

NHSX Data Strategy Consultation: “Data Saves Lives: Reshaping Health and Social Care with Data”

Response from [use MY data](#)

22 July 2021

Introductory Note

This response has been coordinated by the Secretariat of [use MY data](#), on behalf of members.

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

Contact details and follow-up

Our members are happy for [use MY data](#)'s response to be used or shared without restriction.

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

Our comments are provided below and follow the template for submission of responses, as detailed at <https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data-draft>.

Background

As with other consultations, we contacted the [use MY data](#) Advisory Group Members asking for comments on the areas identified within the Terms of Reference. We also wrote out to our wider membership and provided a simple template for them to submit thoughts. We also took email responses directly from Members if they preferred that method of submission.

We then collated the responses into this single document, from which the online form was populated.

We hope these comments are useful and thank you for the opportunity to contribute. If any points need clarifying, please do get in touch.

The only independent UK movement of patients, relatives and carers
focussed on the use of patient data to save lives and improve outcomes

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

Our mission statement

- **use MY data** is a movement of patients, carers and relatives.
- **use MY data** endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.
- **use MY data** aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.
- **use MY data** supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

What we do

- We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.
 - We work to bring a patient voice to all conversations about patient data.
 - We have developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are available [here](#).
 - We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
 - ❖ We provide learning resources for patient advocates on patient data issues, including:
 - Hosting events for patients and the public, focussing on patient data topics
 - a library of resources of data security, consent
 - narratives from individuals about the value of collecting and using patient data.
 - ❖ We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.
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www.useMYdata.org.uk
join@useMYdata.org.uk
[@useMYdata](https://twitter.com/useMYdata)

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

Overall, we found it difficult to disagree with most of these vision statements as they appeared to be largely the obvious ones to address. However, it is unclear how these aspirations will be implemented.

Realising the benefits of a truly National Health Record

We support the vision of a comprehensive National Health Record, separated physically from local systems with local systems accessing, updating and analysing that National Health Record so that my full medical record is visible to all relevant clinicians when they are providing care to me no matter where they are based in England (or better still the UK).

Currently if you are taken ill and go to a hospital away from home that hospital may not be able to see your health records when making potentially life-saving decisions about the care you should receive. In most areas, even your local hospitals may not be able to see your GP record in an emergency.

use MY data believes these data limitations can and should be overcome as a key step in delivering the best care or service wherever you need it.

use MY data supports a move to ensure all parts of your health and social care record are available and accessible to you and your health professionals across the country when you need treatment or advice.

Why does use MY data support this change?

Because in making the best decisions about what advice or treatment to give you, clinicians need to know your full health background - your health history, your current health problems and treatments and medications, your allergies. In fact, all the data held by your GP, hospitals and mental health and social care providers that have previously treated you.

This use of your data to provide you with the most appropriate healthcare is the key reason why use MY data supports this change but there are two other important benefits that this access to health records will bring:

- Personal access to your health record. Through full security controls, you should be able to access your health records to better understand the trends in your health and potentially to add health data such as daily blood pressure readings to enable professional monitoring of your progress. Also, to check if any health incidents are missing and if there are any errors on your health record which you can then ensure are corrected.
- Once this data is available nationally it could enable a separate, free-standing anonymised version of the data to allow approved researchers to carry out strictly controlled research in order to identify better approaches to prevention and diagnosis, to support smarter and more personalised treatments and to promote well-being and good health

Some words directly from our Members:

“The vision statements as laid out are just that - visions. It is difficult not to agree with them as a list of visions, but we must ensure the strategy is grounded in reality.”

“As visions, I have few objections, but it lacks a set of clear and comprehensive objectives to underpin the achievement of these 'visions'. No mention is made of budget or capacity to back up these commitments.”

“The vision statements are generally good. However, some phrases mean little. e.g., Chapter 6 'separating the data layer'. While this is explained later in the strategy it probably needs another phrase at the vision level.

“I agree with the vision statements.”

“I support the vision/priorities and I think most members of the public would if they are properly explained. I think there is a massive challenge to get the NHS bodies/staff behind the priorities and really committed to sharing data across all the NHS and Social Care and, to a certain extent, ceding control over 'their' patient data and local priorities”

“A move to such a cloud-based health records database would also be a key enabler to allowing me to see my full health record and towards creating a nationally managed and secured comprehensive planning and research repository”

“A parallel national database to support planning and research”

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

Not at all important	Slightly important	Moderately important	Very important	Extremely important
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Do you have any comments on the priorities as set out in the strategy?

