NHSX Data Strategy Survey

This survey is for those wishing to engage on the draft Data Strategy for Health and Social Care. We want to hear from you about our plans.

We welcome your feedback on the strategy itself and how you would like to be engaged in future. We are asking for your feedback on:

- the commitments in the strategy and their delivery
- our vision statements for each chapter (noted at the beginning of each section)
- the three overall priorities which underpin the strategy (noted in the executive summary)

The survey takes around 10 - 15 minutes to complete. Thank you for taking the time to respond

Would you primarily count yourself as (select one):

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

To what extent to 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?

Now that we are moving from an emergency phase to a business-as-usual approach to COVID, it's a good time to take stock of lessons learnt during the pandemic about using data well for patient care, and the government is to be commended for embarking on this now. A coherent data strategy is needed in order to realise the benefits of data-driven care for all citizens.

The vision statements are difficult to disagree with but it is how they will be put into practice that is key. Enabling interoperability between systems so data can be shared across health and social care is critical but, whilst recognised as such for many years, has been difficult to implement operationally.

We welcome the wider sharing of and access to data. Having full access to information to support care is going to be critical to pharmacists as the profession moves towards more and more clinical service delivery. The ability to share information about services provided as well as access full information to target appropriate care and support is key. In addition, bringing patients closer to their data also means opening up opportunities in the medicines space to provide additional support and guidance, whether this is in the form of apps that support medication reminders or more sophisticated tools that highlight when patients are non-compliant or miss doses leading to poor outcomes.

We were also pleased to see the aim on reducing the data collection burden. Pharmacists, like many healthcare professionals, are being put under a lot of pressure to provide information some of which could be 'passively' collected, particularly so as pharmacy becomes better integrated into systems and are recognised as part of the frontline clinical delivery team

Cyber security is a crucial area that needs to be considered and addressed. Support will be needed for many smaller organisations, such as community pharmacy and other community services to increase their ability to implement cyber security as it is becoming more and more difficult to counter cyber threat.

Analytical skills is another area that needs further consideration. The government needs to think about how it will support existing practitioners to upskill with the necessary analytical skills to make sense of the big data that is being collected.

However, we believe that the biggest risk to this agenda is patient and public distrust. The key overarching issue with any data strategy is assurance of public trust when it comes to handing data which is not being used for direct care. Research indicates that "social license" is important when using data for research i.e., people are willing for their data to be used to help others for the common good but in return for this, they want an assurance of confidentiality and transparency on how their data will be used. The transparency statement referred to on p14 of the document is vital and needs to be accurate, up to date and readable/understandable. The strategy calls for appropriate sanctions for healthcare professionals who fail in their duty of confidentiality but what this strategy needs more of is assurance and information on how NHS Digital will handle patient data. How is the strategy going to actually support increasing patient confidence in the use of their data?

Another key issue is the huge gap between the strategy's vision of patients/citizens interacting with their patient data and the current reality. While smart phone use is almost ubiquitous in society, only around 2 million people use the NHS App. This suggests that patient access to their own data is probably still relatively low, and there is not a culture of individuals checking and verifying their own data. Patient engagement with their own data would need to increase for data-driven care to become a significant factor in personalised care, and for the benefits of data driven care to be seen and understood in popular culture.

<u>How do you rate each of the three priorities outlined in the strategy?</u>

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?

It is essential that the purpose of any data captured is established before that data is captured. If the data is not going to be useful then there is no point in capturing it.

Population health data across an area can be analysed to determine the services and support needed for the population on that area. Analysis can help to determine what can potentially be put in place to prevent certain outcomes, for example, if the population in an area has a higher than normal rate of CVD, this could be linked to smoking so smoking cessation services could be commissioned.

Looking at data over time can show whether interventions have made improvements, so the implementation of interventions can be monitored against outcomes to see if the quality of care for people has improved.

The first priority around understanding data to support data-driven innovation is a current failing in our healthcare system. When trying to deliver digital innovation in the workplace, healthcare staff are often unclear as to what and how to interrogate digital systems to get the data they need for innovation. Work is needed to provide staff with an understanding of interpretation and interrogation of data, and visions of how data can change the future of healthcare.

A major concern of the public is around data use, storage and sharing. There is a large proportion of the public who mistrust digital systems and the potential of them being hacked and the risk of their information being ‘sold’ or shared outwith their field of comfort. The right foundations are essential (in terms of the technical/security, the legalities and also the regulations around this) to providing patients and the public with the assurance they need to feel safe and happy with their data being shared.

A challenge to the implementation of any of these priorities is the issue of legacy systems and a historical lack of data standards which makes information exchange and interoperability difficult and complex.

There is no mention of the increasing need for hardware/devices and electricity to power these changes which is likely to have a detrimental impact on the environment if not managed appropriately.

Also, there is a slight concern for the potential exclusion of patients who are unlikely to be able to participate in sharing their information due to a variety of reasons. The role of carers and access to information about the person they are caring for needs to be strengthened.

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?

