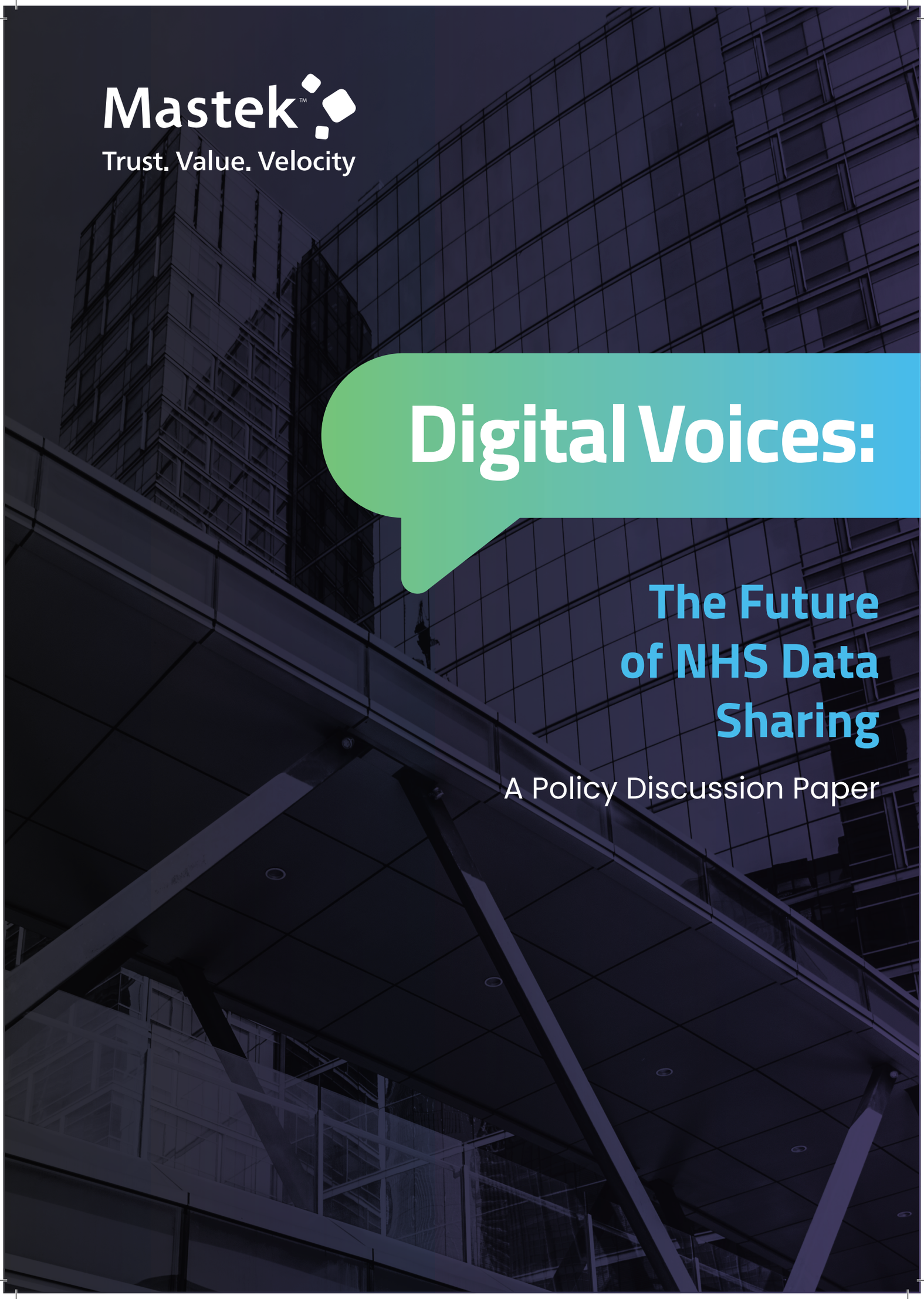

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Digital Voices:

The Future of NHS Data Sharing

A Policy Discussion Paper

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Foreword:
Abhishek Singh

The NHS has an unparalleled opportunity to harness the power of its data to transform the delivery of care, enhance patient outcomes, and address some of the most persistent challenges in healthcare. Yet, this potential will remain untapped unless decisive and coordinated action is taken to address the barriers to effective data sharing.

