

DHSC Data Strategy – consultation questions

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Would you primarily count yourself as?

- Public or citizen
- NHS hospital non-clinical (e.g. administrative, operations, finance)
- Social care professional or carer
- Health and care arm's length body staff
- HealthTech or CareTech professional
- Patient or service user
- NHS Digital, Data and Technology (e.g. analyst, data scientist, technical architect)
- Public health professional
- Information governance professional
- NHS leadership or management
- NHS planner or commissioner
- Local government staff (e.g. management, delivery)
- Health and care regulator staff
- NHS hospital clinician (e.g. doctor, nurse, radiotherapist)
- Primary care staff (e.g. GP, nurse, pharmacist)
- Policymaker (central or local government)
- Researcher or academic
- Other
 - Third sector organisation (representing the views of young people)

To what extent do you agree or disagree with the following vision statements for use of data in health and care?

Our most important responsibility is to deliver truly patient-centred care, which puts people before systems, so people will have better access to their personal health and care data and understand exactly how it is used:

- Disagree
- Partly disagree
- Neither agree nor disagree
- Partly agree
- Agree

Staff can only do their best when they have the right information, so staff will have easy access to the right information to provide the best possible care:

- Disagree
- Partly disagree
- Neither agree nor disagree
- Partly agree
- Agree

Leaders and policymakers have a responsibility to continually improve how the people we serve receive care, so leaders in every community will have up-to-date sophisticated data to make decisions and help the health and care system run at its best:

- Disagree
- Partly disagree
- Neither agree nor disagree
- Partly agree
- **Agree**

Service users and their carers will have high quality, timely and transparent data to improve outcomes, and can easily access to help them make choices about their care:

- Disagree
- Partly disagree
- Neither agree nor disagree
- Partly agree
- **Agree**

Our researchers can only deliver results based on the information available to them, so they will be able to safely and easily access data to provide innovative solutions to health and care issues for the benefit of every citizen in every community:

- Disagree
- Partly disagree
- Neither agree nor disagree
- Partly agree
- **Agree**

To maximise the efficiency and effectiveness of our infrastructure, we will ensure the data architecture underpinning the health and care system can easily work together to make better use of data, no matter where it is kept:

- Disagree
- Partly disagree
- **Neither agree nor disagree**
- Partly agree
- Agree

Time and safety are both essential, so innovators will be supported to develop and deliver new solutions safely and sensibly for the benefit of all citizens, staff and the system:

- Disagree
- Partly disagree
- **Neither agree nor disagree**
- Partly agree
- Agree

Do you have any comments on the vision statements as set out in the strategy?

- Free text response

We support the vision statements laid out within the strategy. It is important that data drive improvements to healthcare and reductions in health inequalities.

How do you rate each of the three priorities outlined in the strategy?

To build understanding on how data is used and the potential for data-driven innovation, improving transparency so the public has control over how we are using their data

- Not at all important
- Slightly important
- Moderately important
- Very important
- **Extremely important**

To make appropriate data sharing the norm and not the exception across health, adult social care and public health, to provide the best care possible to the citizens we serve, and to support staff throughout the health and care system

- Not at all important
- Slightly important
- Moderately important
- **Very important**
- Extremely important

To build the right foundations – technical, legal, regulatory – to make that possible

- Not at all important
- Slightly important
- Moderately important
- **Very important**
- Extremely important

Do you have any comments on the priorities as set out in the strategy?

- Free text response

Ensuring that there is transparency throughout the process of development and implementation of the strategy will improve public understanding of the proposed changes and improvements. It is vital that this is achieved, as it underpins the success of the wider strategy and subsequent priorities.

Regarding priority two, it is important to recognise the data sharing needs with children and young people's social care and education.

