Local Government Association response to the draft Health and Care Data Strategy: Data saves lives: reshaping health and social care with data

This response is the Local Government Association's (LGA) response to the draft health and care data strategy 'Data saves lives' as published in June 2021. In developing our feedback, we have consulted with and shared our response with the Association of Directors of Adult Social Services (ADASS).

We welcome the opportunity to comment on this draft strategy for how data will be used to improve the health and care of the population in a safe, trusted and transparent way, addressing current cultural, behavioural and structural barriers in the system to deliver a health and care system underpinned by high quality, readily available data. Through the pandemic local authorities have turned to innovative approaches to ensure the continued delivery of critical services for vulnerable adults. Data has been a key enabler of this, and will continue to be, as councils progress through the recovery phase and work within the context of the 'new' normal**.**

Our response includes our overall comments on the strategy alongside the structured response, as requested via the online format. Whilst Chapter 4 focuses specifically on improving data for adult social care, we have commented on each chapter's commitments as there is relevance for social care and broader local government across all sections. The strategy is overwhelmingly positive, but to achieve the potential benefits it is essential that it is enacted across the whole of health and social care as a collaborative approach that takes account of the role of all public, private, voluntary and community organisations that all work together in supporting people to be well, safe and independent. The final strategy must truly reflect the ambition to support the whole health and care system, including population health and inequalities, and not be dominated by the clinical interactions and NHS focused references.

If you have any queries about this response, please contact Philippa.lynch@local.gov.uk

About the Local Government Association

The Local Government Association (LGA) is the national voice of local government. We are a politically led, cross party membership organisation, representing councils from England and Wales. Our role is to support, promote and improve local government, and raise national awareness of the work of councils. Our ultimate ambition is to support councils to deliver local solutions to national problems.

Overall comments

We must ensure that this data strategy truly represents the breadth of health and social care.

1. For this to be a truly joint and integrated strategy across care and health, the governance arrangements need to reflect this, as do the names of the organisations charged with delivery.
2. This strategy sets out the role that data will play in the digital transformation of health and care and how it can inspire effective collaboration across the NHS, adult social care, and public health. It is essential that, in taking this forward, it is a collaborative approach that takes account of the role of all public, private, voluntary and community organisations that work together in supporting people to be well, safe and independent. The final strategy must truly reflect the ambition to support the whole health and care system, including population health and inequalities, and not be dominated by the clinical interactions and NHS focused references.
3. The strategy is overwhelmingly positive, but the emphasis on health and social care is not well balanced - social care requires parity throughout the strategy. Social care is an essential part of the fabric of our society which, at its best, enables and transforms lives. It makes it possible for millions of us to live the lives we want to lead, where we want to live them – whether we need support with our mental health, because of physical disabilities, learning disabilities, or because we are older and need additional support. And such support is often more cost-effective than waiting until people require more acute health services.
4. The current title – with a focus on 'saving lives' - misses the point of what social care aims to do. The benefits of social care are often about **improving** lives – supporting people to live the life they want, by increasing wellbeing, quality of life and independence – to enable people to keep doing what they like to do in the communities they call home. This can also be said for health too. The ambition to 'deliver truly patient-centred care' should be amended to reflect the wider application for 'person-centred' care with a focus on preventative care, recognising that not all individuals will be a patient.

Importance of public engagement and understanding of core aims of the strategy

5. Sharing information and data should primarily be designed to enable better integration across health and social care to deliver improved outcomes for individuals, and a shared goal to join up and coordinate care around the individual. It is essential that the data strategy for health and care aligns with and supports that goal and contributes to developing models of care that are preventative and person-centred, supporting people to live the lives they want to lead.
6. The strategy includes the statement that 'the public's data belongs to them' and references throughout to people 'owning' their data. The strategy needs to say more on how the public will have control of the use of their data and how this will be managed across health, local authorities and especially social care providers. Ensuring that individuals are informed and engaged is key to ensuring that what we do to support them is personalised. We strongly support steps to ensure that people and their families understand what information is held by the health and care organisations that support them, and how their information is used.

7. Consent and confidentiality are also complex issues. Maintaining individuals' confidence in the way that their information is managed is essential to ensuring their trust. Guidance on maintaining patient confidentiality in the new data sharing context is key to supporting professionals in their relationships with the people they support.
8. The strategy's commitments on *Bringing people closer to their data*, in particular the commitment for increased access to records and information about how data has been used, are very positive – there needs to be a further explanation of how this will be done in care settings. The strategy makes references to public engagement, but it is not clear in the strategy how meaningful this will be, and how this will be approached. In practice a variety of different methods may be needed across health and care.
9. Making people aware of how information about them is used is important, and elaborating on what tools will be available to make this information accessible would be helpful. Where this revolves around "digital access" and "systems" the strategy needs to consider and outline how it will address disparities in digital access and skills, and ensure that an emphasis on "digital" does not lead to unequal health and social care outcomes between digitally active citizens and others.