The NHS's data is a resource of global significance and incredible value, and it's appropriate use could enable breakthroughs in clinical decision-making, research, and operational efficiency. Patients rightly expect their information to follow them seamlessly through the healthcare system, and clinicians depend on timely access to accurate data to make informed decisions. However, the reality is often characterised by fragmentation and inefficiency, with vital information locked away in siloes.

Tackling this issue requires a deliberate, focused approach. Key programmes that offer tangible benefits to patients and clinicians must be prioritised, supported by a long-term vision and multi-year funding commitments. Equally, there must be a commitment to patient involvement, transparency, and trust. Patients must have a voice in shaping how their data is used, and where it is shared, alongside clear assurances about privacy and security.

However, technology alone will not solve these challenges. The shift to a culture of open, secure, and efficient data sharing is essential. Building confidence across clinical and operational teams in data-sharing frameworks and governance is as critical as the technological infrastructure. It is also vital to foster visible, trusted leadership to champion these efforts and communicate the benefits to both staff and the public.

At Mastek, we have long supported the NHS in navigating complex digital transformations. Our work focuses on enabling data integration, ensuring interoperability, and delivering secure, user-friendly solutions that align with the unique needs of healthcare organisations. Through our partnerships, we have seen first-hand how thoughtful use of data can lead to measurable improvements in patient care and operational efficiency.

The opportunities presented by better NHS data sharing are vast, but so too are the stakes. Failure to act risks squandering the potential of this unique resource and perpetuating the inefficiencies and frustrations experienced by patients and staff alike. Conversely, with a strategic and sustained commitment, data sharing can become a cornerstone of a more effective, patient-centred NHS.

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Executive Summary

NHS data sharing should have a relentless focus on core programmes that deliver the maximum impact for patients.

To fully realise the potential of NHS data, sharing initiatives must prioritise core programmes that deliver tangible benefits for patients, clinicians, and taxpayers. By focusing on streamlining data flows to ensure electronic health records travel with patients throughout their care journey, the NHS can address long-standing frustrations around fragmented care. This patient-centred approach ensures resources are directed towards impactful areas such as improving care coordination, speeding up diagnoses, and reducing administrative burdens. Aligning national priorities with local challenges will empower healthcare providers to deliver meaningful improvements in care and patient outcomes.

NHS data sharing should be informed by a long-term vision and backed by a multi-year funding settlement that accounts for revenue costs and capital investment.

Sustained transformation in NHS data sharing requires a clear, long-term vision underpinned by a stable, multi-year funding settlement. This approach enables investment in foundational infrastructure and innovative systems while covering ongoing revenue costs for maintenance and scalability. Predictable funding provides NHS leaders with the confidence to plan and implement data-sharing systems that address fragmentation, bridge operational siloes, and improve care delivery. Such funding also supports the development of secure platforms to facilitate advanced research and public health interventions. A long-term, ringfenced financial commitment will ensure these efforts have the resources to deliver enduring impact.

NHS data sharing should be defined by proactive patient involvement and consistent, informed patient consent.

For NHS data-sharing initiatives to succeed, they must be built on proactive patient engagement and transparency about how data will be used. Involving patients in the design and ongoing evolution of these initiatives ensures their expectations and concerns are addressed, strengthening public trust. Consent processes must go beyond a one-off formality, offering regular opportunities for patients to make informed choices about how their data is shared. This patient-led approach ensures data-sharing efforts reflect public values while fostering trust and enabling innovations, such as clinical trials and personalised treatments, to deliver clear benefits for patients and the public.

NHS data sharing should be supported by enforceable data standards to drive interoperability and secure data access.

To maximise the potential of NHS data sharing, clear and enforceable standards must be in place to ensure interoperability across systems and secure access to critical healthcare data. The Data (Use and Access) Bill represents a crucial step in this direction, granting the Secretary of State the power to mandate Information Standards for IT providers handling NHS data. These standards must apply retrospectively to legacy systems as well as new partnerships, ensuring seamless data access between primary, secondary, and social care settings.

