



NHS data: Maximising its impact on the health and wealth of the United Kingdom

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A total of **26 one-to-one interviews** were held with individuals with a strong interest in this topic. Interviewees included representatives from government, the NHS, academia, industry (technology and life sciences), research institutions, charities and data privacy organisations. We have not consulted the public or healthcare professionals for the purposes of this paper, as we chose to focus on experts in the data policy and governance space. Part of the rationale of the paper is to understand which issues should be explored with the public and how to do so.

In addition to the interviews, a **half-day workshop** was held with the same individuals to share insights from the interviews and to explore each topic in group discussion (the people marked with * above attended the workshop). Questions covered during the interviews and the workshop included the following (as the main headings):

- What are the key domains of action that the UK needs to take to maximise the value of its health data, whether that is for better individual direct care, better healthcare delivery in the NHS, or better R&D?
- How would you begin to value the potential of NHS data?
- What investment is needed at national level? How do we realise the potential of this investment?
- What needs to be done to ensure public trust?
- What regulatory frameworks are required (e.g., legal, compliance, security)?

Foreword

The UK is the best placed large economy in the world to use its health data assets for transformative health, scientific and economic impact. Good progress is being made and all levels of society – including the Government, the NHS, academia, charities and industry – are committed to this agenda. However, there is a risk that this is being done in a piecemeal way. No single organisation is unequivocally tasked with leading the way, and the endeavour has lacked a comprehensive strategy.

Our vision is to provide the public with better, more efficient care, driven by responsible innovation that is underpinned by the UK's extensive health data. Our goal in creating this paper, therefore, is to fill that gap by proposing a single overarching framework to guide the proper use of the UK's health data assets. We have tried to answer some of the essential questions this enterprise poses but acknowledge that there are many questions that need further research and inquiry. Our main message is this: the goal of any strategy must be to deliver benefits to people in the UK, and specifically to the NHS. Benefits to other parties will come as a corollary and are important considerations for the strategy.

To achieve the greatest benefit for British citizens and patients, it is essential to adhere to three main principles:

1. Patients must feel a sense of agency and control over what happens to their data;
2. Health data must always be used in a way that is safe, secure, legal and ethical; and
3. There must be a concerted effort to fairly distribute benefits to people across the UK.

We believe these are the *sine qua non* of a successful UK health data strategy. Get it right, and we can generate enormous value for patients, clinicians, taxpayers and the economy. Get it wrong, and the public will withdraw their support. By following our proposals, the NHS can remain the most trusted institution in the UK while maximising the extraordinary potential of its data assets.

We hope that this paper acts as a catalyst and framework for a much-needed national conversation on how the UK's health data can be best used to improve the health and wealth of the entire nation. Following on from this, we need to generate additional evidence through a series of work programmes involving academics, policy makers, industry, NHS leaders and most of all the public. The Institute of Global Health Innovation intends to actively contribute to these efforts in the years ahead. These insights will enable the UK to make the most of its advantages, with concomitant benefits for patients, the NHS, the R&D community and the innovation economy. We hope that this work will not only resonate in the UK, but also help governments and health systems internationally to implement strategies to maximise the benefits of health data for their citizens.

We would like to thank the many outstanding contributors who have given their time and energy so generously to this work. We look forward to their continued contribution as we move forward.



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Executive summary

The NHS occupies a special place in the psyche of the British nation. It is one of our most treasured institutions, and while trust in other parts of the national infrastructure has fallen, the public still overwhelmingly believes in the purpose and benefits of our health service. Among its many strengths is the NHS's ability to bring together a comprehensive, longitudinal dataset for 65 million people in the UK. **In a world where big data has increasing value, the UK has an opportunity to leverage its health data assets to benefit people in the UK and across the world** – both through better health and through the generation of more research and development and economic growth.

Ensuring that we maximise the benefits of this opportunity is non-negotiable. The UK, like most developed nations, faces significant long-term challenges in healthcare, both from an ageing population – the number of people aged 85 or older in the UK will double in the next ten years – and the growing cost of new kinds of precision medicine. Using health data to improve the quality and efficiency of care delivery, and give new therapeutic insights to the research

community, offers the best hope of turning the tide on the rising cost of healthcare. Further, there will be a premium for the country that cements its position at the head of the pack.

The Government is well aware of the scale and urgency of the opportunity, and in the last 15 years it has undertaken some important initiatives to improve the breadth, depth and quality of the UK's health data assets. These include the creation of the UK Biobank and multiple disease registries, especially in the field of cancer care, and the Global Digital Exemplars programme in hospitals. The key ambition is to keep the UK at the forefront of world class research.

To take advantage of this increasingly rich data environment, a number of organisations – including NHS Digital, HDR-UK and Genomics England – have been created to both improve curation and provide greater access to data for research purposes. The current Secretary of State for Health and Social Care has created a new body, NHSX, to provide the overall strategic direction for efforts to digitise healthcare, with

concomitant benefits for the UK's health data assets. Further, organisations such as the Academic Health Sciences Networks (AHSNs) and the Accelerate Access Collaborative (AAC) aim to drive the adoption and spread of products, services and businesses that can improve care within the NHS and elsewhere. These efforts, and related initiatives in Northern Ireland, Scotland and Wales, combine to enable **an ecosystem in the UK that promotes the development of solutions and technologies within the NHS and in close collaboration with partners** from academia, life sciences and the technology industry.

It is important, however, to be realistic about the challenges that remain. The NHS is the most trusted organisation in the UK when it comes to looking after confidential personal information; yet a previous attempt to corral the UK's health data for research purposes through the Care Data programme experienced significant problems and had to be curtailed. Furthermore, the salience of data issues among the general public is rising, as is scepticism about the use of such data by private sector organisations. Proving that NHS and other health data are being used to benefit the wider public is critical to retaining trust in this endeavour.