Maximising the potential for an integrated approach

10. Social care plays a key role in making connections in our local communities between a wide range of public, private, voluntary and community organisations that all work together in supporting people to be well, safe and independent. Links with housing are particularly important, so as to support people to remain independent at home and in their community for as long as possible. NHS services and social care are equally important and the needs of one should not be addressed to the detriment of the other: all should unite around embedding a far more preventative approach to wellbeing that works closely with public health and housing.
11. The development of Integrated Care Systems provides an opportunity to bring together data and knowledge in an integrated way. The LGA, the NHS Confederation, NHS Clinical Commissioners, NHS Providers, ADASS and ADPH have recently published joint principles that must underpin effective integrated care. They include:
    - subsidiarity - decision-making as close to communities as possible
    - building on existing, successful local arrangements
    - a person-centred and co-productive approach
    - a preventative, assets-based and population-health management approach.

    These principles should be applied to the strategy, to ensure that information can be shared and utilised effectively across all public, private, voluntary and community organisations that work together in supporting people to be well, safe and independent. In particular, there should be a strong focus on addressing individual and population health and wellbeing and health inequalities and evidence-based action on prevention and early intervention.

A commitment to provide adequate resources to deliver the ambitions of the strategy will be essential to its success.

12. The strategy aims clearly require significant investment to achieve. A commitment to provide adequate resources to deliver the ambitions of the strategy will be essential to its success. Costs associated with the safe and proper sharing of data could be considerable – especially for care providers and councils already under financial pressure – and there is no explanation of how these costs will be met in the strategy.
13. There is a need to invest in the digital transformation of social care. All of the funding examples in the draft strategy are in health with no similar commitments for social care. It is essential to ensure that local government has the necessary influence, capacity and resources to work alongside health partners to deliver transformation.

Need for parity in the development of Shared Care Records and engagement with people with lived experience

14. We support the inclusion of councils and now adult social care providers (where they have digitised records) in the Shared Care Record Programme and it is important that a collaborative approach is taken going forward. There must be parity between the needs of health and social care in the development of SCRs and NHSX will need to continue to support adult social care providers so that digital and data advancements do not further widen inequalities.
15. The current direction in ensuring flexibility to address and adapt to local needs alongside the national requirements is encouraging. For councils, the shared care records will need to extend beyond health and care into other key local services that have a significant bearing on individuals' support and quality of life.
16. Going forward it is essential that this programme engages people with lived experience (people accessing care and support, families, carers and also the frontline workforce) to ensure that Shared Care Records meet their needs as well as those in leadership roles in health and social care. If we achieve a shared approach where a greater cohort of professionals are able to access the data of individuals across health and social care, then we need to ensure that it also empowers professionals and individuals accessing care and their families to challenge one another if that information suggests a different intervention/support would improve outcomes for the person in question.

Maximising timely insight and intelligence whilst minimising unnecessary burden

17. During the COVID-19 response there has been a rapid development of a nationally co-ordinated approach to data collection from care providers at a registered location level across the adult social care market. There are mutual benefits at all levels, and plans to continue with some degree of national overview and intelligence about the care market. However, individual councils need the ability to continue to manage relationships with their local providers. Any future approach must be driven from the local needs of councils and care providers, but with the adaptability, flexibility but also consistency that supports the ability to 'focus in' and 'scale up' when appropriate.
18. We already capture a vast amount of detailed data, but this is not utilised in a way that supports the timely, place-based intelligence needed. Too often information is captured and stored in silos at organisation levels. Whilst there is increasing focus on the aggregated data required by central government, we must not lose sight of the need to review the timeliness and accessibility of shared data at an operational level, particularly at the interface between health and social care. There is currently a 6+ weeks lag in systems being able to see

critical data, due to the insistence on publication controls and the inability to access shared systems. Where information is captured in relation to individuals, characteristics can be linked dynamically to both organisations and locations to get valuable intelligence - for example, information relating to hospital admissions could be mapped back to local health or council geographies to help understand any patterns affecting needs and care pathways.

19. The insights and analysis that can be drawn from data are vital for local leaders to plan, commission and improve their services to best suit the needs of the populations they serve. Similarly, for national leaders, insights and evidence drawn from data can provide better oversight and understanding of the health and care system to develop improved policy, guidance and national assurance. We are in the privileged position of having access to more data than ever before for health and social care. However, subject matter expertise is required to accurately analyse, interpret and make use of it. There is a need to invest in developing local government digital and intelligence capabilities and capacity – this is both for the analysts and system developers, but also for leaders and frontline staff to make effective use of the data and intelligence gained for planning and operational use.
20. To minimise the data burden on all care providers (including councils and the NHS) across the system the data standards and interoperability designed into the Shared Care Records should be utilised to facilitate secondary use of data through extracting and building intelligence from individual client and care provider level data. Within robust and appropriate controls for data security and confidentiality this can provide significant opportunities for valuable insight and intelligence to drive operational and strategic decisions and improvements without creating additional data reporting burdens.
21. A key question which requires a definitive answer is who owns the aggregate data collected through the proposed collection processes and how will this be used? We have concerns that such data may be used as a means of performance management and statistical overview for health and social care by national bodies, as well as a basis for research. If this is the case, why this is collected and how this will be used locally, at ICS and regional levels as well as nationally must be clearly communicated at an early stage to key stakeholders and with those individuals and organisations who have agreed to share their data. To maximise the benefits of any collection and aggregation of data, it is essential that it is made accessible to all that need it, including councils and providers, on a timely basis so that it can be used to inform operational decisions and activities.

Build on existing learning at local and national level

22. We welcome the strategy's commitment to supporting and promoting the use of care technologies and approaches to commissioning innovation. This should be done in a sector-led improvement way, building on existing learning at local and national level. There is much learning that we can draw on from our shared experience and technological and data sharing advancements through our response to the COVID-19 pandemic. However, we must ensure that our approach going forward takes a broader view and remains relevant in the future.