Beyond compliance, a robust governance framework should be established to guide the expansion of existing Secure Data Environments (SDEs), providing controlled and scalable access to healthcare data while maintaining patient trust and regulatory compliance. A dedicated working group of NHS and ALB digital leaders should oversee this expansion, ensuring alignment with national priorities and operational needs. By embedding enforceable standards and structured governance, the NHS can unlock the full benefits of data-driven innovation while maintaining security, accountability, and interoperability.

NHS data sharing requires a cultural transformation not just a technological solution.

The successful implementation of NHS data-sharing initiatives hinges on cultural transformation as much as on technological solutions. Overcoming hesitancy among clinicians and administrators about data ownership, governance, and compliance requires instilling confidence in legal frameworks and data-sharing protocols. Operational leaders must champion these initiatives, embedding them into everyday practices and building momentum within local NHS organisations. Nationally recognised figures should also act as visible advocates, inspiring trust and communicating the benefits of data sharing to staff and patients alike. By embedding a culture of data sharing at all levels, the NHS can unlock the full potential of its data to improve patient care.

Consent processes must go beyond a one-off formality, offering regular opportunities for patients to make informed choices about how their data is shared.

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Background To This Discussion Paper

This discussion paper has been developed following two parliamentary roundtables convened by Mastek which brought together digital leaders from across the NHS, Parliament, and associated Arm's Length Bodies (ALBs) to discuss the challenges and opportunities for improved data sharing across their organisations. The participants in these discussions were:

Noel Gordon, Former Chair of NHS Digital and PLMR Healthcomms Adviser

Erika Bannerman, Managing Director, NHS Shared Business Services

Professor Steven Riley, Director General for Data, Analytics & Surveillance, UK Health Security Agency

Rebecca Cosgriff, Director, Data Partnerships & Portfolio Strategy, LIfeArc

Rebecca Llewellyn, Director of Data Management and Transformation, NHS England

Dr Layla McCay, Director of Policy, NHS Confederation

Wendy Clark, Deputy Chief Executive, NHS Blood and Transplant

Professor Matt Brown, Chief Scientific Officer, Genomics England

Chi Onwurah, **MP**, Chair of the Science, Innovation and Technology Select Committee

Sadik Al-Hassan, **MP**, Co-Chair, Life Sciences APPG

Abhishek Singh, President UKI and Europe, Mastek

Assad Tabet, Senior Vice President, Healthcare and Life Sciences, UKI and Europe, Mastek

Rob Shaw, Adviser, Mastek

Disclaimer

This paper represents a synthesis of this discussion. However, its findings and recommendations do not represent the opinions or views of any participants listed above and should not be attributed to any single individual.

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The Current State of Data Sharing in the NHS

The wealth of data that is held by the NHS is the envy of equivalent healthcare systems across the globe. The NHS is world leading in the volume and richness of the data that is generates and collates and has the potential to empower profound improvements in the coordination of care, the targeting of public health interventions, and the development of cutting-edge technological solutions through clinical trials and medical research.

However, there is a widely recognised frustration, held by the British public that their healthcare data is not flowing between different parts of the NHS as it should. Several participants in these roundtable discussions recounted the incredulity of patients that their healthcare information was not being shared between their GP and their consulting clinicians in an NHS hospital. This incredulity is based on an assumption, widely held by the British public, that their data will travel with them as they interact with different points of care during their healthcare journey.

The reality is that personal and operational healthcare data in the NHS is often found in siloes than anywhere else. The fragmentation of NHS data risks squandering the unique opportunity that it presents in tackling some of the most entrenched challenges facing the NHS; from extended waiting lists, an inability to discharge patients in hospital care, to dramatic increases in the number of patients living with complex, long-term conditions.

Urgent action is required if we are to maximise the unique opportunity of NHS data and to ensure that it is accessible to NHS staff, wherever it might be required to support the delivery of care.