Highlighting the benefits of choice

It is important that we, as patients, have control over how, and know where, our data, and our tissue samples collected during testing and medical interventions, are used. We should be able to make informed decisions and be given the opportunity to opt out of sharing our data, if we wish.

Within this it is crucial that we are aware of both the benefits and the risks of data sharing. It is after all our own unique personal data.

There are significant safeguards to manage the potential risk of data usage.

Firstly, we support and promote the consistently safe, transparent and informed sharing and use of patient data, while respecting any individual patient's choice to opt out of sharing the data but to continue to use NHS services.

We also recognise and support the several ways that our privacy is shielded when our healthcare data is shared for research or for the benefit of the NHS or other patients, for example by removing any information which identifies us, by using an independent review process for data sharing, by ensuring strict legal contracts are in place before data is transferred to another party, and by implementing robust data security standards. These are contained in the principles of the Five Safes.

There are significant benefits of using patient data for research

The benefits of sharing and using patient data are not always understood or communicated well. But most treatments and care provided by the NHS are based on data and information from patients. Using this data improves health care and treatment, advances medical research and ultimately reduces suffering and saves lives.

A key benefit is that researchers can analyse millions of people's health in this 'real world' data, which allows them to study rare diseases that affect small numbers of people, or side effects of treatments that are serious but don't occur very often, but without identifying any individual patients, because the data is anonymised and our privacy is protected by law and by regulators.

Some comments directly from our Members are:

"Technical, legal, regulatory - but where does public awareness, support, involvement and governance fit in this? Where is the involvement role for patients in decisions about uses of patient data?"

"Not sure priorities are mentioned? If this is the 'Taking this further' section then most seem appropriate."

"Priorities are OK; but the biggest challenge will be delivering on them. It would be useful if the strategy made some reference to a programme Board or other similar process - assuming there is one to ensure things are delivered on time. If there isn't a Programme Board, there should be!"

"I agree with the priorities"

"Fully support the priorities. However, I would like to see a bigger commitment towards easing data-driven research and product development and moving the conclusions of research and development into use in the NHS to improve health"

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 nor disagree	Agree	Strongly agree
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Chapter 2: Giving health and care professionals the data they need to provide the best possible care commitments

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
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Chapter 3: Supporting local and national decision makers with data commitments

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
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Chapter 4: Improving data for adult social care commitments

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
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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 nor disagree	Agree	Strongly agree
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Chapter 6: Helping colleagues develop the right technical infrastructure commitments

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
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Chapter 7: Helping developers and innovators to improve health and care commitments

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
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Which commitment(s) do you agree with most? Can you tell us why?

Chapter 1: Bringing people closer to their data

At our March 2021 webinar we explored the topic of patients being able to see, interact and even make corrections to their own health records. The webinar highlighted the reality about patient accessible, and/or patient-held records, across the UK, together with the constraints, blockers and enablers.

Following the webinar, we polled the delegates to ascertain their priorities for next steps for use MY data to take. This document is a summary of those next steps, in the form of a Call to Action.

Currently English GPs are required to give their patients online access to their own GP records if the patient requests this access.

use MY data became concerned that this was perhaps not well known to patients and not always working well in practice. We held an online workshop for our members on 3 March 2021 to brief members on this service and to understand whether patients valued this access and what concerns they had.

We also examined with patients whether this access should be extended to include data held in hospitals, and not just GP Practices.

As a result of feedback from those who attended the workshop, use MY data has prepared this Call for Action. There are two main themes:

- a) The NHS should provide better information for GP Practices and patients about the rights of patients to see our own record and how we can overcome any problems in that access,
- b) The NHS should extend this right so that patients can access our hospital data too.

Benefits of online access to our records

The feedback from the majority of participants was that they valued the intent of being able to access their health records and, in particular, they appreciated the opportunities:

- to look back and reflect on information discussed with their GP during consultations
- to identify trends over time on results such as blood tests as a prompt to their taking action
- to identify missing or incorrect information and have the record corrected
- to be able to access health care records when needing treatment in other parts of the country or even overseas (for example via an app or a portal) so that those doctors can see our GP Record and make better informed care decisions in possibly life-threatening circumstances.