All of these commitments are need in order to make the sharing of data across systems a reality, and to support the use of data to provide better care for individuals and populations.

Chapter 2: It is essential that health and care professionals have access to the data they need to provide the best possible care to the person. Many people are now living with multiple long-term conditions, and from a medicine's safety perspective, it is essential to know all of the medicines a person is taking, any reasons for changes to these medicines as well as what conditions they have been diagnosed with in order to improve patient and medicines safety. Patients are often the only ‘constant ‘in their healthcare and currently carry the burden of information sharing between multiple medical teams and organisations.

Many people have to repeat their stories and information (either because it’s not adequately documented or shared across systems that aren’t intra-operable) and this is a constant source of frustration and wasted time for healthcare professionals and patients alike. The lack of joined up systems poses massive risks for medicines related harm especially in vulnerable older people e.g. 1 in 3 older people will suffer medicines-related harm after care transition.

It is important that health and social care professionals feel supported and confident in data sharing with clear guidance to enable an understanding of circumstances where data should not be shared.

Having ready access to data may also facilitate more remote working for health and care staff where appropriate as well as enable more informed remote consultations.

Chapter 1: People must have access to their health and care data and be enabled to share this with others if they so wish. This will also support remote monitoring, where people can share the data they collect with health and social care professionals to provide better data around their condition(s).

Chapter 5: It is essential that data is collected across the system and not just from one part, such as GP practices or hospitals, as this only demonstrates a particular element of care. Data can provide opportunities to benchmark and to see if quality improvement initiatives, when implemented, have an impact on the system and patient care. Data can also be used to develop AI that can support the delivery of care and assist health and social care professionals in undertaking their practice. Over time, data analysis can help to predict the expected outcomes from a particular intervention, or set of interventions. It also enables earlier interventions to be made, thereby preventing more complex interventions at a later stage.

Which commitment(s) do you disagree with most?

It is difficult to disagree with any of the commitments as they are all needed to ensure interoperability across systems, and that relevant data is shared both locally and nationally to improve health and social care for patients.

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

☐ Technical Deliverability

☐ Timeframe

☐ Impact on staff

☐ Data protection and security

☐ Ethical objection, fairness or inclusiveness

☐ Transparency

☐ Accountability

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

No comment

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

The commitments don’t mention using the data to support workforce planning across the health and social care workforce. If you know the local population and their needs then this can be used to help distribute the workforce across the system.

The data strategy does not specifically address health inequalities. Data can really help with exposing these inequalities, for example drilling down into population health management data to identify people living with frailty and then providing different interventions for different local populations. There is also a significant problem with digital exclusion, for example some older people, those with cognitive impairment, people from deprived areas and this also needs to be addressed as part of this data strategy.

The ability to use data from multiple sources to help stratify populations, aid decision making, direct interventions and resources e.g. to tackle inequalities, would be a great outcome from the implementation of this strategy but we do not believe that this is sufficiently described in the document.

With regards to personalised care more information is required on how health inequalities with be overcome or avoided, particularly with regards to how personalised care will be funded. For instance, currently CCG's have a formulary which codes medicines to be used and this could change from area to area. If medicines are to be truly personalised how will this be accounted for? Moreover, will this include an element of genomics or will it be based solely upon how a patient responds to medicine/prescribers' choice?

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

○ Through your professional body or representative group

○ By attending webinars led by NHSX

○ 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

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

- Quick progress in terms of interoperability and data sharing including ensuring the access is quicker and slicker without compromising patient safety
- Demonstrating that data sharing improves outcomes and safety for patients
- Having clinical standards that enable and support interoperability between systems

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

- Systems being slow to integrate with each other and share information
- Patient and public concerns and lack of trust in the way information is being shared

Do you have any further comments on the strategy?

We have some specific comments as listed below:

- p16 - simplifying information governance should focus on limiting local variations in procedures, and making guidelines clear for all staff.

- p18 - Duty to Share information extended to organisations will need some safeguards to ensure that it is not misused for political reasons. The National Data Guardian and Data Alliance Partnership will have a role in this.
- p19 - reduction of data collection burden could potentially be supported by PRSB standards, but ultimately this will be streamlined by good local system workflow.
- p26 - it is important that data ethics is part of data scientists' professional development.
- p27 - "proportionate sharing of personal information for support of health and social care system" more detail on scenarios would be helpful here, to avoid concerns about public trust
- p31 - coverage of non-local authority funded services - the scope of this should cover as many different types of service as possible.
- p36 - screening for clinical trial inclusion characteristics would be very useful.
- p44 - separation of the data layer from the application system operation - this is a potentially useful technique, but it is important that clinical context is not lost in the data separation.
- P47 - whilst it is useful to have published standards and APIs, safeguards need to be put in place to ensure that systems are interoperable and that any system procured via an NHS approved and endorsed framework mandates the use of such standards.
- p54 - evaluation methodology for artificial intelligence (AI) - this would be great as there is a lot of talk around AI, but perhaps not so much understanding.

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