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The Importance of Long-Term Investment in NHS Data Sharing

Effective data sharing between constituent NHS bodies and relevant Arm's Length Bodies (ALBs) will be built on consistent Government priorities and predictable Government investment. With the advent of the NHS 10 Year Plan,[i] there is a unique opportunity for the Government:

- to galvanise NHS and ALB staff towards a mutually agreed upon vision for the future of NHS data sharing,
- to delegate responsibility for its implementation,
- and, to commit to a multi-year funding settlement towards its delivery.

The Government's long-term vision for NHS data sharing must have a narrow focus on core programmes which deliver maximum impact for patients, clinicians, and taxpayers. It is crucial that these priorities for the future of NHS data sharing receive the backing of local and national NHS and ALB leaders who will be charged with its implementation. The misalignment of national priorities with local challenges and implementation will set any long-term vision for NHS data sharing up for failure, before it has even begun. Any national vision for NHS data sharing must account for immediate challenges and local priorities but, most importantly, must chart an end goal and a direction of travel for local leaders to work towards.

The Government's long-term vision for NHS data sharing must have a narrow focus on core programmes which deliver maximum impact for patients, clinicians, and taxpayers.

The Government's long-term vision for NHS data sharing should be focussed on five key areas:

1. Shaping data flows to allow electronic health records to travel with a patient's treatment journey.
2. Prioritising patient benefit and ensuring patient choice in all data sharing initiatives.
3. Fixing the plumbing of NHS operational data sharing by implementing and integrating the Federated Data Platform.
4. Building NHS back-office interoperability to support workforce planning and deployment.
5. Developing the NHS's research offering through secure access to anonymised NHS data.

A long-term vision for NHS data sharing will also mean nothing without the allocation of multi-year, ringfenced funding to support its implementation. No multi-year funding commitment is without risk; however, it grants essential license to NHS leaders and their ALB counterparts, to partner with the Government in its ambitions to "fix the foundations" of NHS data sharing;[ii] and ensuring that the necessary "plumbing" to support secure NHS data access is in place.

This multi-year funding settlement should account for the year-on-year revenue spend that will inevitably underpin the infrastructure requirements to support expanded data sharing; whilst also ringfencing capital investment towards the implementation of new systems and technologies where required. Any additional funding requests that arise with a multi-year funding period, must support the delivery of the long-term vision for NHS data sharing and a commitment to the productivity targets that have been agreed upon.

Transforming NHS Information Standards to Support Data Sharing

However, it is also vital that the Government's risk appetite for investment in NHS data sharing goes beyond its financial settlement and extends to the legislation that it puts in place to enforce compliance with data sharing initiatives. The powers granted to the Secretary of State, as outlined in the Data (Use and Access) Bill, to develop and enforce Information Standards on IT providers who are involved in the processing of NHS data is a crucial first step in ensuring data interoperability between NHS systems and its partner ALBs.[iii] The development of core standards for NHS data processing, should be developed with a clear end goal in mind, and the Government should make full use of the powers granted to it, in this legislation, to enforce compliance on IT providers.

The development of core standards for NHS data processing, should be developed with a clear end goal in mind.

It is crucial that these standards not only apply to new NHS data partnerships, but to existing, legacy contracts that are already in place. No NHS data initiative is implemented from a blank slate, and their introduction inevitably has to reckon with the complexity of existing systems that will often be patched onto older legacy systems. If the Information Standards, as described in the Data (Use and Access) Bill are to have a concrete impact on the ability of the NHS to share data across its constituent bodies, it is vital that the powers granted to the Secretary of State are applied retrospectively to existing NHS data partnerships; and enforce compliance on existing IT providers.

Bridging Data Sharing Between Primary and Secondary Care

It is also vital that compliance to these Information Standards in the Data (Use and Access) Bill is equally binding to IT providers who are responsible for the processing of NHS data in both primary and secondary care. If we are to envisage a future where a patient's data and their electronic health record is able to travel with them as they interact with different aspects of NHS care; and where that data might be anonymised and stored in secure data environments in the support of public health interventions and research efforts, it is essential that the Data (Use and Access) Bill's Information Standards equally apply to IT providers involved in the processing of patient data in primary care.