Commitments in each chapter – Please indicate how much you agree or disagree that the commitments in each chapter of the strategy are the appropriate ones to pursue

Chapter 1: Bringing people closer to their data commitments

- Strongly disagree
- Disagree
- Neither agree or disagree
- **Agree**
- Strongly agree

Chapter 2: Giving health and care professionals the data they need to provide the best possible care commitments

- Strongly disagree

- Disagree
- Neither agree or disagree
- Agree
- Strongly agree

Chapter 3: Supporting local and national decision makers with data commitments

- Strongly disagree
- Disagree
- Neither agree or disagree
- Agree
- Strongly agree

Chapter 4: Improving data for adult social care commitments

- Strongly disagree
- Disagree
- Neither agree or disagree
- Agree
- Strongly agree

Chapter 5: Empowering researchers with the data they need to develop life-changing treatments, models of care and insights' commitments

- Strongly disagree
- Disagree
- Neither agree or disagree
- Agree
- Strongly agree

Chapter 6: Helping colleagues develop the right technical infrastructure commitments

- Strongly disagree
- Disagree
- Neither agree or disagree
- Agree
- Strongly agree

Chapter 7: Helping developers and innovators to improve health and care commitments

- Strongly disagree
- Disagree
- Neither agree or disagree
- Agree
- Strongly agree

Which commitment(s) do you agree with most? Can you tell us why?

- Free text response

Commitments to reduce health inequalities

We support the commitments within the strategy that aim to improve health outcomes and reduce health inequalities, specifically the following references:

“We will undertake further work on harnessing data to improve health outcomes and reduce health inequalities”

“Including access to data that allows targeting research at those who are most at risk of poorer health, that is to investigate health inequality”

Health inequalities are experienced across the life course, with some young people more likely to experience poorer health outcomes than their peers. Also, adolescence is a period during which young people develop long-term conditions, begin accessing healthcare and other services independently and adopt healthy behaviours (such as physical activity). Improved data collection, sharing and reporting on young people’s health and health inequalities is essential to better understand the needs of this population group and to improve their health outcomes and experiences of healthcare services. Data sharing for children and young people’s data must be included within this strategy to deliver these commitments for all ages.

Commitments to provide patient-centred care

We support the commitments within the strategy to use data to “provide holistic care”. Data sharing across agencies will enable individualised care tailored to the patient. It is important that these commitments are extended to cover children and young people. Through our work, young people have told us that they want healthcare clinicians to “see me as more than my condition”. In order for data sharing to provide holistic care for this age group, it needs to include data from children’s social care and education.

The strategy also provides commitments to enable the involvement of patients as “partners in their care”, by improving patient access to their own data. The strategy must consider what this means in practice for children and young people. Where it is developmentally appropriate, young people should be respected to be treated as “partners” in a similar way as adults. However, it is important that young people are fully consulted and communicated with what this involves. There must be clarity about the age at which young people can access their data and this age should be consistent across the healthcare system – for example, young people aged 13 and over are typically considered to be able to access their own medical record and can use the NHS App. There will be important safeguards that are required for involving younger children and young people in accessing their data.

Which commitment(s) do you disagree with most?

- Free text response

If you disagree with any of the commitments, can you tell us why? Tick all reasons that apply:

- Technical deliverability
- Impact on staff
- Ethical objection, fairness or inclusiveness
- Accountability
- Timeframe
- Data protection and security
- Transparency

Please provide any additional comments about why you disagree with any of the commitments

- Free text response

Is there anything obvious that is missing from the commitments that you feel is important?

- Free text response

Children and young people

We would like to see more detail on how the strategy will apply to children and young people and their data. For example, chapter two makes a commitment on the “duty to share” anonymous data between health and adult social care, but does not mention how information will be shared between health and children’s social care or how children’s social care data systems will be interoperable with health. Likewise, chapter four is completely focused on adult social care.

There are no specific commitments other than a general reference that “it is important to work together” with the Department for Education, who is responsible for children and young people’s social care. Viewing young people solely through the lens of social care will only capture the young people supported through that system and the healthcare needs of other children will not be represented within the data.

Chapter two makes reference to how data integration can improve “health and education outcomes”, yet there are no specific commitments or information within the strategy on how health and education records will be shared in order to achieve this.

