BMA

BMA response – NHSX Draft Data Strategy

About the BMA

The BMA (British Medical Association) is a professional association and trade union representing and negotiating on behalf of all doctors and medical students in the UK. It is a leading voice advocating for outstanding health care and a healthy population. It is an association providing members with excellent individual services and support throughout their lives.

BMA feedback

Comments from the BMA are italicised and presented in blue. In each section, we have presented a response to the vision and responses to individual commitments and, in some cases, excerpts from each chapter. We have also provided feedback on the three overall priorities that underpin the strategy. Our feedback has been drawn from across the association and constituent committees.

Three overall priorities

1) First, 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

- *The BMA agrees with the sentiment behind this priority; as a greater range and quantity of patient data are collected in increasingly centralised repositories, it will be critical to ensure patients have a greater degree of transparency and control over how their data is used. Where central government bodies seek to build an understanding of how data is used, they must ensure comprehensive and appropriately funded public education campaigns are a core part of any efforts.*

- *Where patients are given greater control over their data, effort should be made to ensure that they have the requisite knowledge and, if necessary, training to be able to execute control in an informed way, for example when inputting and/or correcting data held within their GP record. Thought must also be given to how this vision can be realised in an equitable way so that factors including age, income or background do not dictate the level of access provided. As expressed in the BMA's response to proposed changes under GP Data for Planning and Research, it is imperative that any data shared by patients with the health and care system for secondary uses can subsequently be deleted if requested and any onward dissemination halted (for the purposes of research for example).*

- *Where possible, changes made by patients to data they have shared should be implemented without placing additional burden on clinical colleagues, who serve as data controllers, to verify or check newly inputted information outside of the context of a scheduled appointment.*

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2) Second, 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

- *Clear definitions both of where additional data may be collected and where it may be shared - including use-cases for data linkage as well as clarity on the type of data that will be shared - should be laid down before any further data sharing takes place.*

- *Where data sharing becomes the norm, no additional liability or burden should be placed onto clinicians to achieve this or, where it is, it should be proportionately resourced and supported. For example, non-essential/urgent information that is shared to the GP record should be labelled as such to ensure that there is no expectation of review, outside the context of a GP appointment.*

- *Additional administrative data collected as part of the commitments made within the strategy should not be used to benchmark or performance-manage service providers where it does not accurately reflect the reality on the ground. This is the case with GP appointment data for example, where it is accepted that data collected does not paint a true picture of the demands on general practice as there is a proportion of activity that cannot be recorded or has not been recorded due to time constraints.*

- *While we are supportive of data sharing to provide the best care possible, all Caldicott Principles must continue to apply. In particular:*
- *use the minimum necessary confidential information;*
- *access to confidential information must be on a strict need-to-know basis; and*
- *Ensure no surprises for patients.*

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

- *Putting the right foundations in place is critical to providing the best possible chance of success. In order to build these foundations – particularly the 'technical' foundations - substantial new funding will be required to support clinicians in primary and secondary care with the hardware and software needed to safely and efficiently share data. New funding will also be needed to provide training and inspire confidence in the idea that increased sharing does not bring with it the risk of increased professional liability. Similarly, where regulatory changes are required, they must be implemented across the board in order to ensure ongoing protection for clinicians who may be sharing a greater quantity and wider range of data than they currently do.*

- *Due consideration should also be given to the current workforce climate. In our recent report on staffing, the BMA identified significant shortfalls in the number of clinicians per patient. With the number of patients per GP practice 22% higher now than in 2015[1] GP practices are*

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[1] Medical staffing in England: a defining moment for doctors and patients, BMA, p.26

under significant pressure, as are secondary care doctors, where the growth of activity since 2010 (26%) has far outstripped the growth in workforce (2.34%).[2] In light of this, commitments made to put in place foundations to ensure more data can be shared safely must proceed in a way that does not place any additional burden on clinical staff, and must be implemented in full consultation with the profession.

Chapter 1 – Bringing people closer to their data

Vision - 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.