If these Information Standards are restricted in their application to secondary care, then they will likely also be restricted in the application to NHS operational data, which, while crucial, will often have little tangible, immediate impact on a patient's experience of the care they receive, including the ability of NHS staff to have immediate access to their care history, irrelevant of where they are being treated. As mentioned previously, a patient's appreciation of the value that any particular data initiative has on the care and support that they receive, will be a key determinant of that initiatives perceived success.

Finally, the Government should not rely on the introduction of Information Standards and the proposed sanctions that are outlined in the Data (Use and Access) Bill should NHS IT providers fail to comply. It is crucial that the Government considers options for reforming current data controllership in the NHS, including the legal basis of current data controllership (as defined in legislation) to allow for a greater degree of data sharing between primary and secondary care, and for data to travel with a patient when accessing NHS care. The Government's move to have NHS England act as data controller, when patients give their consent for their data to be used for the purposes of research, is a welcome first step.[iv] However, the Government must commit to exploring a range of options for future NHS data controllership to support the continuity of routine data access, across primary and secondary services.

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Bridging Data Sharing Between the NHS and Arms Length Bodies

The effective use of data within NHS teams and Arm's Length Bodies (ALBs) is essential to streamlining patient care, reducing inefficiencies, and enabling coordinated healthcare interventions. However, current approaches to data sharing require modernisation to ensure secure data access rather than traditional data-sharing models. Rather than setting up new Secure Data Environments (SDEs), the focus should be on expanding the existing SDE infrastructure to facilitate wider collaboration across ALBs.

The Department of Health and Social Care (DHSC) should take a more active role in sponsoring and enabling the expansion of Secure Data Environments, ensuring that organisations such as NHS Business Services Authority (NHS BSA), NHS England (NHSE), the Medicines and Healthcare products Regulatory Agency (MHRA), NHS Resolution, the Care Quality Commission (CQC), the UK Health Security Agency (UKHSA), Genomics England, NHS Shared Business Services (NHS SBS), and NHS Blood and Transplant (NHSBT) align their data strategies with this model. These organisations collectively play a crucial role in the efficient functioning of the healthcare system, and integrating their data-sharing frameworks within Secure Data Environments will enhance operational efficiency, regulatory oversight, and patient outcomes.

A dedicated working group consisting of Chief Technology Officers (CTOs), Chief Digital and Information Officers (CDIOs), and Chief Information Officers (CIOs) should be established to discuss how the development and expansion of existing Secure Data Environments can better accommodate ALBs and improve data-sharing processes. This group would be responsible for identifying priorities for secure data access, ensuring interoperability across NHS and ALB systems, and addressing the legal and operational challenges associated with secure data access. By shifting the focus to controlled access through expanded SDEs, organisations can ensure real-time, secure, and scalable access to healthcare data while maintaining compliance with data protection regulations.

The use of SDEs will also accelerate medical innovations and advancements that will support the future of care. By enabling controlled access to regulatory, clinical, and operational datasets, researchers and policymakers can drive progress in areas such as AI-powered diagnostics, personalised medicine, and real-time public health interventions. For example, expanding SDEs to facilitate collaboration between MHRA and NHS BSA would enable faster pharmacovigilance, ensuring real-world monitoring of medical treatments and medical devices. Similarly, a secure environment for NHS Resolution and CQC would support system-wide patient safety improvements through enhanced data-driven insights. The role of UKHSA in managing public health responses, the expertise of Genomics England in precision medicine, the operational capacity of NHS SBS in financial and procurement processes, and NHS BT's critical role in organ and blood donation logistics all demonstrate the need for an interconnected, privacy-preserving, and access-driven data ecosystem.

By prioritising data sharing through the expansion of existing Secure Data Environments, NHS organisations can unlock substantial benefits in terms of operational efficiency, patient safety, research acceleration, and regulatory oversight. The DHSC must lead this transition by establishing clear policies, providing resources for SDE expansion, and ensuring that legal frameworks facilitate, rather than impede, responsible, controlled, and scalable access to NHS data.