There remains some confusion about who is responsible for overseeing the UK's emerging health data strategy. Any strategy must not only cover separate NHSs in each of the four home nations, but also include a number of organisations – some of which are listed above – that are involved in setting policy. There also remains confusion around which organisation is ultimately responsible for developing and delivering the vision for maximising the potential value of NHS data for people in the UK. Important first steps and shared learning have been made by the UK Health Data Research Alliance, but this remains a major challenge. It needs to involve senior decision-makers across government and especially the NHS, united behind an official narrative that all stakeholders – including the public, clinicians, the NHS, government, academia, charities, and the life sciences and technology industries – can support. In an encouraging sign, NHSX has committed to develop a National

Centre of Expertise to focus on this topic and is developing a full programme of work for 2020. This organisation should have a mandate to create the conditions to deliver the vision, such as appropriate levels of government investment and clarity on challenges regarding data protection and patient confidentiality.

It is equally important to make sure that the governance of the UK's health data policy properly reflects the views of patients, their families and NHS staff. Efforts to involve the public in the conversation regarding what constitutes acceptable uses of their health data have been piecemeal. This lack of transparency fuels suspicion of the NHS – one of the most trusted institutions in the UK – and damages public trust. Certain aspects of how health data can be processed remain in a legal “grey area”, particularly with regard to secondary uses of health data (the use of data beyond the reason it was originally collected, such as secondary research). The NHS also lacks the capacity – for example, data scientists and engineers, clinical informatics experts – to combine, clean and package data at scale to the point where it is useful and of most value.

We need a national conversation with locally delivered engagement involving all stakeholders to address these issues, as this topic is too important to solely involve senior government and NHS leaders. First and most critically, we must seek input from both the public and from clinicians – as trusted guardians – regarding what they believe to be acceptable uses of health data, and this must be done on an ongoing basis. This public involvement should build on excellent local efforts such as the “citizen juries” by Connected Health Cities and Understanding Patient Data and the engagement efforts of the HDR UK Public Advisory Board and OneLondon programme. These should be combined with a national communications strategy regarding the use of health data in partnership with the Association of Medical Research Charities (AMRC). We must be much more transparent about current uses. We need a dialogue to ensure people's views and concerns are reflected in decisions about which uses of data, and benefits generated from these,

are acceptable or not. This is sure to require an investment in the tens of millions over the coming years.

Finally, to maximise the potential of NHS data assets to improve the health and wealth of the nation, the Government needs to make a substantial upfront investment, many multiples greater than what we currently see and estimated to be billions of pounds. As a starting point, all health data must be digitised. Data quality must improve dramatically and so must be refined or “curated” at scale to maximise the benefits for people in the UK. This requires a huge amount of investment to enable machine-readable data to be collected at source; provide technological infrastructure required for storage, manipulation and linking, ensure mainstream medical staff are appropriately skilled; and attract and retain the necessary data science and engineering capability. On its own, this investment should more than deliver a return for the UK population in terms of clinical benefit and improved service delivery. There is a significant question about who should provide this investment. The case for public funding is strong, but there may also be a role for the “right” kind of private money targeted at specific projects that require additional financial support; this needs to be explored further.

An additional consequence of this investment will be a dataset that is more attractive for academia and the life sciences and technology industries to license and use, facilitating the creation of technologies that will directly benefit people in the UK. The resulting economic growth and job creation is likely to generate billions of pounds for the UK economy. **It is imperative that we create the right mechanisms for technology and science to thrive, and equally important to make sure that the NHS realises fair value from the data or capability that is contributed.** We must also make sure that the benefits are shared across the UK, and not simply in those areas that are already doing well.

In doing so, **it is essential to engage with the public on a continual basis to understand what arrangements are acceptable to them.** This should include an explanation of what “health

data” includes and an open debate on specific uses of health data, the kinds of organisations with which the NHS should collaborate, and the role each should play. It should also include the principles that organisations should adhere to around transparency, accountability and fairness in data use. This paper puts forward a value-sharing framework that lays out a number of arrangements the NHS can explore and the risks and benefits of each. This includes arrangements such as revenue- and equity-sharing, or one-off payments for data licenses (where appropriate).

The purpose of this document is to create a first step towards establishing a vision, strategic framework and underlying principles to underpin how health data should be used to improve patient care. We need to agree: the areas of action needed to maximise the value of NHS data; the current situation and existing barriers for each of these areas; recommendations to explore further; and outstanding questions that should be resolved using evidence-based research. Answering these questions will be the focus of the next stage of our work.

Introduction: Maximising the impact of the UK's health data

OPPORTUNITY

While the NHS is considered one of the best health systems in the world, there is still room for improvement in UK health outcomes.¹

Achieving a step-change in the nation's health outcomes requires a broad range of measures including, but not limited to, more spending. One of the opportunities open to the NHS is to use data-driven solutions and technologies to improve direct care, make the delivery of care more efficient and promote the development of new therapies.

In healthcare, huge amounts of data are collected, but the potential benefits they could deliver have not been fully realised. If used effectively and appropriately, health data can generate huge value for people in the UK. These benefits can be categorised as follows:

- **Health and social value (primary goal):** Provide benefits to patients and to the public by using data to improve preventive measures and enable better, faster, more cost-effective provision of care. For example, by enabling patients to access their health records to improve care delivery or by accelerating development of drugs.
- **Economic value:** Create jobs and economic growth by enabling the life sciences and technology industries to develop data-driven solutions, technologies and therapeutic interventions that directly benefit people in the UK.
- **Financial value:** Provide direct financial flows for the NHS through appropriate licensing and value-sharing arrangements with the right partners.