Structured response in the requested format to: Data saves lives: reshaping health and social care with data (draft)

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

Responses Disagree; Partly disagree; Neither Agree nor Disagree; Partly Agree; Agree

Vision statements	LGA Comments
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	**Partly agree** It is important throughout the strategy to set the ambitions in the right context – with the emphasis on why we are doing this (to improve care and outcomes for people) rather than on the more technical use of 'data'. The benefits of social care are often about improving lives to enable people to keep doing what they like to do in the communities they call home. The ambition to 'deliver truly patient-centred care' should be amended to reflect the wider application for 'person-centred' care, recognising that not all individuals will be a patient. This should be reflected throughout the strategy. This vision statement should not just focus on individuals' access to their personal health and care data but their ability to contribute to and have greater control over their records. We strongly support steps to ensure that people, their families and carers, understand and can control what information is held by the health and social care organisations that support them and how their information is shared and used. Ensuring that individuals are informed and able to influence what information is held and shared about them is a key element to ensuring that care and support is personalised.
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	**Partly Agree** The health and care workforce is made up of dedicated staff who will aim to do their best for the people they support whatever the circumstances. The priority should be adjusted to reflect the importance of ensuring appropriate access to the right information for those providing care and/or planning care, minimising unnecessary burden and disruption where access is difficult and impacts on their ability to provide the best care and /or the wellbeing of staff. Consideration should also be given to ensuring that unpaid carers and people like personal assistants who aren't part of the more mainstream workforce but are key to an

Vision statements	LGA Comments
	individual’s care/support/outcomes also have timely access to the information they need. The benefit for individuals in not having to repeat their story to numerous organisations and professionals should not be understated. The terms on which information is shared need to be clear to avoid any unintended adverse consequences, such as people not seeking the care they need through fear of how it may impact their social care/support with the emphasis on dialogue with patients and service users. Guidance on addressing confidentiality within the new approach to data sharing is also key to supporting professionals in their role and gaining the trust of the people they support.
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	**Partly Agree** This statement would benefit from rewording to replace ‘how people we serve receive care’ to ‘how people we serve access care’. Also, the focus is not simply about continually improving, but about providing the care and support that people need. National, local and personal priorities, choice and accountability will need to be considered. The data doesn’t need to be sophisticated, but does need to be fit for purpose and provide useful and usable intelligence in a timely manner that helps to inform local decisions. As an example, there is a need to review the timeliness of data shared across the interface between NHS services and social care – there is often a significant lag in the ability to access shared data due to NHSD and NHSE publication constraints, and often the information is not available at the relevant organisation level / geography, even when the underlying individual level data would support that analysis. Subject matter expertise is required to accurately analyse, interpret and make use of the intelligence available. There is a need to invest in developing local and national digital and intelligence capability and capacity for analysts and system developers, front line staff, leaders and policymakers to make appropriate and effective use of the data and intelligence gained.
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	**Agree** This statement should be broadened to address enabling individuals to access and contribute to their care and health data to maximise a person’s choice and control over their care and support.

Vision statements	LGA Comments
	Ensuring that individuals are informed is a key element towards personalised care and support. We need to ensure that individuals and their carers only need to explain their story once to ensure that needs, outcomes and preferences are understood and addressed in the way that care is delivered, throughout the system.
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	**Partly agree** Further clarity on the research intentions of using care and health data would be helpful. For example, does this include secondary uses / population health management? This statement seems very broad and may create an impression with the public that data will be 'freely shared'. Most research will be targeted on a specific scope and will identify and source the information required. A more consistent approach to data standards and interoperability will improve our capability for secondary use of data for research. There needs to be a commitment to ensuring a greater balance between clinical research and research for adult social care and population health and wellbeing. Improved outcomes in both will have benefits for healthcare. Equally we must ensure that the findings of such research reach the adult social care workforce such as Principal Social Workers, social workers etc. Councils and organisations that work to support councils have numerous requests from researchers for information and endorsement, but we seldom see the outcome of their research and having spoken to others in the sector neither do they.
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	**Agree** We welcome the work around data standards and interoperability and in particular the current direction in ensuring the flexibility to address and adapt to local needs alongside the national requirements is encouraging. For councils in particular the data architecture will need to extend beyond health and care into other key local services that have a significant bearing on individuals' support and quality of life. For social care, and social care providers (whether private or not for profit) this will require a significant transformational investment. If this is not funded by central government this will be a burden/tax on already financially vulnerable services, and is a risk to achieving the infrastructure required.

