

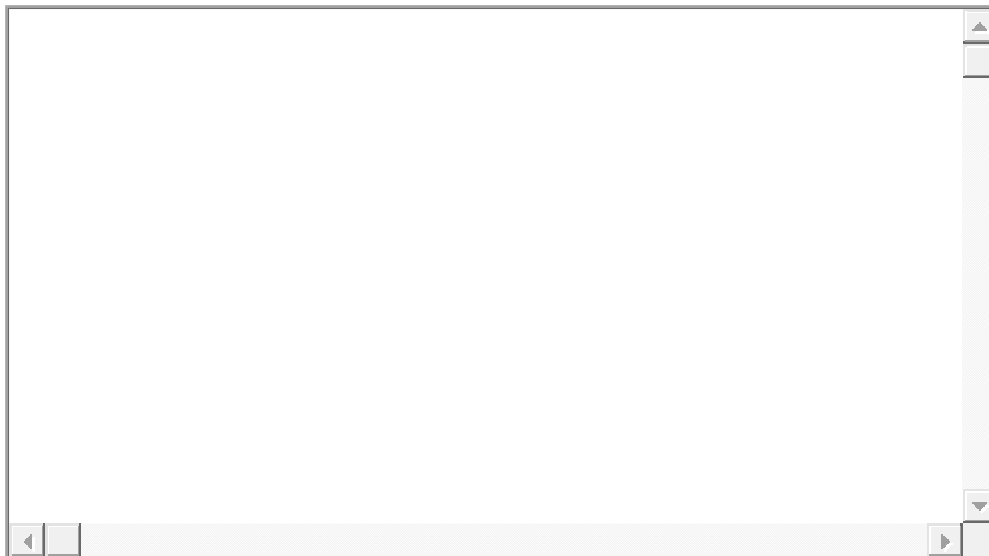


14a. How do clients assess the robustness of security protocols when choosing data infrastructure services? How do they ensure that providers are keeping up with those protocols during their contract?

Below provides a list of considerations:

- Staff security: clearances & training
- Data storage and processing locations
- Data centre security standards (CSA CCM version 3.0)
- Penetration and other testing
- Data sanitisation processes
- Data in transit: Transport Layer Security (TLS)
- Security governance
- Security certification
- ISO/IEC 27001 certification
- ISO 28000:2007 certification
- CSA STAR certification
- PCI certification

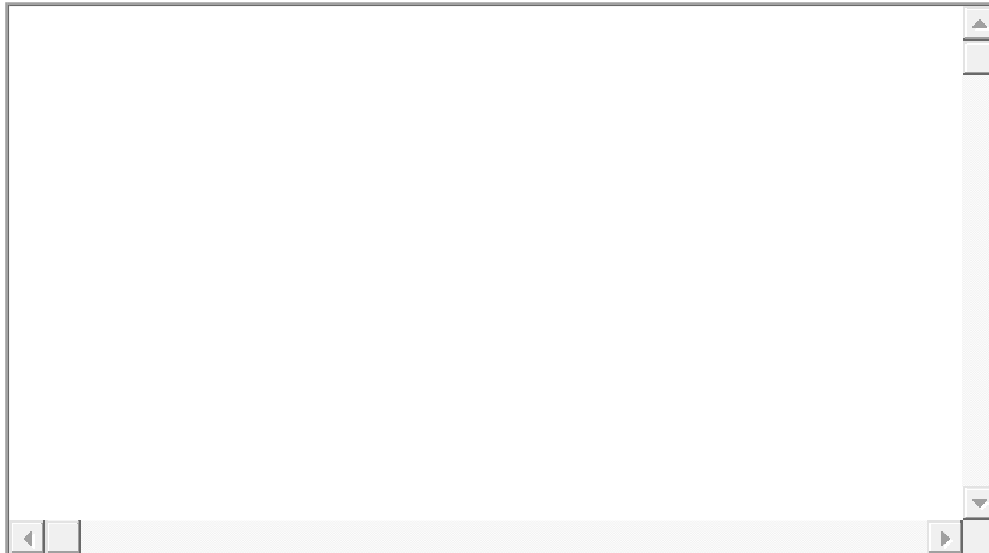
At the moment compliance to security standards and quality of protective measures is usually hard to verify and enforce, especially for smaller participants in the increasingly distributed and multi-participant networks and data processing chains. A security breach can happen at any level of the infrastructure, from a datacentre to individual user (see slides by Svitlana Surodina [here](#)). Education and provision of tools is essential.