The UK is well placed to capture the opportunity of using the data to prevent disease and improve how we deliver health and social care services. This is because the NHS, as a single-

payer system under a common legal framework, could create a single longitudinal dataset for a large and diverse population. In addition, other complementary strengths include:

- A health service that is the most trusted institution in the UK;
- A strong record of innovation in health and life sciences and a vibrant technology industry;
- World leading research universities and other research assets;
- The strategic importance of R&D investment for the Government, especially in the life sciences;
- A stable, balanced and well-respected legal and regulatory system.

Numerous efforts to deliver benefits for people in the UK through the use of health data are already under way and can be built upon:

- **NHSX**, with investment of more than £1 billion per year, is responsible for setting national policy for NHS technology, digital and data (including data-sharing and transparency).² Of note, NHSX have recently announced a £250 million investment to create the **NHS Artificial Intelligence Lab** in collaboration with the Accelerated Access Collaborative (AAC).³
- **NHS Digital**, with a budget of around £500 million per year, designs, builds and operates the core national infrastructure, platforms and applications on which the NHS and social care system relies. An example of their recent work is the **NHS App**, that allows patients to manage GP appointments, order repeat prescriptions and view their records.⁴
- **Health Data Research UK** is an independent, non-profit organisation

bringing together 22 research institutes across the UK, which has in turn funded **seven Digital Innovation Hubs**, through the Industrial Strategy Challenge Fund (ISCF), to enable a UK-wide life sciences ecosystem that provides responsible and safe access to health data, technology and science, research and innovation services.

- **Genomics England** has been allocated more than £250 million for the introduction of whole genome sequencing in the NHS, including towards projects such as the **100,000 Genomes Project** that enables research into treatments for rare diseases and common cancers.⁵
- **UK Biobank**, established by the Wellcome Trust and partially funded by the Government, aims to improve the prevention, diagnosis and treatment of a wide range of serious and life-threatening illnesses.

CHALLENGES

While well positioned to take advantage of the opportunities generated by health data, the UK and the NHS also face significant challenges.

What we call “NHS data” is in reality a very diverse set of datasets, with varying value and utility. Electronic health records, where they exist, while useful to support clinical practice, provide largely unstructured data that is often difficult to link to other care settings. Data from pathology (e.g., blood test results), radiology (e.g., mammogram images), and molecular studies (e.g., genome sequencing) are already showing significant promise, for example helping identify new targets for a drug therapy. Datasets like Hospital Episode Statistics (HES) can be useful to inform population health analyses and the allocation of resources across health and social care services. However, joining these varied data together into clean, curated and useful forms is not straightforward.

Estimating the value of and potential benefits from the data is very difficult, which makes the development of robust business cases and the negotiation of fair value sharing agreements a big challenge. This is a common

problem with intangible assets. While valuation methodologies exist and have been recently used by the Government,⁶ their applicability to the NHS context needs further development.

While progress has been made, the UK still lacks a clear strategy to maximise the impact of health data. Such a strategy will need to be underpinned by a clear framework that robustly addresses questions of privacy, ethics, security and what value is provided to the NHS in the sharing of these data.

Public involvement in the use of their health data has been piecemeal and inconsistent, and past efforts have attracted criticism. Both the NHS Connecting for Health Agency (responsible for delivering the National Programme for IT) and Care.Data received widespread criticism for issues such as a lack of clear objectives, data security and failure to deliver clinical benefit.^{7,8}

Data quality needs to improve dramatically. There is wide variation in data quality across the NHS, as data is captured across a huge number of systems with bespoke data structures and a significant number of hospital records are still paper-based. Machine-readable data needs to be collected to improve both direct clinical care and R&D. Legacy infrastructure and tools are also hindering attempts to move to the cloud.⁹

The NHS currently lacks the capacity to curate data at scale. It requires data science and engineering talent on a very large scale. The NHS needs to invest in people – including the doctors and nurses providing everyday care, as identified in the Topol Review – and talent to ensure the system has an appropriate workforce of skilled experts and form ambitious partnerships with the most innovative technology vendors to leverage the best cross-industry expertise in data management.

We currently lack the investment to make this happen. This investment is required to attract and retain talent, provide education and training, upgrade data infrastructure, and improve data quality.⁹

While there are a number of NHS organisations with differing accountabilities with regard to NHS data, **it is unclear which organisation**

would be responsible for developing the UK's strategy to maximise the impact of health data and overseeing its delivery. This needs to be addressed urgently. A single organisation should be accountable for developing and delivering a vision, co-produced with the public and with key stakeholders in the system.

Finally, while the UK has an opportunity to be the global leader in this area, **other countries have made notable achievements and could leapfrog the UK.** Some notable efforts are summarised in the exhibit.

BASIC PRINCIPLES

In recent years, a number of organisations have proposed principles that should guide the appropriate use of NHS data. These include those currently being drafted by Health Data Research UK and those published in the Life Sciences Sector 2 Deal and the DHSC's Code of Conduct for Data-Driven Technologies. The following principles, based on previous efforts, are most relevant for the purposes of this paper:

- **Ensure any use of NHS data aims to improve the health, welfare and/or care of patients in the NHS, or the operation of the NHS.** This may include the discovery of new treatments, diagnostics, and other scientific breakthroughs, as well as additional wider benefits.⁴⁶
- **Demonstrate active and ongoing engagement with patients and the public** in the design, development and governance of their activities involving health data to provide assurance that these activities are in the public interest.
- **Encourage the availability and use of data for research and innovation that serves public interest,** by making data Findable, Accessible, Interoperable and Reusable by adopting the FAIR Guiding principles for scientific data management and stewardship.⁴⁷
- **Ensure arrangements agreed by NHS organisations are transparent** and clearly communicated in order to support public trust and confidence in the NHS and wider government data policies.