Vision statements	LGA Comments
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.	**Agree** “Innovators” are referenced throughout the strategy and would benefit from clearer language. For example, if this means industry partners who can add expertise/tools that we currently do not have in the health and care sector, we should be clear about this and feel confident in highlighting the benefits. This vision statement may benefit from a revised wording of “innovators will be encouraged and supported to develop and deliver timely new solutions safely for the benefit of citizens, staff and the health and care system” with the focus on encouraging and enabling innovation. Individual use-cases will determine the level of urgency and safety would be assumed within the context of ‘fit for purpose’ as appropriate. In addition, introduction of new solutions safely and for all citizens, staff and the system will also need to consider local considerations, priorities and infrastructure. The initial phrase ‘time and safety are both essential’ is superfluous.
Do you have any comments on the vision statements as set out in the strategy?	Comments detailed for each above

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

Responses: Not at all important; Slightly important; Moderately important; Very important; Extremely important

Priorities	LGA Comments
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	**Extremely important** Given recent interest in the health and care data opt-out it will be important to raise public awareness and build trust and confidence in how people's data is being used and how this is supporting the health and care sector to have the information it needs to provide the right care and support. We would like to see the strategy do more in terms of reconciling the possible tensions between the imperative for increased data collection/sharing and maintaining public trust and confidentiality. The rise in opt outs in response to recent events make it unsustainable for the strategy to remain silent on what sharing people can opt out of, when they can do so, and how. Opting in and opting out should not be a once in a lifetime event. How this is done, and for what information is important. Prioritising transparency is positive however the strategy associates this directly to "control" that the public will have - transparency and control are not the same. The question about how to maintain public trust while opening up data usage in the ways envisaged should be at the heart of the strategy. It is essential that the public has control over their own personal data, however this must be balanced with the need for the health and care sector to have access to the information it needs to deliver the care that is needed, and ensure that we have the evidence and intelligence to shape future care and support for individuals and the wider population.
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	**Extremely important** Data sharing needs to be the norm to underpin truly integrated health and care. However, the approach needs to work for all stakeholders, including citizens, and must not be driven by the needs of one sector to the detriment of another. Legislation, governance, guidance and system architecture must be designed to support effective information sharing and not create unnecessary barriers. There will need to be support to the care and health workforce to support a culture-shift to making appropriate data sharing the norm.

Priorities	LGA Comments
	The terms on which data will be accessible need to be clear to avoid any unintended adverse consequences, such as people not seeking the care they need through fear of how it may impact their care and support.
To build the right foundations - technical, legal, regulatory - to make that possible	**Extremely important** These must be proportionate and usable and not create barriers to progress. Effective communication and guidance of how these foundations are applied is essential to support and enable the data sharing needed, but also to ensure public trust and confidence in the approach.
Do you have any comments on the priorities as set out in the strategy?	Comments detailed for each above

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.

Responses: Strongly disagree; Disagree; Neither agree or disagree; Agree; Strongly agree

Chapter and commitments	LGA Comments
Chapter 1: Bringing people closer to their data Harnessing data to improve people's safety - we will improve information governance guidance so staff are confident in sharing people's data for their individual care, including publishing the Information Governance Framework for Integrated Health and Care (July 2021) - we will undertake further work on harnessing data to improve health outcomes and reduce inequalities, including the AI Ethics Initiative which will report in 2022 to 23 on its research call exploring how to use those technologies to improve health outcomes for minority ethnic populations in the UK (ongoing)	**Agree** Additional comments: • The draft commitments could be stronger in affirming their approach to refining and delivering them in a collaborative, open and co-produced way. • It is essential that guidance, legislation, governance etc are designed to support effective information sharing and do not create barriers. • NHSX may wish to consider how digitised personal child health records may connect with the roadmap for Shared Care Records.

Chapter and commitments	LGA Comments
- we will digitalise personal child health records to ensure families and professionals have the information they need, when they need it. This work is supported by the Early Years Healthy Development Review published in March 2021 which sets out how better data-sharing could improve the experiences of parents, carers and staff (2023) Bringing people closer to their data - we will make sure that the technology is in place to enable everyone across England to have easy access to their own health and care data (2022) Giving people confidence - publish the first transparency statement setting out how health and care data has been used across the sector (2022) - give citizens the ability to see what research their data has informed, and who has had access to their data, as soon as the technology allows (ongoing) - embed an open-working approach across health and social care, consistent with protecting privacy, so the public can easily find and understand the data delivery work (ongoing) - lead the Health and Care Information Governance Panel to develop guidance, frameworks and standards such as data sharing and transparency so the public can be confident in our handling of their data (December 2021)	• We agree with the need for the right technology to be in place to support everyone in England to have access to their own care and health information. However, the draft strategy is light on its approach to supportive digital inclusion as part of this. There are connectivity, accessibility, affordability and skills implications with this ambition, and we would encourage NHSX to consider how this will be supported in parallel with the progression of this strategy. Local government in partnership with people in communities, health, adult social care providers and the voluntary and community sector play a leading role in supporting digital and data inclusion. • It is important to ensure transparency in how health and care data is used across the sector – the scrutiny will be beneficial. The public will need to be assured that the data is being used appropriately (i.e., addressing fears of 'selling' inappropriately), and we should look to provide clear evidence of where such use has had beneficial outcomes. Different approaches will be needed across health and care given the varying nature of the interactions with the system and the different services and user groups. • It is also important to engage the public in owning their own data – more empowered and engaged in determining the outcomes that they want, and how they want their information shared. It would be helpful to consider the access as being 'on loan' and not a permanent gift, with individuals empowered to amend arrangements as appropriate. It is also essential that there is clarity about the sharing and use of information where the 'opt out' may not apply and why.
Chapter 2: Giving health and care professionals the data they need to provide the best possible care	**Agree** Additional comments:

