

ABHI Response DHSC Health Data Strategy Consultation

Submitted 17th August 2021

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

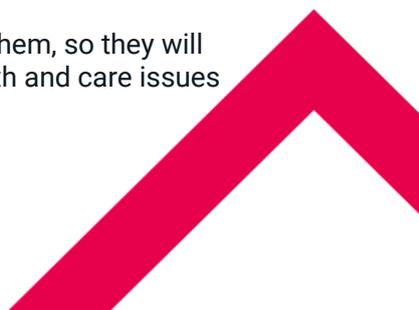
Leaders and policymakers have a responsibility to continually improve how the people we serve receive care, so leaders in every community will have up-to-date sophisticated data to make decisions and help the health and care system run at its best

- 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?

ABHI welcomes the government's commitment to ensuring that data helps citizens, the system and researchers. Collecting, managing and using data effectively presents us with the opportunity to reshape how citizen and patients interact with the system, how services are delivered and improve efficiencies. However, the increased use of technology also raises important questions around issues such as data quality, transparency, privacy and other ethical considerations. As with any new form of digital health technology, there are also questions regarding whether tools that help clinical decision-making have any unintended consequences, particularly for under-represented groups and those who are not digitally connected

The document generally, and the first chapter in particular, puts great emphasis on the role of the people in controlling, accessing and understanding their own data. To complement this there needs to be a sustained and systematic communications campaign to ensure that citizens understand the value of their data (when combined with many others), the benefit to be gained by sharing that data and the safeguards in place on the use of the data. Many reports have highlighted the concerns of the public in sharing data with industry, yet without access to this data many innovations may never become readily accessible to NHS patients. This document needs to highlight the vital role of industry in supporting the health and care system and delivering new breakthroughs in prevention, diagnosis and treatment. Access to relevant data is also a vital part of the safety regime, enabling companies to know as soon as possible if a device is underperforming or if it is used inappropriately so that interventions can be put in place to prevent harm to patients.

Greater explanation on the use of Trusted Research Environments and how anonymisation and pseudonymisation can provide technical protections needs further explanation and we hope that



the forthcoming 'Goldacre Review' will provide further insight. It is also crucial that industry can use the TREs to import their own algorithms, tools and platforms.

ABHI wants to actively engage in the debate to make sure digital innovation works for patients, healthcare professionals and healthcare systems. It is crucial that we make use of the incredible resource that is real world data, but we must ensure it is developed in the right way, with an open conversation about new technology, in order to benefit from the opportunities without downplaying the potential risks.

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?

"Appropriate data sharing" should also include researchers and industry, these groups also need to have clarity around data sharing rules. The commitment to "share anonymous data for the benefit of the system as a whole" should extend to industry/researchers. To support this we need clear definitions and processes for assessment of benefit, as well as clarity on governance rules. Governance and safeguards need to be set at the national level thereby enabling wide adoption and avoiding variances in local interpretation of the rules.

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?

- Develop data infrastructure services to enable the flow of data across the system to support interoperability building upon existing interoperability solutions and standards
- Progress towards creating at-scale data assets that bring together the different types of health data to develop new tools for prevention, diagnostics and clinical decision-support
- Agree a target data architecture for health and social care outlining how and where data will be stored, shared and sent.

Which commitment(s) do you disagree with most?

- Whilst not disagreeing with the concept of “Giving health and care professionals the data they need to provide the best possible care commitments” need to be mindful of the vast amount of data presented could be a burden and there should be a consideration regarding how data is presented and made accessible to ensure it is relevant to an individual’s/teams clinical practice.

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

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

- Chapter 1: Would like to see a commitment and timeline on the proposals regarding the “new privacy enhancing technologies (PETs)”
- Chapter 6: forum for industry and system to discuss vulnerabilities etc
- Chapter 7: several commitments are related to AI specifically but are relevant and needed for all Digital Health Technologies, scope should be broadened
- Chapter 7: the “publish the Value Sharing Framework and Guidance” needs to take a broader approach to value and include a test to ensure that it is not detrimental to, but enhances, the UK as a globally competitive location for economic investment and growth
- Chapter 7: ensure that the implementation of the open-source approach does not damage Intellectual Property and hence make working with NHs undesirable

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

There is no financial commitment, or a proposal to put forward a bid for such funding. It has been estimated that the cost of aggregating and curating patient records for data driven research and innovation are £2-3bn and that the value of the curated NHS data set could be as much as £5bn per annum, delivering around £4.6bn worth of benefit to patients per annum¹

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

• ¹ EY report, Realising the value of health care data: a framework for the future, July 2019

- 
- 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

Benefits to individuals, peer groups and wider society of 'data donation'

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

- Public buy-in ensured by the system showing it can be trusted with their data and to share their data appropriately. A robust, transparent and risk stratified regulatory system is at the core of this
- Appropriate funding to create properly curated and interoperable datasets
- Reimbursement mechanisms to provide the necessary funding to systems for the ongoing management of data and associated technologies

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

- Continued uncertainty on the legal, ethical and (for industry) commercial basis for data sharing leading to public mistrust in data sharing
- The need to overturn the legacy perception that NHS is inappropriately collecting, using and sharing patient data particularly with commercial entities.
- Local divergence in interpretation of data sharing rules, safeguards and governance

Do you have any further comments on the strategy?

There are references to use of 'highest standards' and 'best data driven technologies, whilst we understand the communication benefit of saying the highest standards, this should be about appropriate standards and technologies to avoid over complexity and unnecessary bureaucracy that could slow the system and prevent maximum benefit being achieved.

The data strategy needs to be seen within an international context and other policy initiatives, such as the Life Science Vision. The UK should look at international alignment to support UK developers and hence economic growth and employment, becoming an exemplar for global data usage, security and sharing. Cross-broader data flows and adequacy with other jurisdictions are key to building a successful UK health data economy.

While NHS data will always have an inherent value to the system to realise better service and patient outcomes, to fully reap the benefits there needs to be an explicit strategy to work with industry partners and we are pleased to see this recognised in Chapter 7. However, it should also be recognised that in this instance the UK is in a globally competitive environment and that



whilst we have great potential with the NHS dataset there is a need to accelerate delivery against this strategy so we can build a strong competitive position internationally.

As part of the strategy, consideration needs to be educational initiatives to bridge the gap between different levels of digital literacy across patients, clinicians and key stakeholders. We welcome the emphasis on collaboration throughout the document. Improved collaboration with diverse groups to ensure better representation is vital to successful delivery of the strategy.