- **Ensure arrangements entered into by NHS organisations agree fair terms for their organisation and for the NHS as a whole.** In particular, the boards of NHS organisations should consider themselves ultimately responsible for ensuring that any arrangements entered into by their organisation are fair, including recognising and safeguarding the value of the data that is shared and the resources that are generated as a result of the arrangement.⁴⁶
- **Ensure arrangements agreed by NHS organisations fully adhere to all applicable national level legal, regulatory, privacy and security obligations,** including in respect of the National Data Guardian's Data Security Standards, the General Data Protection Regulation (GDPR) and the Common Law Duty of Confidentiality.⁴⁶

AREAS OF ACTION

Through our research, we have identified six areas of action to maximise the impact of NHS data on the health and wealth of the United Kingdom:

1. Public opinion and engagement
2. Data governance and legal frameworks
3. Data quality and infrastructure
4. Capabilities
5. Investment
6. Value sharing

For each area, we have described the current state (including successes and challenges) and put forward recommendations to explore further.

Exhibit 1: Learning from other countries

US: Digital health companies have attracted significant investment through venture capital, with analytics and big data companies attracting almost \$2 billion of funding by Q3 of 2019.⁴⁵ In the public sector, the Government has allocated close to \$2 billion in funding to precision medicine initiative *All of US*. This research programme is engaging 1,000,000 volunteers of all life stages, health statuses, races and ethnicities, and geographic regions, using data from electronic health records, bio specimens, physical evaluations, sensors, and other technologies.⁴²

ESTONIA: Estonia has been an early adopter of using digital technologies across the public sector, and each citizen has access to their own health record, which is linked by a unique citizen identifier.⁴⁰ Datasets are linked, and all interactions are logged and visible to the patient through blockchain technology.

CHINA: China has significantly boosted its investment in big data and advanced analytics. For example, an investment of 60 billion yuan (£6.7 billion) is funding the China Precision Medicine Initiative in a bid to sequence 100,000,000 genomes by 2030.⁴²

FRANCE: The French Government has recently mandated the creation of a 'Health Data Hub' which is aimed at boosting and facilitating the use of health data for research by public and private entities, with the ambition of making France a global leader in the innovative uses of health data.⁴³

ISRAEL: The Government has invested almost \$300 million to create a national unified dataset that will take millions of individual patients' information and help collect and curate it in a uniform manner to maximise its utility.⁴⁴

AUSTRALIA: The Government allocated \$374.2 million in 2017 towards a digital health record to which every Australian would have access ("My Health Record"). Following an opt-out period in 2019, approximately 90% of the population have access to a digital health record.⁴¹ While data available through My Health Record is somewhat limited, the underlying policy and infrastructure changes are in place.

1. Public opinion and engagement

SUMMARY:

- The NHS is one of the most trusted institutions in the UK and this trust has been built over decades.
- Work has been done to understand what people in the UK think about health data use but a much more detailed understanding is needed.
- There is limited understanding of opinions across demographic and socio-economic groups.
- As trusted guardians in the NHS, there needs to be more proactive engagement with clinicians and other front-line staff on this topic.
- Citizens have not been involved in setting the rules and principles by which decisions about data use are made.

The NHS is one of the most trusted institutions in the United Kingdom, with a recent survey by the Open Data Institute reporting that the majority of respondents were confident that the NHS would use their data ethically. This research also showed that people are more likely to share personal data with the NHS than any other UK organisation and that satisfaction with the NHS compared favourably with the opinions of other similar European countries.^{18, 19} This trust has been built over decades and underscores the importance of public engagement and support for the success of any effort that involves the use of health data.

A detailed understanding of what the public thinks about data being used and shared is critical to the effort to maximise the impact of health data. We know that people in the

UK generally accept the use of health data for provision of individual care and are open to some secondary uses of data by the NHS, for example, the use of properly anonymous patient data where there is a clear public benefit (e.g., research).^{20, 21} On the other hand, people tend to be against sharing health data where it is perceived to solely benefit the private sector, where health inequalities may be exacerbated or where data-sharing may distract from delivering quality patient care.

Our understanding of the public's view on sharing data with commercial organisations is improving, but there is more work to be done. Wellcome Trust surveys show a decline in support for "Health data being accessed by commercial organisations if they are undertaking health research" (53% in 2016



vs. 39% in 2018).^{22,23} A recent workshop showed that people are more likely to accept anonymised patient data being shared with industry when the NHS receives a benefit *and* when the NHS is involved in the development of the resulting data-driven solution. Participants were also more likely to accept data being shared with industry after being “exposed to information and discussion about particular ways that commercial organisations might be involved in developing healthcare products and services” (18% vs. 45%).²⁴ Similarly, deliberative research in Scotland in 2013 suggested consensus was that private sector access to personal data should only be granted where this is likely to result in some form of public benefit.²⁴ Specific concerns have been raised about access to data by insurance companies, leading to coverage being denied or premiums being more expensive. Some legislation already exists to prevent this, such as the *Code on Genetic Testing and Insurance*, which forbids insurance companies asking for or taking into account the result of a predictive genetic test.²⁵ Legislative mechanisms such as this can be used to protect against other perceived and real risks.

Aside from understanding acceptable uses of health data, it will be important to more deeply understand the trade-offs citizens are prepared to make between sharing data for clinical or other benefits and the risks in terms of potential loss of privacy. The benefits from the use of health data for individual direct care and for certain secondary purposes are clear (e.g., to inform a patient’s course of treatment, or for research to yield new treatments). However, benefits from other secondary uses, such as for service planning, can be less obvious, creating a challenge when engaging with the public. Some benefits from secondary uses of data may not accrue despite the best efforts from parties involved. For example, attempts to develop new interventions using NHS data might be unsuccessful. We need to better understand the public’s view of these trade-offs even at the risk of limiting the uses to which these data can be put.