Chapter and commitments	LGA Comments
<u>Simplifying information governance</u> - embed the Information Governance Portal as the one-stop shop for help and assistance, guidance and advice (December 2021) - complete the key priority areas in our work to align national information governance guidance (April 2022) - with the Health and Care Information Governance Panel, create fit-for-purpose rules around different types of data (such as pseudonymised), so that staff can clearly understand rules around the use of data (April 2022) - we will develop a national Information Governance Strategy to address training for frontline staff (April 2022) - we will review tool kits and language to bring into line with simplification work (July 2022) - with the NDG, develop new e-learning packages on the use of data for frontline staff, information governance professionals, and Caldicott Guardians (2021) <u>Creating a new duty to share</u> - we will introduce legislation in due course to create a statutory duty for organisations within the health and care system to share anonymous data for the benefit of the system as a whole (ongoing) <u>Delivering shared records</u> - ensure that each Integrated Care System has a basic shared care record in place to enable sharing of key information between GP practices and NHS trusts (2021) - deliver comprehensive shared records in line with the commitments in the NHS Long Term Plan so that authorised staff for other care partners can easily and appropriately access data regardless of where care is delivered (2024) <u>Reducing the data collection burden</u> - have in place a system-wide target for the rationalisation of data collections to reduce the time spent by health and care staff inputting and processing data for national use (by 2021 to 2022 and reviewed annually) <u>Harnessing safe and effective innovation</u>	• It is essential that guidance, legislation and governance are well designed, and that data roles and responsibilities are clear, to support and enable effective information sharing and not create barriers. This also needs to support a culture shift to support the normalisation of data sharing. This should build on the National Data Guardian's Caldicott Principles. • The introduction of legislation to create a statutory duty for organisations within the health and care system to share anonymous data for the benefit of the system as a whole needs to be carefully considered and used sparingly to ensure that any burdens are proportionate and appropriate, considering existing statutory / regulatory data returns for councils and adult social care providers. This will be a new burden for social care providers who have not been used to providing this level of data before (and to a degree for councils) so it will be helpful to understand how this burden is being managed and resourced. • We welcome the development of Shared Care Records, but to support its implementation across the Integrated Care System, and the ability of all care partners to share and not just access information, it is essential that local councils and adult social care providers are fully engaged in and able to influence this programme. Harnessing the local ICS relationship is key in developing an approach that works locally to address and adapt to local needs alongside the national requirements. • We agree with the commitment to supporting digital home care and would welcome the opportunity to explore how local government can continue to support this important agenda building on existing local work.

Chapter and commitments	LGA Comments
- scale up our digital home care projects to support many more people with care at home, including those resident in care homes, improving their health outcomes (March 2022)	
Chapter 3: Supporting local and national decision makers with data Integrating local care systems with a culture of interoperable by default - we will ensure the inclusion of adult social care providers (where they have digitised records) to integrate with basic shared record solutions across health (September 2022) Building analytical and data science capability - we will develop an analyst workforce observatory, including an annual census to inform how to better harness the professional skills of analysts and data scientists, and support their professional learning and development (March 2022) - we will develop an online Analytics Hub, working with AnalystX, to share, promote and endorse training, events and other resources (2021) - we will grow the Analyst X community and build the team of future analytical leaders through a champions programme (March 2022) - we will pilot a data and analytics accelerator (March 2022) - we will develop and roll out a unified set of competency frameworks aligned to the government Analysis Function skills (2022) - through the 'Developing Data and Analysis as a Profession Board', we will: ○ agree frameworks, guidelines and policies to operate in ○ build the ecosystem of the profession through communities of practice (local, regional, national and virtual) ○ signpost and provide development opportunities for analysts (ongoing) Working in the open - we will begin to make all new source code that we produce or commission open and reusable and publish it under appropriate licences to encourage further innovation (such as MIT and OGLv3, alongside suitable open datasets or dummy data) (end of 2021) Sharing data for wider purposes	**Agree** Additional comments: • We welcome the engagement of adult social care providers in this Shared Care Records Programme. However, in taking this forward it is essential that we take a collaborative approach that takes account of the role of all public, private, voluntary and community organisations that all work together in supporting people to be well, safe and independent and not be dominated by the clinical interactions. • NHS services and social care are equally important and the needs of one should not be addressed to the detriment of the other. NHSX will also need to continue to support adult social care providers that do not yet have digitised records so that digital and data does not further widen inequalities. • We welcome the commitments to investing in analytics capabilities. However, this must be an offer that works across the whole health and care workforce, including for staff in local government and adult social care providers. It should not be dominated by the NHS and central government analytical workforce capability. • There is a need to invest in developing local government digital and intelligence capability and capacity. This is for analysts and system developers, but also for leaders and front-line staff to make effective use of the data and intelligence gained for planning and operational use. Subject matter expertise is required to accurately analyse, interpret and make use of the data we have. • The strategy needs to facilitate rather than overly prescribe, and put in place mechanisms and resources