Some Patients have some concerns about online access to their records

Attendees at the workshop did express some concerns about access:

- Will the data be secure, or can unauthorised people access the data and, in accessing their own data, will patients leave a digital footprint which might be misused?
- This has been Government policy for several years. Why has progress been so slow?
- Do patients have access to the full GP record including free text and hospital letters?
- How can I persuade my GP to let me have access to my record?
- How can patients ensure errors are corrected?
- What about access to older information such as childhood vaccinations?
- GPs seem to use the fact that family members and carers are referred to in my record as a reason for not allowing access. What's the position?
- If patient access can be done for GP records, then what about hospital records?

The use MY data Call to Action for the NHSX Strategy

On the basis of what use MY data learnt from the workshop and from other patient discussions, use MY data calls on the NHS to take actions to ensure that:

1. all GPs are aware of their duty to make records available to their patients via the online service, that they know how to do this, how to overcome any problems and they know how to deal with any potentially confidential references to third parties
2. better information is created and widely distributed to patients to ensure they know their rights of access, they know how to initiate the service, what to do if their GP does not cooperate in providing this access, how to overcome any technical problems, what information they can expect to see and what information can be legitimately withheld and what to do if they observe missing or incorrect data
3. there is a plan for improvement in the service both to include more effective access to the GP record
4. all these principles are applied in order to allow patient access to hospital records

Chapter 2. Data for health professionals

Is there a mismatch between ministerial ambition for national data separated from local systems and local thoughts exemplified in the workshops?

The local thoughts included a focus on, by 2024, creating an enhanced summary care record and regional system interoperability. Such local progress may make it harder to achieve national goals. We need to have a clearer statement of the endpoint so that short term plans move us towards it rather than entrench local structures. Achieving local interoperability does not sound like a national shared record separated from the individual applications.

There is a commitment to ‘comprehensive record sharing by 2024’. However, the workshops suggested that will only be an enhanced summary care record shared regionally rather than full health records shared nationally. Whilst that would be progress it would not deliver what I believe is the ministerial vision and we need more clarity on what is to be delivered and when.

Chapter 3. Supporting local decision makers

All the discussions at the workshops were about developing local management and planning systems. Can we not identify common problems for which common solutions can be developed?

Chapter 4. Integrating social care

Data in social care presents significant challenge. There are few data standards, use of the NHS Number has been historically low and there is limited technical capacity. There should be a focus on getting the basics right first.

Chapter 5. Data for research

In our previous submission to the Goldacre Review we noted a point raised by one of our Members, frustrated by the continued lack of access to data for research:

“We have narrowed the doorway and then put bouncers on the door. We are now trying to negotiate with the bouncers, but what’s really needed is to put the doorway back to how it was.”

- We continue to see unreasonable timeliness of large data controlling bodies in providing access to data for research
- The benefits of using the data must not be overshadowed by perceptions of risk, or behaviour which is disproportionately risk averse
- Trusted Research Environments should provide a more robust mechanism to enable research
- Transparency must be an essential and integral part of any successful solution - ‘say what you do and do what you say’
- There must be inclusion of patients in all decision-making processes around data access and release
- Engagement with the public and patients on the benefits of data sharing but also the privacy assurances will be vital - building on the successes of the pandemic
- All analytical and research outputs should adopt the Patient Data Citation.

We subscribe to the philosophy that data saves lives. We would therefore argue that not using data costs lives.

Some specific words directly from our Members are:

“The one which puts the patient at the heart of their data and allows them to access data generated in primary and secondary care. I have to engage with both primary and secondary

care to manage my chronic conditions and this will simplify things enormously. At present I Have to pester staff for hard copies of test results and enter them on my own spreadsheet”

“A comprehensive shared national health record accessible throughout England (first of all) at all points of care and accessible to the individual, This is best achieved by separating the data from the applications and the originating organisation. This is critical to improving care wherever it is delivered, to being transparent to the public on their health record, to responding to national emergencies and to providing the means for a national health data repository to support and govern and control data-driven health research and product development.”

Which commitment(s) do you disagree with most?

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:

Overall, we found it difficult to disagree with any of the commitments.