We still don’t know what large segments of the UK population think about health data usage and sharing. More engagement and research

are required to understand the views of people that are underrepresented in existing studies, including people from the devolved nations of the UK, from rural areas, from Black, Asian & Minority ethnic groups (BAME) and of lower socio-economic status.

We also need to consider the thoughts and attitudes of clinicians and other front-line NHS staff. In the past, their objections were a significant factor in the failure of programmes such as Care.Data. The Wachter Review (2016) recommended a long-term national engagement strategy to obtain buy-in from leaders of NHS trusts (e.g., Chief Clinical Information Officers, CCIOs) and clinicians, and to engage and listen to front-line workers. The review also recommended the campaign focus on meeting the needs of “patients, their families, healthcare professionals and the entire nation”, not simply cost savings.²⁶

It is not enough to understand and take into account public attitudes. Citizens must be actively involved in setting the rules and principles by which decisions about data use are made. This shouldn’t be a one-off exercise but embedded into governance. In addition to involving citizens, there is a clear opportunity to be proactive about how information regarding the use of health data is relayed to the public. For example, we can make better use of real-world examples where people in the UK have benefited from data-driven solutions, and we can provide ongoing transparency on the organisations that are involved and the role they will play. For example, in Scotland the Public Benefit and Privacy Panel is a publicly-convened panel that streamlines governance processes for the scrutiny of requests for access to NHS Scotland originated data to benefit the citizens of Scotland for purposes other than direct care.²⁷

Efforts to engage with the public are complicated by the fact that the words used to describe patient data and its uses can be confusing, as evidenced by research commissioned by Understanding Patient Data who have published their own guidance on terminology.^{28,29} Terms such as “anonymised” and “consent” can have different meanings in different contexts.

RECOMMENDATIONS:

1. Better engage with citizens and NHS staff on the topic of health data. There are a number of ways that we can promote the sense that this is something done *with* people in the UK, not something done *to* them. For example:

- a. Understand which data licensing and value-sharing models are the most appropriate/ethical, building on existing regional initiatives.
- b. Involve citizens or citizen bodies in decisions regarding the use of health data, for example, through public representation on decision-making boards.
- c. Engage early with NHS staff, including senior trust leaders (e.g., CCIOs) and clinicians to understand their opinions and concerns.
- d. Ensure we understand the attitudes and concerns of all segments of the UK population.
- e. Ensure that these efforts are all brought together to form a more cohesive narrative.

2. Use what we already know combined with what we can learn through better public engagement to develop and implement a communications strategy led by the NHS on the use of health data, prioritising communications that foster trust, not just information transfer. For example:

- a. Describe tangible benefits for citizens using real world examples.
- b. Develop a communications strategy for mass and social media, including an approach to tackling misinformation.
- c. Communicate more clearly how health data is used, by which organisations and for what kinds of projects. For example, by improving the visibility and usability of NHS Digital’s register of approved data releases and as part of the UK Health Data Research Alliance Innovation Gateway.³⁰
- d. Train NHS staff to involve patients in decisions about how their health data can be used. NHS staff should be aware of resources outlining best practice use of health data and, where appropriate, how and when to seek consent for secondary uses of health data.

2. Data governance and legal frameworks

SUMMARY:

- Data governance standards in the NHS have been significantly improved in the past ten years thanks to efforts such as the National Data Guardian.
- However, the legal framework governing the use of personal data in healthcare remains complex and creates a number of legal and societal challenges.
- Some exemptions that provide a legal basis to process personal data are unclear, and there is a risk of such exemptions being perceived as “loopholes”.
- Exemptions regarding data processing for “reasons of public interest in public health” and “scientific research purposes” both require a basis in UK or EU law.

The standards for data governance in the NHS have been significantly developed in the past ten years – thanks in part to the creation of the National Data Guardian (NDG) role, held by Dame Fiona Caldicott – and introduced to ensure that the health data of patients and the public is safeguarded. To improve the security of healthcare data, the NDG recommended ten data security standards for all healthcare organisations to implement. This resulted in the Data Security and Protection Toolkit (DSPT), requiring all organisations that have access to NHS patient data to use this online self-assessment tool to demonstrate their capability in implementing the security standards.³¹

The legal framework governing the use of personal confidential data in healthcare is complex and, in some instances, unclear. It includes the NHS Act (2006), the Health and Social Care Act (2012), and the Data Protection Act (DPA, 2018). The Data Protection Act 2018 is the UK’s implementation of the General Data Protection Regulation (GDPR). Legislation in the DPA is covered by the Information Commissioner’s Office (ICO), the

UK’s independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals.

While it might be possible to perform research using anonymised data, often the anonymisation removes some, or a significant part, of the value of that data. Many uses of health data involve mining big datasets to obtain insights, whether regarding public health more widely or in respect of specific diseases, targets, drug discovery or drug development. For example, it is often necessary to know if a disease outbreak is more prevalent in men or women, of a particular age range, in a particular geographic area, or with particular socio-economic considerations. However, retaining these identifiers increases the likelihood that this data is deemed to be merely ‘pseudonymised’ rather than ‘anonymised’ meaning that GDPR will apply to its use. The deployment of more complex privacy-enhancing technologies is necessary to enable sophisticated data obfuscation, amongst other things.

GDPR requires a legal basis to exist in order to permit the processing of personal data. In addition, it **prohibits the processing of “special categories” of personal data** (including data concerning health, as well as genetic and biometric data) **unless a specific exemption applies.**³² Such exemptions include where:

1. **Explicit consent has been given by the data subject** to processing for one or more specified purposes;
2. **Processing is necessary for medical diagnosis, the provision of health or social care or treatment** or the management of health or social care systems and services; or
3. **Processing is necessary to protect the vital interests of the data subject or another person** where the data subject is physically or legally incapable of giving consent;
4. **Processing is necessary for reasons of public interest in public health**, such as protecting against serious cross-border threats to health on the basis of EU/UK laws (provided there are suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy);
5. **Processing is necessary for scientific research purposes** based on EU/UK laws (which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject).