The BMA broadly agrees with this statement, however any moves to improve patient access to data must take into consideration disparities and inequity between groups in terms of resource, training and ability to access data. While the ability for patients to input some data into records is welcome, due consideration should be given to the following:

- *Clear parameters should be set outlining the type and quantity of data that can be written in by patients.*
- *Expectations about the result of writing data into records – for example, submitting data should not become a shortcut to securing an appointment.*
- *Clear guidance on the expectations of doctors to review user-submitted data should be issued to avoid the creation of additional workload.*
- *Trust must be built to ensure that patient-submitted data is not used in a way that may undermine the doctor-patient relationship, for example through sharing beyond the health and care system, with other government departments or by generating an automated communication with the patient about a serious health issue.*
- *Before full record access is provided, a review of records and possible redaction of parts of a record will need to take place. It is imperative that full access is not provided before records have been reviewed and this process cannot place unreasonable additional burden on general practice, especially at a time when GPs are tackling the backlog on non-COVID care from the pandemic.*

Section comments/commitments

'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'

- *We support all efforts to improve transparency for the public about how data is used both for individual care and to run the NHS, however, the strategy does not provide detail about:*
- *how greater transparency will be achieved; and*
- *how greater transparency equates to the public having increased control of their data.*

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[2] Medical staffing in England: a defining moment for doctors and patients, BMA, p.29

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- *It is not clear whether increased transparency means that the public will be given more choices over how their data are shared. The strategy is silent on mentioning rights for patients to express their preference or to opt-out. It is also unclear how a commitment to the public having control aligns with the intentions set out in chapter 3 where sharing health data with the DWP, local authorities and Jobcentre Plus is discussed without reference to patient consent.*

'we will undertake further work on harnessing data to improve health outcomes and reduce inequalities, including the AI Ethics Initiative which will report in 2022/23 on its research call exploring how to use those technologies to improve health outcomes for minority ethnic populations in the UK'

- *Further commitments to addressing inequalities by other protected characteristics, alongside ethnicity, would be welcome.*

'We know from research that the public is supportive of their data being shared, both for their own care and for the wider benefit of others'.

- *We agree people are supportive of sharing to achieve a public good – but crucially this statement does not mention the pre-requisites for this support, as detailed in the National Data Guardian's recent report Putting good in to practice: A public dialogue on making public benefit assessments when using health and care data. These pre-requisites are authentic public engagement, transparency, treating identifiable data with the utmost care and having safeguards in place to protect society against data manipulation. One of the headline findings from this report was that the public participants were clear that transparency cannot be separated from public benefit. In other words, public benefit could occur only when transparency needs were met.*

'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'

- *Digital by default can only move forward with clear planning for those who cannot or will not access digital records. The need for non-digital access should not and does not have to hold back progress in rolling out greater digitisation of records, but an indefinite period of parallel digital and non-digital records (where these are requested by patients) should be part of any moves towards digitisation.*

'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'

- *Clarity on how technology will be provided to patients to ensure accessibility, or if it will not, how accessibility can be encouraged without provision of hardware/software/training to patients.*

'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'

- *More detail on whether a feedback loop will be put in place for people to express concern about how their data are used and clarity that this programme will not drive people to seek answers from their GP.*

Chapter 2 – Giving health and care staff the data they need to provide the best possible care

Vision - Our vision: 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.

- *The BMA strongly agrees with this statement. For the purposes of our response to Chapter 2, we will focus on two distinct aspects of data:*
  1) administrative and aggregate patient data and
  2) identifiable individual patient data.
- *More broadly, staff must be given sufficient, funded training that reflects both the varying levels of digital competency across the service and the significant time pressures they are under to deliver care. This is rightly referenced in the strategy but should not be mandatory (where it is not required) and should be scaled to meet the needs of a workforce with different levels of digital literacy.*

Administrative/aggregate level

- *During the pandemic, it has been a source of frustration to clinicians that dashboards created from sources including GP and hospital data were not immediately made available to them by default - for example, the Covid Data Store was not made easily accessible to GPs, CCGs, ICSs to support planning at a local level despite requiring significant data input from them.*