Some words directly from our Members are:

“I agree with the commitment to allow people to see how their data is used for secondary purposes but there seems an unachievable immediacy about that commitment. Data is released for secondary purposes from 1000's of sources currently (e.g., all GP practices are Data Controllers). If we put a short-term focus on getting them to report all releases then we will consume massive resources, reduce clinical productivity and will inevitably fail to do it completely leading to media-driven outrage undermining the whole programme.”

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

Acknowledging and raising awareness of the use of patient data

In 2015 use MY data proposed the inclusion of a citation on all publications using patient data, to state that the data used within the publication comes from patients. The citation

would be a recognition of some of the benefits of using patient data and would acknowledge the patient contribution as well as highlighting how the data has been used.

The agreed citation wording is: 'This work uses data provided by patients and collected by the NHS as part of their care and support.'

The citation is being widely used across a range of outputs and publications from large numbers of academic institutions and commercial organisations and has been adopted national bodies such as the HDR-UK, NIHR, Public Health England, the Office for National Statistics and many research charities.

We would like to see this Patient Data Citation recognised within the Strategy.

Some words directly from our Members:

"Unhappy that patient-reported outcomes measures (PROMs) data is referenced but patient-reported experience measures (PREMs) is not."

"The Artificial Intelligence section is a worry - so much short-term focus on building capacity yet no medium-term perspective of possible challenges and problems."

"There is very little if any comment on communication with the public e.g., bringing people closer to data adds no value if that data is indecipherable."

"Yes; a UK wide strategy. While I recognise that health is a devolved matter there needs to be a UK strategy to make sure that data generated in the 4 nations is sent to UK databases (there are a number of examples in the strategy) For instance, I suffer from a rare disease - about 1 in 10,000 people have this condition. So, for Northern Ireland this means about 190 people - hardly statistically significant in research terms. Thus, there is a need to aggregate data UK wide for research."

"In addition, many UK citizens travel to devolved nations; for their own safety their care data should be available in those nations NHS facilities. If we really believe that data saves lives, then the UK Government needs to place certain obligations on the devolved Governments."

"If we achieve the commitments then data will be stored differently, controlled differently and used differently. It is likely that the current data governance, controllership, opt-out arrangements and accountability for data completeness, accuracy and timeliness may no longer be appropriate, and I think there needs to be a commitment to re-thinking those issues in parallel to the 'easier' technical thinking represented in the current strategy. Potentially we can release front-line staff from some of those burdens thus improving clinical productivity whilst giving greater control to the individual and improving data control and security standards and data-contracts. It is essential that these issues are thought through in parallel to the technical thinking so that one does not get out of alignment with the other and so that patient and clinical confidence in the innovations is developed rather than squandered."

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

Regular email updates and direct communication, not just passive (“it’s on the website”)

Stakeholder briefings but allowing time to question and discuss. Previous briefings have been far too rushed.

Through an involved patient voice/group working within the Strategy team

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

The broader public discussion needs to include all these things. But this does need to be a discussion rather than just an information-giving approach.

We believe it is essential to involve patients and the public in the design of the communications and the overall implementation plan, and in its delivery.

We need a continued and increased focus on the benefits (both in immediate personal care and long-term improvements). We must ensure that those benefits are seen to be local as well as national.

All data release registers should include planned benefits with a date and irrevocable commitment to report against realisation of those benefits and other benefits/learnings. The recent work led by HDR-UK about the lack of data release registers and the lack of consistency in those which do exist is relevant here.

Our recent experience in pushing for a data release register from the COVID-19 Data Store has, after 10 months of promises, still not seen any register published. This type of promise without action decreases trust even further.

Strong messages on security of data and controls over misuse.

Much greater transparency around data breaches with a clear statement of the impact, where the responsibility lay, the consequences for the responsible agency/agent and what will be done to prevent in the future.

We would like the patient voice to be included as an equal in the development and rollout of the broader public discussion.

Transparency should include:

- Case studies on how it benefits direct care and the downsides for health outcomes based on the current data islands.
- Comprehensive data use registers covering all uses beyond direct care and internal NHS planning.

Further clarity is needed on certain key questions, which seem not to be addressed in the Strategy:

- A clear statement of who is accountable for the accuracy, completeness and timeliness of the data held.