This legal framework may create a number of legal and societal challenges. Exemptions 2 and 3 are drawn narrowly and therefore may only apply in very limited circumstances. As such, it is likely that the most applicable exemptions for secondary uses of health data are 1, 4 and 5 above. However, it may be difficult to rely on Exemption 1 (consent) for a number of reasons, including difficulties obtaining consent at the time of collection for secondary (potentially then unknown) uses of data, the extent to which consent is able to be freely given (as required under GDPR) if the data use relates

to research into a medical condition the data subject suffers from, as well as the impact of the related right for a data subject to withdraw consent and request erasure of the data.

Consequently, there will likely be an increased reliance on the other statutory exemptions listed rather than consent, which in turn may be subject to public challenge as exemptions may be perceived as “loopholes” for using personal data. Additional laws regarding the confidentiality of patient medical records and the sharing of identifiable patient medical records will also need to be navigated (for example, implied consent to sharing only if the sharing is for the purposes of ongoing treatment).

The final two exemptions regarding data processing for reasons of public interest in public health and scientific research both require a basis in UK or EU laws. Notably, the ICO has recently stated that this legal basis for data processing is provided by the Data Protection Act 2018 itself. This appears to differ from the position taken in the EU, which has tended to look to other legislation as the legal basis for permitting data processing for research purposes. For example, in early 2019 the European Data Protection Board considered whether the Clinical Trials Regulation could be an appropriate legal basis for permitting processing of special category data under the public interest or scientific research exemptions.³³ The European Data Protection Supervisor (EDPS) also notes in its preliminary opinion on data protection and scientific research³⁴ that Exemption 5 above is “*a new area and requires adoption of EU or member state law before the use of special categories of data for research purposes can be fully operational*”, and that “*[the exemption] in principle provides for processing of special categories of data for scientific research but only on the basis of EU or member state law. However, such laws have yet to be adopted.*”

If this type of systematic data commercialisation is adopted, further consideration will be needed to ensure the NHS can comply with its obligations as a data controller generally. These include duties around data subjects’ right of access,

rectification, restriction and objection under GDPR, which may only be derogated from in a scientific research context if certain conditions are met. Compliance with data subjects right to information (or the relevant exemption to that right) will also need to be considered. Ensuring such compliance might be costly from a technical and legal perspective, however the potential sanctions if the NHS fails to do so are also significant (up to €20m or 4% of global turnover, whichever is higher).

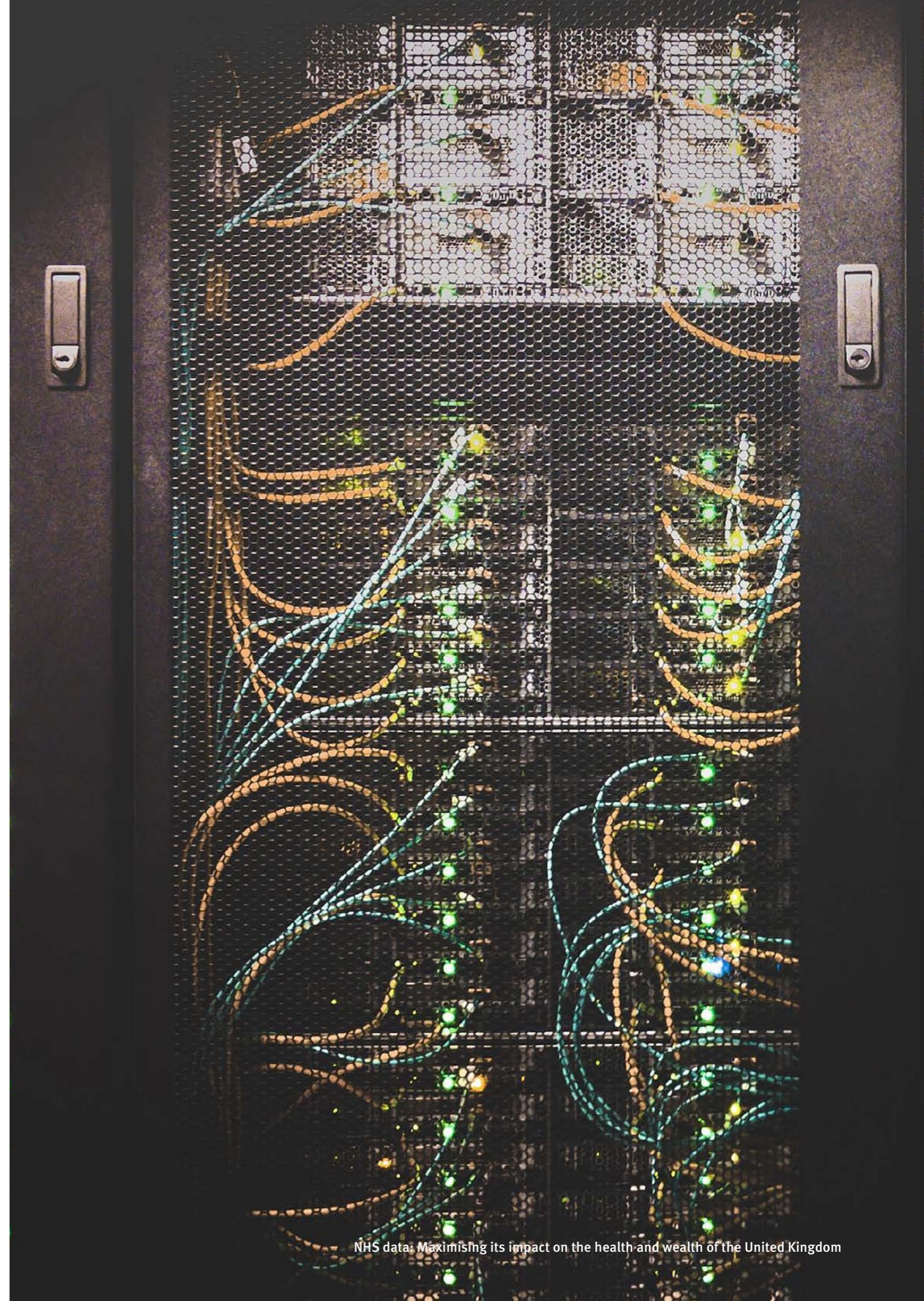
Some forms of non-personal health data are already available to the public and not subject to GDPR. This includes anonymised aggregated information created by the government, for example, the evidence-based information on common health conditions on the NHS website.