Individual/Clinical

- *Since last year, the expanded summary care record (SCR) view has provided clinicians in secondary care with a wider range of information. This represents a step in the right direction, however it is a comparatively rudimentary way of displaying information when compared with alternatives, and it does not enable those clinicians to write anything into the record.*
- *The Local Health and Care/Shared Care Record programme will provide greater access to information and will likely become the primary source of providing clinicians with patient-level data across health and care. It has enormous potential to better enable the sharing of data for direct care within the NHS and between the NHS and social care but should be descoped where data is being used for anything other than direct care. The BMA has expressed concerns over the way that this data is used in representations with NHSX, particularly with regards to secondary uses (research and planning). In light of this, a clear distinction must be made between data stores used for direct care and stores used for planning and research.*

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Section comments/commitments

'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'

- *BMA strongly supports the creation of rules to support staff to safely share data. These rules should be tailored to different healthcare settings (primary, secondary, social) in recognition of the different demands and processes in each area. Explicit clarity on rules around sensitive data, protected from disclosure under the Gender Recognition Act for example, should be provided as part of any guidance document.*

'we will develop a national Information Governance Strategy to address training for frontline staff'

- *Provided that this is delivered with adequate funding and support for the staff, who will need to take time away from providing services to complete training, this is a positive and necessary step.*

'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'

- *An equality impact assessment should be carried out to ensure that any distrust in greater data sharing from patients can be mitigated and to ensure that patients are not discouraged from accessing services on the grounds that, rightly or wrongly, they believe sensitive data about them may be shared without their consent.*

'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'

- *As stated elsewhere in this response, BMA supports the delivery of shared care records where they are used exclusively for direct care. We remain committed to ensuring this and are continuing a dialogue with NHSX to this effect.*

Chapter 3 – Supporting local and national decision makers with data

Vision - 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.

- *The BMA fully recognises the need for data to be made available for local and national planning but remains committed to ensuring that data shared will be used responsibly and in a non-partisan way, particularly at a national level and particularly where patient data is potentially reidentifiable.*
- *The proposal that data may be shared across government departments is concerning, especially if the intention is to share more disaggregated data.*

Section comments/commitments

'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)'

- *Consideration should be given to the possibility that products developed at the expense of the NHS could be used by companies to further develop products which will ultimately be sold back to the NHS for profit. This could be mitigated by price restrictions and greater collective bargaining for products used widely throughout the NHS.*

'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'

- *Greater clarity is needed on whether this commitment refers to sharing confidential health data. If the intention is for confidential data to be shared, detail on how consent will be sought must be put forward. It is well established in professional and ethical guidance that patient consent is required for confidential health information to be shared with third parties such as government departments, local authorities and job centres (save in exceptional circumstances).*
- *Failure to seek consent before sharing data with government departments would cause significant and lasting damage to the trust relationship between doctors and patients and may understandably make patients reluctant to share information with doctors to the detriment of their health – and ultimately better healthcare data and better healthcare as set out in this strategy.*
- *Without clarity on data sources and flows, the BMA cannot support the sharing of patient-level data outside the health and care system, across government departments.*

'Integrating local care systems with a culture of interoperable by default'

- *The BMA supports the concept of ICSs providing more joined-up direct care to patients. We are unclear, however, why it is necessary for ICSs to process data to 'plan, commission and develop*

policy' given that the explicit intention of the GP Data for Planning and Research (GPDfPR) programme, once operational, is to '... support local, regional, and national planning, policy development, public health, commissioning...' (as stated in the Data Provision Notice prior to its withdrawal). All flows of confidential data, at both local and national level, must comply with the principles of necessity and proportionality, avoiding duplication. If there are flows of data which are required but which cannot be delivered via GPDfPR we would be happy to engage in discussions about this.

'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...'