Chapter and commitments	LGA Comments
- we will use secondary legislation in due course to enable the proportionate sharing of data including, where appropriate, personal information for the purposes of supporting the health and care system without breaching the common law duty of confidentiality (ongoing) - we will work closely with stakeholders and the public to make sure that these changes are implemented transparently and that appropriate safeguards are in place (ongoing) Collaborating with wider partners - we will work across central government, including with colleagues in MHCLG, DfE, the Cabinet Office, MOJ, DWP and across the devolved administrations to improve appropriate data linkage to support people's health and wellbeing (ongoing) - our public health agencies will draw on multiple data sources to gain new insights into the public's health, with quicker access to high quality health intelligence to inform improved decision-making and responses to crises (ongoing)	to support more effective use of data and intelligence across the board. The current commitments are almost exclusively NHS and medically focused – resources and focus needs to be rebalanced to address social care and the preventative agenda. • In relation to the commitment to "work across central government, including with colleagues in MHCLG, DfE, the Cabinet Office, MoJ, DWP and across the Devolved Administrations to improve appropriate data linkage …" it would be helpful to see reference to how this commitment links to related legislation such as the Digital Economy Act (the DEA does not currently cover data sharing relating to the provision of health and social care) and the development of a Trusted Digital Identity and Attribute Framework being led by DCMS.
Chapter 4: Improving data for adult social care Improving access to information for adult social care providers - collect client-level data rather than aggregate data from local authorities to ensure that we have regular and comprehensive data to enable person-centred, sustainable innovation for adult social care (2023) - DHSC will develop a plan for sharing data with local authorities that looks beyond the pandemic, building on the learning from the COVID-19 response (ongoing) - provide digital skills frameworks to identify what good digital working looks like in practice, supported by the delivery of training opportunities to improve the data and digital literacy of the adult social care workforce (by March 2022) Integration of health and social care data - work with care providers to accelerate the adoption of digital social care records through the NHSX Digitising Social Care Record programme for better access and interoperability with Shared Care Records (2024) - we will introduce legislation in due course to require information from all adult social care providers (both public and private), so that we can build	**Agree** Additional comments: • There is much learning that we can draw on from our data sharing advancements through our response to the COVID-19 pandemic. However, we must ensure that our approach going forward takes a broader view, recognises what was already in place before, and remains relevant in the future. • DHSC's client level data collection proposal needs to be reviewed to take account of the learning over the last 16 months both in terms of how information was shared across organisations to ensure that the most vulnerable were supported, but also the shape of the intelligence we want to draw from that data. • Effective development of data standards and interoperability across the health and care system should, through its capability for systematic use of extraction and analysis of records for local and national

Chapter and commitments	LGA Comments
a better picture of the delivery of adult social care services across England (ongoing) - establish a data framework for adult social care setting out what data we intend to collect and the standards used to collect it so we know we are getting the data we need (March 2022) - work with NHS Digital and NHS England and NHS Improvement to continue to build the foundations needed to support care providers in accessing the information they need to deliver high quality care for people (March 2022) - we will continue to promote NHSmail (or other appropriate services that meet the government’s secure email policy requirements) to all care providers to enable secure information sharing with colleagues and with the NHS (2021 to 2022) Expanding the use of care technologies We will engage and collaborate with a range of partners, including local authorities, care providers (tech-enabled or otherwise), innovators, and the wider health and care system, to build strong relationships and: - improve their confidence in the commissioning and purchasing of care technologies that support integrated working - support the creation of a vibrant CareTech marketplace - spread the use and adoption of these technologies and evaluate how the data they generate can be used to improve the quality of care This will ensure that we continue to focus on the challenges and opportunities that will have the greatest impact in driving digital transformation in social care. (2021 to 2022)	insight, reduce the need for any standalone data collections for national use. • We continue to work with adult social care providers on the national overview and intelligence requirements of the care market by DHSC. Future approaches must ensure and be supportive of councils managing relationships with their local providers, as per the Care Act 2014. Our aim should be for agreeing a common dataset with common standards – this does not need to be a single system of collection provided the relevant data can be shared. We also need clarity as to how the information is intended to be shared and used, especially through any aggregate ‘metrics produced. It is essential that as with developing the collection, the approach to sharing the data needs to be collaborative, commissioner-led, evidence informed and co-produced with care providers so that it is timely, accessible and fit for purpose. • We welcome provision to enhance data and digital literacy and skills, which are critical to adoption alongside basic connectivity. Training opportunities should be sector-led, learning from digital initiatives by care providers and councils that have been co-produced with staff such that workforces embrace data and digital rather than see them as an additional burden. • We welcome the development of shared care records and the support that NHSX is able to provide to enhance councils’ and adult social care providers’ capacity to develop their care technologies in this evolving environment. Supporting collaboration between central and local government and the software supplier market is a key enabler for digital and data to join up and personalise care so people can live the lives they want to lead. Effective and efficient adult social care council case

Chapter and commitments	LGA Comments
	management and health integration systems are vital to councils. Local systems use case management systems every day when working with people to assess their needs and commission and plan appropriate, effective, and personalised care. Councils in England with responsibility for adult social services are continually working to adapt and develop their adult social care digital systems to meet changing needs and the rapidly evolving digital and information landscape. Their further development is critical for joined up care and integrated local health and care systems. Strategic leadership, collaborative forums and commissioning and procurement guidance are all needed for this, alongside skills development and sustainable investment funding. • We welcome the commitment to supporting greater use of care technologies and approaches to commissioning innovation. This should be done in a sector-led improvement way building on existing learning at local and national level with recognition that digital inclusion is vital for successful adoption. • Greater use of care technology offers greater data opportunities (use of data directly from devices to inform/provide real-time care and support). It is important that the data implications of a mixed economy of public and private provision are considered here. The strategy could also be more explicit about the data opportunities associated with the transition from analogue to digital expected by 2025 and how NHSX intends to support the sector with this.
Chapter 5: Empowering researchers with the data they need to develop life-changing treatments, models of care and insights' Providing safe and secure data for analysis and research	**Agree** Additional comments: • Again, the commitments detailed are very health and pandemic focused. The title should refer to 'models of care and prevention of the need for care', underpinned