This includes potential causes and treatments for a huge range of health problems such as back pain, bladder cancer and even bedbugs.³⁵ This is one of many useful public resources that is freely available under what is called the Open Government License (OGL) for public sector information. The OGL allows anyone to copy, publish, distribute, adapt and to “exploit the Information commercially and non-commercially”. However, where any of the above is done, the user must “acknowledge the source of the Information in your product or application by including or linking to any attribution statement specified by the Information Provider(s)”.³⁶ Further, this information is meant to be made available under the same terms to everyone, as governed by the Re-Use of Public Sector Information Regulations 2015.³⁷

RECOMMENDATIONS:

Clarify the legal frameworks relevant to health data usage and sharing by seeking guidance from the ICO on:

- 1. Discrepancies and misunderstandings as envisaged by the EDPS** on a pan-EU level, by increasing dialogue with the research community.
- 2. Data usage and data-sharing in healthcare, for both primary and secondary uses.** This could be done in conjunction with the National Data Guardian and NHSX and should involve industry, academia and research institutions. Notably, the EDPS has suggested EU codes of conduct and certifications in respect of a variety of matters requiring clarification.
- 3. The extent to which a new legal basis for processing is required where the purpose of subsequent processing is compatible with the purpose of the original processing.** For example, if data is initially collected and processed for the purposes of a specific clinical trial and the data controller wishes to reuse that data for other scientific research,
- would the data controller need to identify a new and separate legal basis for the processing of that data if it is compatible with the purpose of the original processing?
- 4. The scope of the “public interest in the area of public health” exemption** in Data Protection Act 2018, Schedule 1, Part 1. Likewise, clarity on the scope of Exemption 4 above when it is relied on in conjunction with the legal basis of processing special category data for the performance of a task carried out in the public interest (Article 6(1)(e) of the GDPR), would be welcomed and has been suggested by the European Data Protection Supervisor.
- 5. The DHSC should instruct the ICO to provide this guidance** as soon as possible, and fund it to do so.



3. Data quality, standards and infrastructure

SUMMARY:

- Outside of primary care, there is a marked difference in data quality, standard adherence and interpretation, and infrastructure.
- Data often requires significant effort to be post-processed, as accurate data are very often not captured real-time.
- Legacy technology and infrastructure are delaying the ability to move to the cloud, further holding data quality back.
- In recent years there have been positive efforts to improve data quality and define standards, such as through the NHS Digital's Data Quality Maturity Index.
- Across the NHS, there are examples where data curation is being done well, for example, NHS Digital's Hospital Episode Statistics (HES), the Clinical Practice Research Datalink's (CPRD) primary care data and the SAIL databank in Wales.

DATA SYSTEMS

Data systems and infrastructure have evolved to varying degrees across the NHS. In primary care, practice management software has been in use since the early 90s.³⁸ The majority of hospitals and secondary care providers, however, remained paper-based until the start of the 21st century. In the past two decades, a multitude of policy and technology changes resulted in a complex ecosystem of electronic health records (EHRs).³⁹

Today all GP settings are digitised, and there is a route to convergence on standardised data for all GP systems. The GP IT Futures programme in England and similar programmes in the devolved administrations are helping to reform the commercial landscape in primary care and to enable a move to open, modern, cloud native architectures with consistent technical and data standards.⁴⁰ Nevertheless, local GP usage and data structure remain varied, existing proprietary IT system providers are resistant to moving towards open standards and Clinical Commissioning Groups (CCGs) must employ staff and still use Commissioning Support Unit (CSU) resources to clean data for returns purposes.

Outside of primary care there is large diversity in clinical systems, data quality, IT investment, timeliness of data and interoperability of systems. While all providers have a patient administration system, a recent survey showed approximately 23% of patient records in acute hospitals are entirely paper-based, and there was limited regional alignment of the systems used to process and store these records. Of the 117 trusts using electronic records, the vast majority (79%) employed one of 21 different commercially available systems, and 10% were using multiple different EHRs within the same hospital. However, of those that used a single system, almost half (42%) were using one of three identified systems. Making these three systems interoperable would improve access to information for more than one million hospital encounters every year, with international as well as national benefit, where internationally-established data coding and interoperability standards are used.³⁹

Legacy technology and infrastructure are delaying the ability to move to the cloud, holding data quality back. Cloud computing allows large-scale, cost-efficient analysis of medical data to support healthcare services, especially when combined with artificial

Health Record System

- Cerner
- DXC Technology
- System C
- Intersystems
- Allscripts
- Meditech
- IMS Maxims
- Graphnet
- EMIS Health
- Teleologic
- Kainos
- TPP
- Advanced
- Epic Systems
- Single-trust vendor systems
- Multiple systems
- 'In-house' systems
- Paper records