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NHS Data Sharing Is, and Should be, for Patients

The development of a long-term plan for NHS data sharing is not just important for the alignment of NHS staff but also crucial in the Government and the NHS's ability to communicate effectively with patients regarding the purpose, opportunity, and benefits of data-sharing initiatives. These benefits extend to improved care, enhanced access to innovative medicines, and increased participation in research and clinical trials.

The Risks of Not Sharing NHS Data

The reluctance to facilitate comprehensive data-sharing frameworks within the NHS has significant implications for patient outcomes, system efficiency, and the UK's leadership in global healthcare innovation. A culture of excessive caution, rooted in concerns over data privacy, security, and governance, has inadvertently contributed to systemic inefficiencies and missed opportunities for improved patient care and medical research.

The lack of seamless data interoperability between primary and secondary care results in critical delays in diagnoses and subsequent treatment, particularly for conditions where early intervention is paramount, such as cancer and cardiovascular diseases. This can exacerbate disease progression and lead to poorer prognoses. Clinicians and healthcare professionals expend significant time and effort navigating disjointed data systems, leading to inefficiencies, duplication of effort, and avoidable administrative costs.

Addressing these risks necessitates a strategic shift towards proactive and secure data-sharing frameworks, ensuring that patient data is both protected and maximised to enhance clinical decision-making and health outcomes.

Securing Patient Support Early and Often

For initiatives like the Federated Data Platform, it is vital that there is a clearly articulated and communicated end goal that demonstrates tangible benefits for both patients and clinicians. This equally applies to platforms like the NHS App, where a long-term vision must be conveyed to patients, ensuring that they understand how the app facilitates better care and supports them in making informed healthcare decisions.

As of May 2024, the NHS App has over 34 million registered users, with monthly logins increasing significantly[1]. This broad adoption presents a unique opportunity to leverage the app as a mechanism for transparent and accessible communication, enabling patients to view their health records, manage appointments, and control their data-sharing preferences. By integrating educational resources and patient-facing information into the app, the NHS can actively guide patients on the benefits of data sharing while providing them with the autonomy to make informed decisions.

1. NHS England (May 2024). NHS App messaging saved NHS more than £1 million in last year. Available at:https://www.england.nhs.uk/2024/05/nhs-app-messaging-saved-nhs-more-than-1-million-in-last-year/.

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Core Principles for Informed Patient Consent in NHS data sharing

A key component of fostering public trust is the introduction of a dynamic feedback loop, where patients receive continuous updates on how their shared data has contributed to medical advancements, policy improvements, and enhanced public health outcomes. NHS England should continue to work with organisations like Understanding Patient Data to continue to co-develop resources such as animations and interactive tools that outline the life saving benefits of sharing data, challenge misconceptions, ensure data-sharing processes are transparent, and ensure that patient consent is continually informed.

It is also essential that patients are meaningfully involved not only in the initial development of Government ambitions for NHS data sharing but also in the ongoing refinement and implementation of these initiatives. Patients' attitudes towards data sharing will inevitably evolve, making continuous consultation and engagement a necessity. By implementing mechanisms that allow patients to provide input and voice concerns in real time, the NHS can ensure that its data-sharing strategy remains aligned with public sentiment.

Going beyond the design and implementation of data-sharing initiatives, individual patients must be given regular opportunities to grant their informed consent regarding the sharing of their personal health data. This process should not be a one-off decision but an ongoing dialogue, supported by sufficient educational resources that enable patients to make well-informed choices. Patient choice in data-sharing participation must not be reduced to a tick-box exercise; consulting clinicians should be equipped with relevant training and information to provide clear, accurate answers to patient concerns regarding data use. This includes expanding the development of accessible, patient-facing resources that support clinicians in their discussions on data-sharing opportunities.

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NHS Data Sharing Requires a Cultural Transformation, Not Just a Technological Solution

There are no shortage of technological solutions which could improve data sharing between the NHS and relevant ALBs. These solutions have been applied with impact in other areas of Government data sharing and across broadly equivalent international comparators. The challenge, therefore, which faces national and local leaders in the implementation of data sharing initiatives, is not a technology one; it is a cultural one.