- *There are frequent references in the document to building on the momentum created by the pandemic. While data was and continues to be a vital resource in dealing with a pandemic, these statements appear to be predicated on the assumption that extensively changing systems immediately in the wake of a crisis is the best approach. We disagree. The aftermath of a pandemic is the right time for reflection on what changes worked well for a crisis situation and should remain permanent and which should not.*
- *This approach is highly relevant in the context of sharing confidential information. Any proposals to change legislation relating to the common law duty of confidentiality must consider the importance of maintaining a confidential health service. Patient and public trust in a confidential health service must be maintained.*
- *Confidentiality allows patients to be frank with their doctors, safe in the knowledge that the doctor is under a duty not to share that information for reasons other than their own care (save in exceptional circumstances). If patients felt that they were unable to be frank with their doctor it may make it much harder if not impossible for the doctor to provide effective treatment – or patients may simply not visit their doctor at all. Appropriate access to data to improve health and from which individual patients and society will benefit from must therefore be given with great care through transparent safeguards and controls to protect confidentiality.*

- *We await further detail about the scope of the proposed changes to secondary legislation. We would strongly oppose any dilution of the existing protections for confidential data which the public expect. We support the longstanding arrangements under the Health Service Control of Patient Information Regulations 2002 (COPI) through which the Confidentiality Advisory Group (CAG) provides independent overview. The CAG's role is to consider applications to access confidential information while promoting the interests of patients and the public. This system of independent scrutiny allows data to flow for beneficial healthcare purposes within a framework of established safeguards which minimise the intrusion to patient confidentiality. The independent oversight from CAG helps to ensure public trust in the health system to look after their data - but does not present a barrier to data flowing with appropriate safeguards and when it is in the public interest.*

- *This approach aligns with research into patients' attitudes towards how their health data is used. Research shows that people are more likely to be supportive of the use of their data, but that such support is conditional upon a number of factors, including security and independent overview. This is particularly important if data are to be accessed by third parties outside of the NHS.*

- *The risks of backlash and damage to public trust are not theoretical as we have already seen with the delayed rollout of the GPDPR programme. If datasets are incomplete due to patients opting out, withholding information, or not seeking medical care this significantly undermines their usefulness. With this is mind it is notable that the strategy does not explain the legislation which exists to protect confidentiality nor the safeguards which must be applied. These omissions are unhelpful at a time when public trust is fragile. Any new data sharing policies should demonstrate robust safeguards at the start of the process, not as a late addition.*

'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'

- *As set out above this is crucial.*
- *It is also important those stakeholders include the whole range of individuals with protected characteristics are included within this work to ensure confidence in any changes made.*

Chapter 4 – Improving data for adult social care

Vision - Service users and their carers will have high quality, timely and transparent data to improve outcomes, and can easily access them to help them make choices about their care.

- *The BMA supports measures to improve the collection and availability of data for adult social care. Where staff in social care settings are able to write into records shared across the health and care system, care should be taken to ensure that any data added does not unduly increase the burden for clinicians working in the NHS and/or that it is coded in such a way as to integrate as seamlessly as possible with any receiving systems.*
- *Where technology is rolled out within the social care sector, it must be done equitably to guard against the evolution of a provider/postcode lottery.*

Section comments/Commitments

'Care providers who are not fully digitised cannot access digital services; we will work with the sector to help providers to improve their internet connections and access to devices.'

- *This is a significant undertaking given statistics included in the strategy that state 30% of providers are only partially digitised and a further 30% are using entirely paper-based systems. Furthermore, where training is required for staff in social care, due consideration should be given to the impact this may have on service delivery and any potential knock-on impact to the NHS in terms of increased demand.*

Chapter 5 – Empowering researchers with the data they need to develop life-changing treatments,

Vision - 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.

- *The BMA has submitted written and oral evidence to the Goldacre review (written evidence attached here). These submissions cover feedback in this area. The Association has also made clear views on GPDPR as part of ongoing engagement with NHSD, X and DHSC.*

Section comments/commitments

n/a

Chapter 6 – Helping colleagues develop the right technical infrastructure

Vision - 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.