15. 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 and data service providers, their supply chain and their clients?

Emerging technologies such as quantum computing can have critical effects on the standard measures and procedures of information security, especially encryption.

From Big Tech (Amazon controls 30% of the UK market for data storage, transport and computation) to decentralised control.

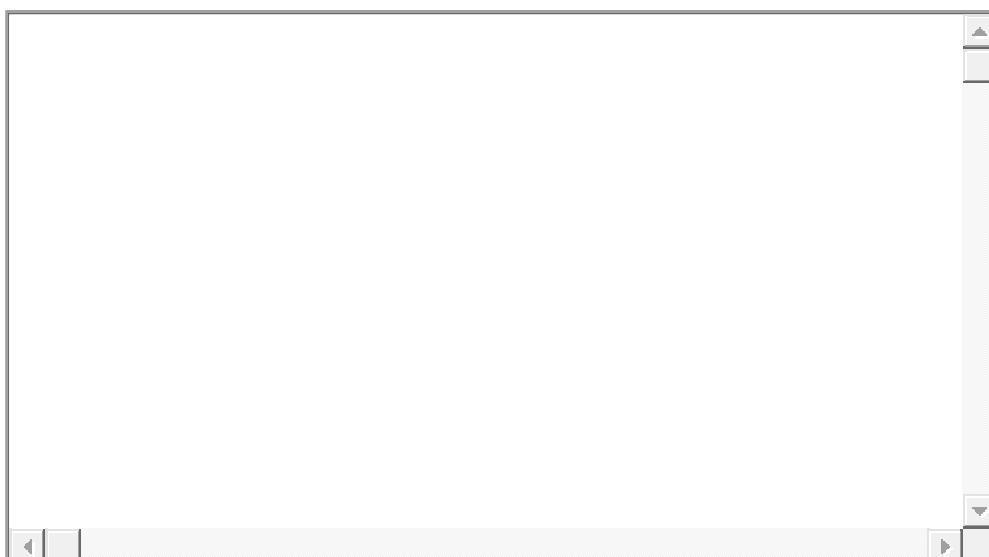


16. What are the most important risk factors in managing the security and resilience of the infrastructure on which data use relies?

Below provides a list:

- Cryptographic tools, encryption, the future impact of Quantum computing
- Emerging tools: opportunities and risks. Blockchain-based consent management, identity resolution - DigitalID
- Cyber attacks on multiple levels, especially small business and individuals

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.