Chapter and commitments	LGA Comments
- create partnerships between academic researchers and frontline analytical teams to enhance the exchange of skills and knowledge (ongoing) - produce a consistent and clear glossary of terminology and legal definitions working with the research community to alleviate confusion and improve the quality of research access requests (October 2021) <u>Sharing data for research</u> - consider and, where appropriate, act on the findings and recommendations of the Goldacre Review into the use of data for research and analysis (end of 2021) - 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 (2023) - progress towards bringing together genomics data assets, and work with NHS England and NHS Improvement to ensure genomic data generated through clinical care is fed back into patients' records (2023) <u>Encouraging clinical research</u> - build on platforms such as NHS DigiTrials to enable and support best use of data and digital tools in study feasibility, identification and monitoring of research participants to enable faster, more efficient and effective clinical trials (March 2022) - publish the first implementation plan to progress UK priorities for clinical research as set out in the UK vision for clinical research delivery, including a key theme on research enabled by data and digital tools (2021) - working with other countries and G7 members to facilitate the rapid generation of compelling evidence through randomised clinical trials of treatments and to enable timely and decisive action on the findings in this pandemic and for future clinical trials (2021) - working with other countries and G7 members to develop a framework to share testing methods and materials would ensure that the data generated could more readily be compared in vaccine development (2021)	by a need to broaden this to address the wider needs across adult social care and preventative work, and ensure that the focus is more sustainable (rather than pandemic focus). • Effective research has the potential for stimulating key developments. Better use of data standards and interoperability across the system will be beneficial in supporting and underpinning research programmes. • There is a need to re-balance the allocation of research funding to support research for adult social care, and population health and inequalities and ensure that there is scope and commitment to share and scale up learning.

Chapter and commitments	LGA Comments
Chapter 6: Helping colleagues develop the right technical infrastructure Modernising our data architecture - agree a target data architecture for health and social care outlining how and where data will be stored, shared and sent (winter 2021) - map the technical debt for national systems, and prioritise what must be addressed and completed through relevant programmes of work (March 2022) - provide services to find and retrieve records from wherever they are located across health and social care (spring 2022) - develop APIs that can be accessed over the internet to access multiple channels including clinical systems, web pages and apps, and for both patients and clinicians to access patient data, underpinning the creation of the NHS Account (March 2022) - improve the process of onboarding to national systems to increase uptake of national services and products such as the NHS Number (November 2021) - develop the roadmap for core services within the NHS using cloud technology (October 2021) - increase the number of APIs available on the national healthcare gateway (August 2021) - develop data infrastructure services to enable the flow of data across the system to support interoperability (October 2021) - build Centres of Excellence (CoEs) in the area of data architecture that focus on promoting best practices, support and training (August 2022) Promoting and developing data and technical standards - we will develop and publish the standards and interoperability strategy to get fit-for-purpose standards widely adopted across health and adult social care (March 2022) - we will introduce legislation in due course to create a power for the Secretary of State for Health and Social Care to mandate standards for how data is collected and stored, so that data flows through the system in a usable way. This will make sure that when it is accessed or provided	**Agree** Additional comments: • Yet again these commitments are incredibly health focused. Where is the approach to helping colleagues develop the right technical infrastructure for adult social care? It is essential that in taking this forward that it is a collaborative approach that takes account of the role of all public, private, voluntary and community organisations that all work together in supporting people to be well, safe and independent. The approach in developing the infrastructure needed must truly reflect the ambition to support the whole health and care system and not be dominated by the clinical interactions and NHS focused references. • We need to change the mindset and focus first on how information (data) is ‘recorded’, with the emphasis on its primary purpose in supporting individuals’ care, rather than ‘collected’ which implies emphasis on the reporting and analytical aspect which is secondary. • There is a danger in being too prescriptive in how data is recorded / collected and stored – there needs to be some flexibility at a local level to determine what works in practice, with support to learn from the best approaches and scale up and adapt and evolve as necessary. • We recognise the importance of standards adoption to support information sharing, but we do not agree with the principle of mandating standards for local government and would instead encourage a collaborative approach in which standards are co-designed with the sector. The current approach for the Shared Records Programmes in ensuring the flexibility to address and adapt to local needs alongside the national requirements is encouraging and preferential to rigid mandated standards which may not work across the board. This