- *The BMA strongly agrees with this statement, however substantial funding will be required to realise it. The IT estate across the NHS is outdated and a lack of interoperability within secondary care and between primary and secondary care can be partly ascribed to historic predatory practices on the part of IT system suppliers who have provided software without the means to make it interoperable 'by default', in some cases charging extra for this functionality or else not offering it at all. The strategy makes a point of emphasising the need for NHS providers to procure software in line with standards to be mandated by the Secretary of State, however as long as suppliers are free to sell software that does not meet these standards, providers risk falling short of such standards. Historically market forces have not driven software suppliers to improve their offer due to the market dominance they already enjoy and the fact that funding for IT has not been prioritised, leaving little scope for buyers to shop around.*
- *In a 2018 survey[3], the BMA found the following:*

  - Almost a quarter (22%) of respondents believe that IT systems at their place of work are not fit for purpose – specifically the electronic medical record (57%) and current operating systems (55%).
  - Over half (56%) also reported that the current IT infrastructure significantly increases their day to day workload.
  - One third (32%) believe that they rarely have all the necessary IT equipment to perform their job to the best of their abilities without disruption. This includes printers, computers/laptops, monitors, smartphones, tablets, Wi-Fi & broadband, with adequate speed and coverage, and scanners.
  - Just over a third (37%) reported that their stress levels are affected significantly because of inefficient IT and data sharing systems.

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[3] *Technology, Data and Infrastructure supporting NHS Staff*, BMA, p. 4

- Over a quarter (27%) lose more than four hours a week because of inefficient hardware/systems – if this were the case for one in four doctors working across the NHS, including foundation doctors and specialty trainees, which is currently 156,750 doctors, this would amount to at least 156,750 medical hours lost every week or indeed 8,150,000 a year. This equates to approximately 4,870 full-time equivalent doctors working 37.5 hours a week over a calendar year (including leave and public holidays). The impact on other NHS staff may be similar.
- Survey respondents were asked what they thought were the barriers to good IT in healthcare - around three quarters (74%) stated that there were too many different systems in use, approximately two thirds (63%) said that both software and hardware was outdated.

- *There is widespread support within the profession for prioritisation of IT infrastructure and the sentiment in this chapter is encouraging, however, the onus falls too squarely on the NHS with little indication given of what the Secretary of State will do to address supplier side issues.*

Section comments/commitments

- *We are broadly supportive of the majority of measures in this section, with detail on a number of specific commitments outlined below.*

'map the technical debt for national systems, and prioritise what must be addressed and completed through relevant programmes of work'

- *The BMA has called for a similar exercise in successive spending review and budget submissions. If the intention is to both map the debt and cost the 'clearing' of that debt, then the BMA is fully supportive. However it is important that the funding required be provided to enable organisations who have fallen behind with the means to catch up, including funding to buy providers and practices out of exploitative multi-year contracts with software suppliers who do not meet information standards applied to the NHS.*

'Separate the data layer from the application layer'

- *We support this move but recognise that substantial support will be required for NHS organisations to make it happen.*

'we will develop and publish the standards and interoperability strategy to get fit-for-purpose standards widely adopted across health and adult social care'
and
'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 (for whatever purpose), it is in a standard form, both readable by and consistently meaningful to the user or recipient'

- *As previously specified, standards to enable interoperability must be built into any software sold to the NHS by default and at no additional cost. Where NHS organisation build their own*

software, they should do so in accordance with standards to enable interoperability. It is important that the strategy acknowledges the fact that not all software sold to the NHS has the functionality required for NHS organisation to comply with standards set by the centre.

Chapter 7 – Helping developers and innovators to improve health and care

Vision - 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.

- *We support the delivery of new solutions for data management within the health sector and recognise many of these come from outside the NHS, however a clearer commitment to foster more internal innovation would be welcome. Whilst the strategy does not specify that 'developers and innovators' does not include NHS employed staff, an emphasis on the role they can play within their employer, system and ultimately the whole service should be made to encourage and demonstrate support for NHS-derived innovation.*

Section comments/commitments

'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'

- *The digital playbook should go further, mandating how software supplied to the NHS should be developed to meet any standards set out by the secretary of state.*

'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'

- *The involvement of clinical representation within this service is essential and clarity on the scope, scale and powers that this service will have would be welcome.*