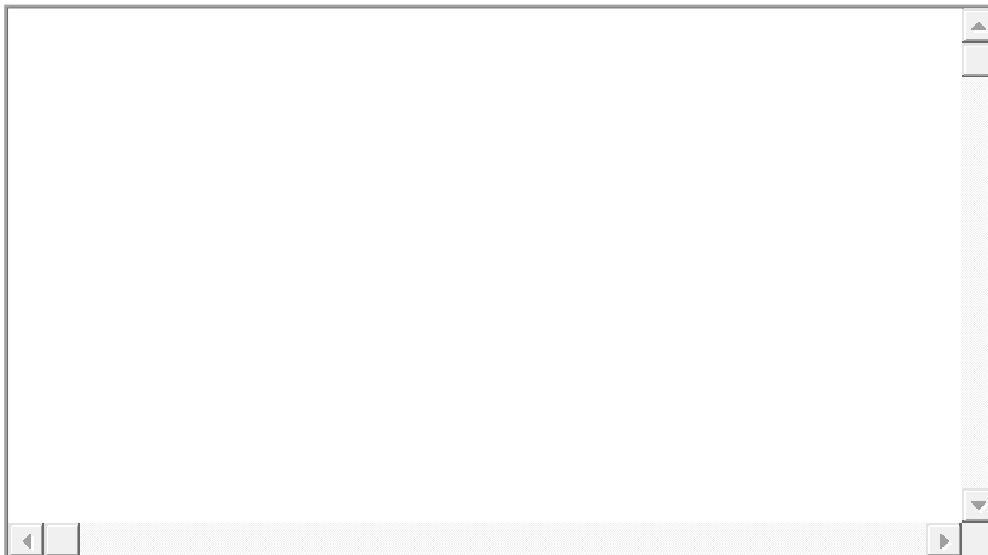


17. To what extent do you agree with the following statement: The government should play a greater role in ensuring that data use does not negatively contribute to carbon usage?

- Strongly disagree
- Somewhat disagree
- Neither agree nor disagree
- Somewhat agree
- Strongly agree

Please explain your answer here. If applicable, please indicate how the government can effectively ensure that data does not negatively contribute to carbon usage.

There are many inefficiencies in data processing that can negatively impact carbon footprint; one of the examples is cryptocurrency mining that requires huge computational power. Other cases include data duplication and excessive generation of synthetic data. Processual and technological measures can help to address that.



Questions on 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.

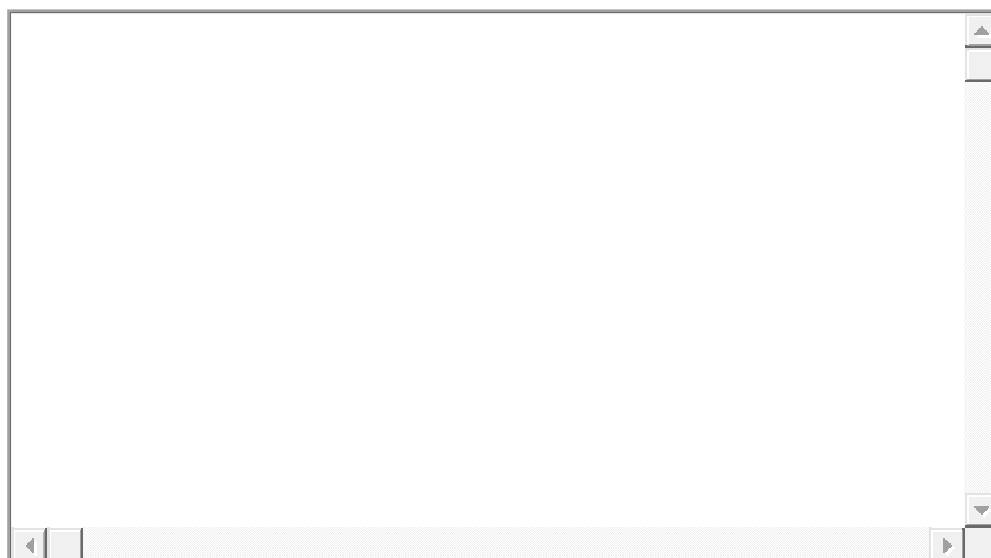
18. How can the UK improve on current international transfer mechanisms, while ensuring that the personal data of UK citizens is appropriately safeguarded?

In the recent APPG Open Life Data Task Group meeting (see minutes [here](#)) we discussed 'Championing the international flow of data' from the point of view of:

- National Security - (biosecurity and cybersecurity)
- IP, Patents and Trade Secrets + Patient Safety (Trade + Medicines and Medical Devices Bill)
- The Value of International Standards and Collaboration in Research (the best way to achieve that – e.g. federated learning?)
- Climate Change, Health and Green Algorithms: calculating the carbon impact of the growth in data-driven healthcare
- Public Trust ('don't sell "my" / "our" data')

As such, we did not touch upon the pros and cons of current international transfer mechanisms in any depth because we sought, instead, to highlight some of the considerations that the Government should take into account before (simply) championing the international flow of data in respect of data pertinent to the promotion of healthy longevity.