Chapter and commitments	LGA Comments
(for whatever purpose), it is in a standard form, both readable by and consistently meaningful to the user or recipient (ongoing) - publish and maintain a standards roadmap, working with vendors and procurement frameworks to ensure effective implementation (April 2022) - develop a core of UK-wide Fast Healthcare Interoperability Resources profiles to be the foundation for new standards (November 2021) - begin tracking the adoption of standards and develop a standards catalogue/registry to improve visibility and accessibility of what exists to support and monitor adoption and make compliance easier (March 2022) <u>Staying ahead of the evolving cyber risk</u> - provide leaders with the data they need to understand their organisation's cyber risk status (March 2022) - work with the Medicines and Healthcare products Regulatory Authority, NHSD and NCSC through the Connected Medical Device Security Steering Group to better understand the risks around connected medical devices across the health and care system (March 2022) - complete 100% of backup reviews for target organisations (in 2021) - develop a long-term plan for cyber aiming for a cross-government approach in the NHS and adult social care (end of 2021) - invest funds to increase DSPT compliance and deliver direct support across the entire adult social care sector (2022) - set clear cyber standards for health and care organisations and suppliers, annually reviewing and publishing standards in the mandatory DSPT (annually) - continue to support the system to drill and regularly rehearse national incident response plans (at least annually) - work with NCSC to set higher standards for parts of the system most at risk of cyber attack (ongoing) <u>Separating the data layer</u> - separate the data layer from the application layer (ongoing)	must build on existing work that has been undertaken by local areas and by the LGA in this area. • We are also supportive of the need to work with suppliers to enable more interoperability between health and care systems so that the right information can be shared at the right time and with the right people. However, the plan's detail on infrastructure and building the centre is largely NHS focused and lacks clarity on the extent to which social care is considered. • We agree that system suppliers must develop APIs that are public and published. NHSX could be stronger in its ask of system suppliers to ensure that purchasers are not 'locked into systems' without incurring extortionate costs for existing APIs which risks inhibiting information sharing progress across care and health – particularly in the case management system market. • The aims which the strategy set out will clearly require significant investment to achieve. A commitment to provide adequate resources where they are needed, would be helpful along with a commitment to understanding the current position for care providers with regard to digital maturity and cyber security. For example, ensuring that local government and the adult social care sector has the necessary influence, capacity and support to make this work.

Chapter and commitments	LGA Comments
- develop a data layer to manage nationally held patient data that meets the criteria set out above with a set of APIs to enable access for patients and clinicians (by 2023) - populate the national patient data layer with diagnostics and medicines data derived from COVID-19 initiatives (by 2023) - build upon the work done in shared care records to standardise API data access to shared care records (end of 2022)	
Chapter 7: Helping developers and innovators to improve health and care Driving interoperability for innovation - publish a digital playbook on how to open source your code for health and care organisations with guidance on where to put the code, how to license and what licences to use, how to maintain and case studies of teams who have done this (2021) - collaborate with the MRC, NIHR, and UK Research and Innovation to ensure that grants for research involving health and care data follow open and reusable code principles (ongoing) Encouraging AI innovation Support up to 100 AI companies through the AI in Health and Care Awards to achieve market authorisation and/or the real world evidence required to support long-term NHS commissioning of their technology (March 2026) Clear and understandable AI regulation - develop unified standards for the efficacy and safety testing of AI solutions, working with MHRA and NICE (2023) - develop a National Health and Adult Social Care AI Strategy (2024 to 2030) to consolidate the system transformation achieved through the NHS AI Lab (2022) - we will support UK regulators to: 1. ensure AI regulation is fit for purpose as part of amending the Medical Devices Regulations 2002 following our departure from the EU 2. streamline the regulation pathway for AI technologies to enable innovators to get their product to market in a seamless, efficient manner	**Agree** Additional comments: • The focus of this chapter needs to be expanded to not just improve health and care but also prevent the need for care and health services. • This is an ambitious and well-intended commitment, encouraging and enabling innovation that benefits citizens, staff and health care. However, we need to ensure that developments are appropriate, proportionate, and do not risk eroding public trust that their data is being used appropriately. Where possible it is important to provide and promote clear evidence of where innovation has had beneficial outcomes. • As with all aspects of the data strategy it is important that social care and population health has a proportionate stake in this development, and that there is scope and capacity to enable local areas to innovate and scale up. • We welcome the commitment to supporting and enabling innovation that benefits people in communities. The proposed National Health and Adult Social Care AI Strategy must not consolidate learning from the NHS AI Lab alone but also from other relevant learning from across the system, including across social care and broader local government.

Chapter and commitments	LGA Comments
3. develop a multi agency service for innovators seeking advice on their regulatory journey in getting their product to market will be piloted in 2021, following the identification of gaps in the regulatory landscape, and rolled out by 2023 4. develop a regulatory position on the acceptability of using synthetic data as training data for AI as a medical device and explore the use of synthetic data for the validation and benchmarking of AI as a medical device 5. enhance and extend Medicines and Healthcare products Agency’s (MHRA’s) Yellow Card technology to deliver data-driven, smart reporting on adverse incidents (July 2023) <u>Supporting innovators to work with health and care organisations</u> - make £140 million of funding available through the AI in Health and Care Award to accelerate the testing and evaluation of AI technologies (2024) - helping regulators develop an approach for independently validating AI technologies for screening (June 2022) <u>Creating fair returns in data partnerships</u> - publish the Value Sharing Framework and Guidance (July 2021) - translate the 5 principles in the context of the adult social care sector (March 2023) - develop a Resource Hub for healthcare leaders on data partnerships (September 2021) - review and update NHS Digital’s data sharing contracts to reflect the Value Sharing Framework Guidance (2022)	
Do you have any comments on the priorities as set out in the strategy?	Comments detailed for each above

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

Please see our detailed comments above.

Which commitment(s) do you disagree with most? Free text

Please see our detailed comments above.

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: Free text
Please see our detailed comments above.

Is there anything obvious that is missing from the commitments that you feel is important? Free text
Please see our detailed comments above.

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.
All of the above. Should also be expanded to truly address health and care data.

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

Please see our detailed comments above.

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

Please see our detailed comments above

Do you have any further comments on the strategy?

None