Any new initiative will be embedded into a culture where there is a justifiable tendency towards caution in the sharing of patient's data. National leaders frequently hear of a hesitancy amongst local teams when it comes to sharing patient's data as a result of a perceived ambiguity regarding the proper legal basis, data ownership or potential sanctions as a result of improper data transfer. Clinical confidence in both the legal framework and the boundaries of any data-sharing initiative is a central determinant of its successful implementation. Any hesitation in clinical participation, therefore, if not adequately addressed, will stifle any future data-sharing initiative, and set it up for failure before it has even begun, and ultimately lead to adverse patient care.

The remedy to this hesitation goes beyond the targeted education of clinical teams and extends to the championship of data-sharing initiatives by operational leaders in positions of authority to drive change within local NHS hospitals and Trusts. Data sharing initiatives should not be restricted to the preserve of information or technology leads within a local NHS board. While these leaders will be crucial in the implementation of data sharing initiatives in terms of the digital interoperability system integration that might be required; it is vital that these initiatives are championed by Chief Operating Officers (or equivalents) and their teams if they are to have the desired impact on day-to-day ways of working and attitudes to data sharing amongst NHS teams and across NHS wards.

Finally, this operational championship needs to extend beyond formal organisational structures within local NHS systems The Government should consider how to leverage prominent national spokespersons as a means of communicating the importance and implementation of any NHS data-sharing initiatives, as well as answering questions from the public. The COVID-19 pandemic highlighted the importance of visible and trusted leadership in the implementation of national NHS health interventions. Building on this legacy, the Government should consider the value of elevating existing NHS leadership in data sharing and identifying "NHS data champions" who can act as trusted and visible voices in communicating the value and intended impact of data-sharing initiatives to both local clinical teams and to NHS patients.

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Conclusion

We welcome the Government's commitment to develop a 10 Year Plan for the future of the NHS. We hope that this discussion paper will act as a valuable resource in informing this vision for the future delivery of care. We are convinced that greater data integration across the different constituent organisations of the NHS and the wider ALB ecosystem holds the keys to tackling the most pervasive challenges that the NHS currently faces.

From waiting times, to discharge into the community, and the remote management of patients with complex and chronic conditions; data has the potential to streamline NHS workflows, target interventions based on an accurate picture of acute need, and support patients to live fulfilled lives. All of us at Mastek are committed to working with the NHS and the Government to achieve this vision.

Background to Mastek

Mastek has a long-standing reputation for delivering transformative digital solutions across various sectors, with a strong and dedicated focus on healthcare. Our healthcare business is driven by a commitment to enhance patient care, improve operational efficiencies, and enable data-driven decision-making for the NHS. Leveraging our two decades experience, deep industry expertise, and innovative technology capabilities, we support NHS organisations navigate the complexities of digital transformation and achieve their strategic objectives.

At the core of Mastek's healthcare solutions is our software engineering abilities and capability to seamlessly integrate data across healthcare systems. This data integration enables the NHS to harness the power of data, gaining valuable insights that drive clinical and operational improvements. By facilitating real-time data access and predictive analytics, Mastek empowers the NHS to make informed decisions, ultimately enhancing patient outcomes and service delivery.

Mastek's healthcare portfolio includes a wide range of services tailored to meet the unique needs of the healthcare sector. From developing secure and user-friendly patient services to implementing robust health related payment systems, we ensure that our solutions are aligned with industry standards and regulatory requirements. Our commitment to data security and privacy, alongside meeting technical standards, ensures that patient information is protected, and the NHS can trust in the reliability, scalability, and safety of our solutions. Our focus on interoperability and seamless data exchange ensures that the NHS can deliver coordinated and comprehensive care, reducing the risk of errors and improving overall efficiency.

In addition to our technological capabilities, Mastek places a strong emphasis on user-centric design and stakeholder engagement. We work closely with the NHS, patients, and other stakeholders to understand specific user needs and challenges. This collaborative approach ensures that our solutions are not only leveraging the latest digital technologies, but also practical and user-friendly. By prioritising user experience and continuous feedback, Mastek delivers healthcare solutions that are both innovative and effective in addressing the evolving demands of the healthcare industry.

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