Without specific commitments written into the strategy, it is likely that actions to improve data collection, sharing and reporting for young people’s data will not be achieved. Specific commitments are required as there are unique processes and safeguards which must be taken into account when considering young people’s data.

We recommend that the NHS number is used as a unique identifier for children and young people, to enable data sharing across health, education, children’s social care and other services. More information on how this can be achieved is available in the Royal College of Paediatrics and Child Health’s position statement: <https://www.rcpch.ac.uk/resources/nhs-number-unique-identifier-children-position-statement>

Detail on transparency

We welcome that DHSC have specifically asked for feedback within this consultation period on how best to increase transparency and communicate progress on how data is being used and shared. We would like to see more detail within the strategy on how to ensure that there will be openness and transparency on the use of data and data sharing.

Achieving transparency requires communication and engagement with the public. We note that three citizens juries have taken place, but no more information has been provided on who was represented at these events and how their opinions will be fed into the data strategy. Communication and engagement with the public must be a two-way process and provide an opportunity for questions and concerns to be addressed – communication that is broadcast without an opportunity for dialogue will not foster trust or transparency.

It is important that communication and consultation of the strategy is undertaken with children and young people, as users of health services. Furthermore, in order to achieve the aim of reducing health inequalities, it is important that engagement is undertaken with groups of young people who are more likely to experience health inequalities (such as care experienced young people).

Engagement with young people to inform the strategy should be age and developmentally appropriate.

Detail on ownership and access of data

We would like to see clarity within the strategy on who “owns” the data and how it can be accessed by patients, with specific commitments for how this would apply to children and young people. Detail is needed on whether ownership and access would be the responsibility of the child’s parent or carer and at what age and developmental stage this responsibility transfers to the young person, which should be consistent across the healthcare system. There are also important implications on data access for young people where there is a safeguarding risk involved for their parent or carer having access to their medical information. Young people accessing specific healthcare, or other, services may not want their parent or carer to be able to access such information on their record and their right to privacy should be considered.

In considering how data will be accessed by patients, it should be recognised that some groups face digital exclusion and barriers to accessing healthcare services via online means. There should be multiple routes to data access to overcome these barriers.

Ensuring everyone benefits from data sharing

Within chapter three, there is a commitment that “local decision makers / leaders will have up-to-date data to make decisions to health the health and care system”. It is important that data sharing is of mutual benefit to improving services of all agencies involved. It is not clear within this commitment whether the data will be publicly available. The strategy references PHE’s Fingertips data tool, currently a publicly available data source which would we would like to see maintained as there is much value for third sector organisations in accessing these data for research and improvement purposes.

How would you like to be informed in the future about the delivery of the commitments in the strategy? Tick all options that apply:

- **Through updates and information on the NHSX website**
- By attending webinars led by NHSX
- Through your professional body or representative group
- Through regional events where you can find out what this means for your area
- Other

What key themes do you think we should be focusing on in our broader public discussion? Tick all that apply

- **Transparency and trust**
- **Access to health data**
- **Choice and control of health data**
- **Health and care inequalities**
- Other

If you chose other, please specify:

- Free text response

What are the three most important things that will help us deliver the strategy?

- Free text response
- 1. Ensuring that the strategy is applicable across the whole life course, by including specific commitments for children and young people and data sharing between health, education and children's social care.
- 2. Consultation and engagement with all groups to ensure trust and transparency, including young people and young people experiencing health inequalities.
- 3. Clear guidance which is consistent with other parts of the health system about the age at which young people can access their own data.

What are the three most significant challenges that could prevent us from delivering the strategy?

- Free text response
- 1. Lack of understanding among children and young people about how the strategy applies to them. Lack of involvement and engagement with young people in policy making and service design could have life-long implications for how they engage with health, and other, services.
- 2. Lack of trust and transparency for how data will be shared and used in order to improve health outcomes and reduce health inequalities.
- 3. Lack of guidance on how young people can access their own data.

Do you have any further comments on the strategy?

- Free text response