We did, however, mention that the UK would need to carefully consider what the Government means in recently having begun to talk about "UK GDPR" so that innovators and the public alike understand how the UK's Data Protection regime is liable to differ from the EU's in future; what the UK-Japan trade deal might mean for public trust in the transfer of pertinent data - which might then make its way to other countries with whom the UK does not currently have a trade deal - with implications for public understanding and trust in consenting to secondary uses of the same; and the fact that an alternative to the EU-US Privacy Shield is needed in the light of the Schrems II judgement since Standard Contractual Clauses (SCC's) may afford individual data subjects insufficient protection where the transfer of sensitive personal data is concerned.

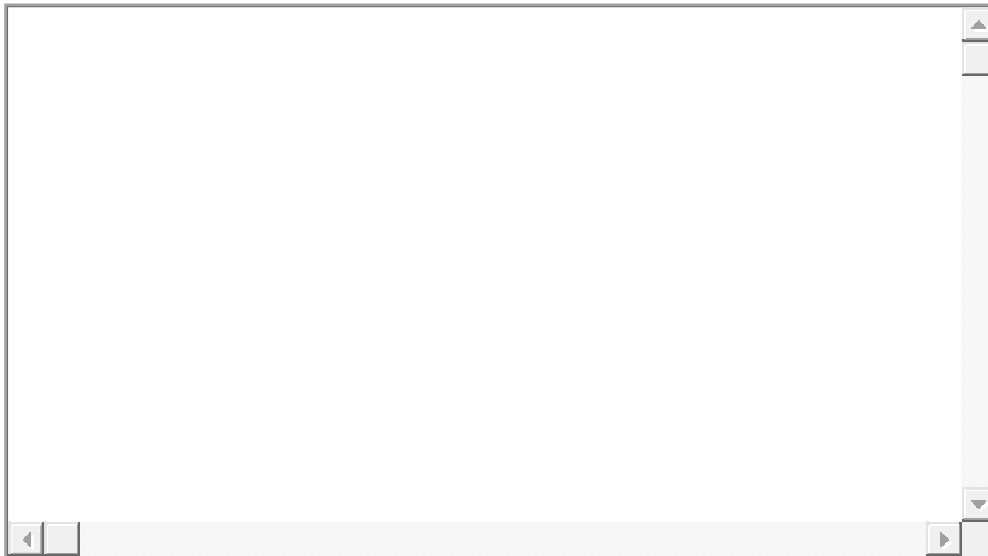


We will seek EU 'data adequacy' to maintain the free flow of personal data from the EEA and we will pursue UK 'data adequacy' with global partners to promote the free flow of data to and from the UK and ensure it will be properly protected.

19. 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?

In the field of healthy longevity there is significant interest in data collaboration in the area of biomarkers- for example, the creation of an open repository for ageing biomarkers to enhance AI-driven research. It is likely that data sharing with more affluent countries is liable to reap rewards in the short term, to the extent that they will benefit from more/better data about older people and those multi-morbidities in the context of building up resilience to Covid-19 and future pandemic threats.

In the APPG Open Life task group participants were less than clear about the state of play regarding future UK data adequacy arrangements – neither did they arrive at a list of countries whom they felt represented priorities, since R&D collaborations impacting healthy longevity are liable to involve broad-ranging academics and entrepreneurs over the months and years ahead.



Next Steps

Thank you again for your participation in this consultation.

The government's response will be published in due course following the consultation's closure at 11:45 pm on 2 December 2020. This will take all responses submitted to this consultation into account, and will be based on careful consideration of the points made in responses.