- A clear statement that a clinician who does not take advantage of the national health record and therefore potentially provides sub-optimal treatment is accountable for the consequences.
- If we have a National Health Record, then presumably we will need a National Data Controller and the accountability of that person to control all uses of the data needs to be clear and he/she needs to be held to account. Would that allow GPs, for example, to move away from responsibilities on wider data control for which they may be unsuited and/or uninterested and focus on care for their patients?

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

There are more than the three requested, because we have listed below the various challenges that were highlighted by Members.

Buy in by the public will be helped by those using patient data adopting some basic principles:

Individual Choice

1. Describe clearly how you have respected the wishes and preferences of patients regarding use of their data
2. Respect the wishes of patients in the National Data Opt-out and any patient-choice mechanisms that Trusts have adopted

Societal Benefit

3. Be explicit that the primary focus must always be on benefit to patients, relatives and carers
4. Demonstrate the benefits of what you do, and what you have done, and publish this openly

Patient Voice

5. Embed patient voices in all parts of the organisation and be responsive and accountable to them
6. Recognise the use of patient data by adopting the Patient Data Citation
7. Be open to questions, and answer these questions openly, clearly and fully

Transparency

8. Be clear that if you receive financial returns from the use of data, commit to delivering fair value to the NHS in what you do and how you do it, and publish your assessment of fair value
9. Be proactive - say what you do, how you do it, and publish this for transparency and in plain language suitable for its intended audience

Security

10. Ensure the security of patient data held in digital and other formats

Some words directly from our Members are:

“Budget, capability, capacity and bringing the public along with the proposals! Funding”

“A programme Board driven at ministerial level”

“Clarity, consistency and consensus”

“Clear leadership and vision.”

“Getting NHS organisations/staff onboard so that they express confidence in the direction and make sure that short term decisions support rather than inhibit the direction of travel.”

“Gaining and retaining public support”

“Mixed public/professional workshops should be used to develop the ideas further and to question/challenge/enhance professional thinking.”

“Clear communications of the benefits of:

- All clinicians treating me being able to see my full health record and thus provide better care with fewer risks
- Not having to repeat my health history repeatedly
- More efficiency and identification of opportunities to level-up across the NHS to help tackle inequalities
- Availability of better data to support research to drive better outcomes.

Clear communication of the controls and penalties around misuse of data”

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

There are more than the three requested, because we have listed below the various challenges that were highlighted by Members:

“Budget, capability, capacity and bringing the public along with the proposals!”

“Public scepticism”

“GPs/BMA opposition”

“Stove piped data controllers”

“Misinformation, mistrust, inertia”

“Failure to articulate and communicate and thus convince stakeholders of the vision and its consequences and benefits”

“Lack of understanding or commitment to the vision within the NHS and possibly even opposition and intransigence within the NHS and its bodies leading to failure to get behind the goals and instead to rely on local/short-term thinking and problem fixing”

“Major ****-ups leading to loss of confidence”

“Real commitment across the NHS to separating the data layer as the key enabler to achieving the technical/operational goals.”

Do you have any further comments on the strategy?

“Changes are needed in legislation, accountability and data control. Planning how we make the necessary changes in those areas whilst retaining public and professional confidence so that these are enablers to the ambitions rather than barriers to achieving them.”

“Rather than giving a single summary, we have listed below the various words used by our Members in their responses:

“A pretty average document, poorly formatted, very poor ministerial section which just seems to comprise a wish list with a few ideas about activities rather than a comprehensive strategy document”

“There is a statement in the strategy that says 'we do not sell data for the benefit of private companies' I have heard this statement being challenged by people in the field. I think NHS X/Digital need to absolutely clear in the strategy about when data does change hands for money.”

“The vision talks about 'increased transparency. I would have thought total transparency should be the vision.”

“We need to be realistic about social care. There needs to be a massive programme to develop and implement data standards and a sector-wide commitment to data use, recording and sharing. This needs to be done consistently with the programme so that all of social care (not just the lead organisations) can join in and benefit from the strategy in due course.”

About use MY data

use MY data endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care and well-being for all.

use MY data supports and promotes the protection of individual choice and privacy in the sharing of healthcare data to improve patient treatments, outcomes and experience.

use MY data aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service design and improvement, and in research, aimed at improving clinically informed patient decision making, treatment and experience.