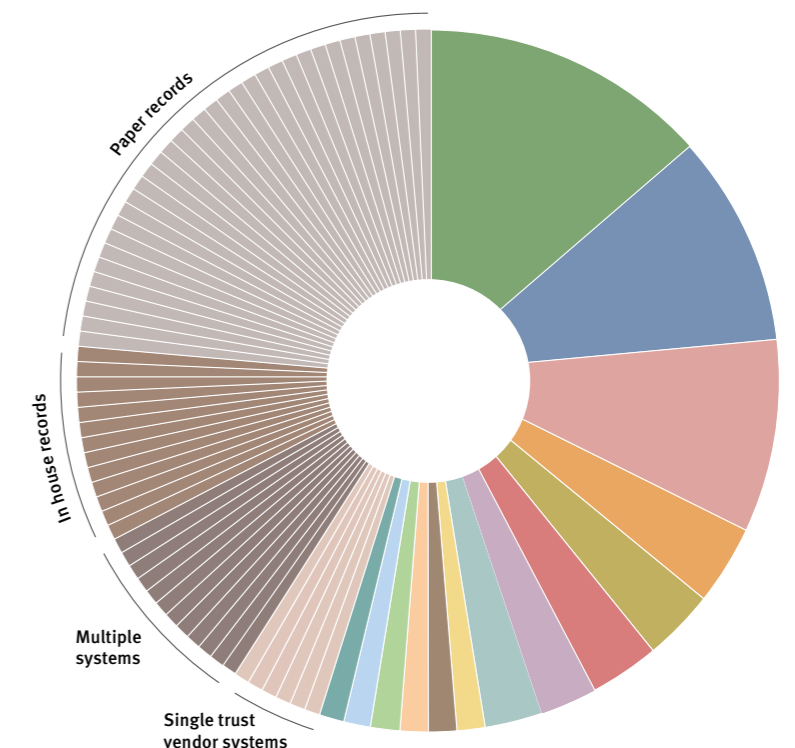
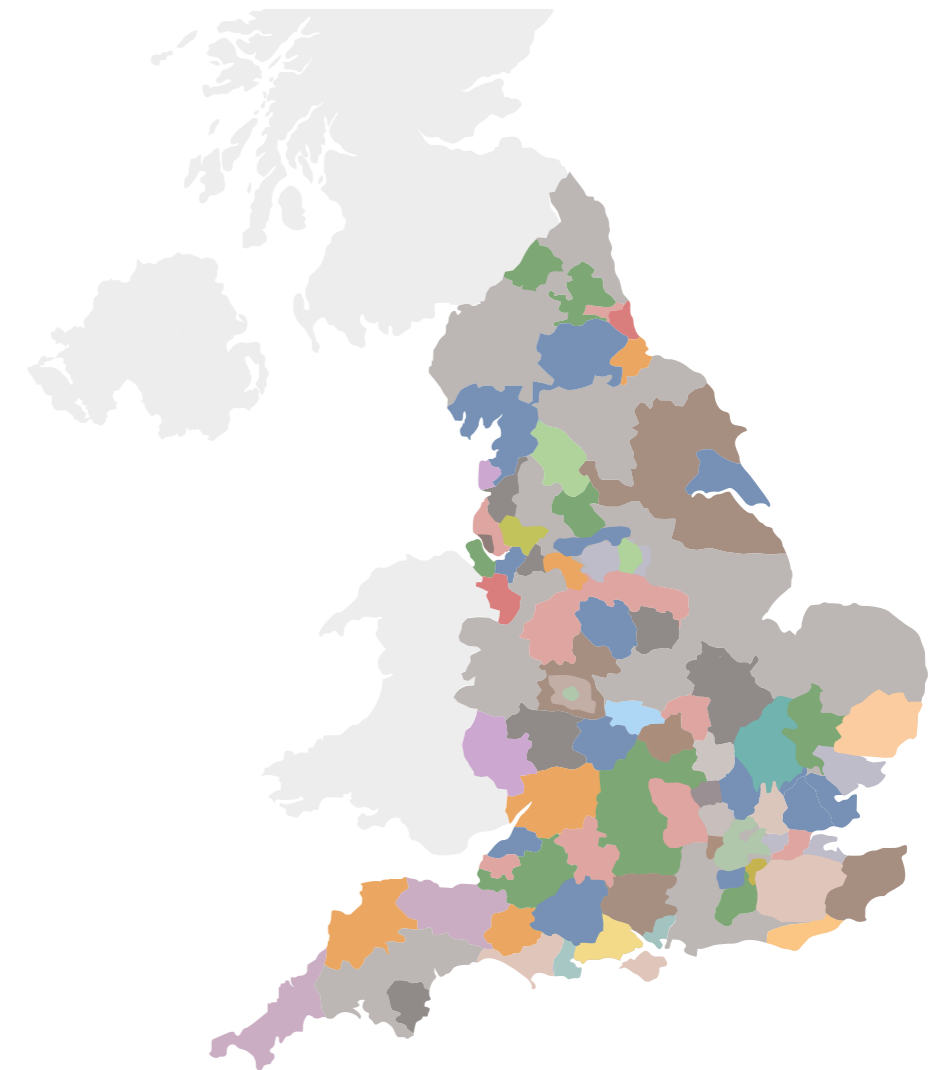


Figure 1: Frequency of use of health record systems by trusts and distribution of health record systems in NHS England. Each LSOA region in England was assigned the health record system of the hospital trust patients from that LSOA most frequently attended during the study period. LSOA, Lower Layer Super Output Area; NHS, National Health Service.³⁹

intelligence.³¹ When integrated properly, the security of cloud-based solutions has the potential to exceed that of on-premise solutions.⁴¹ Furthermore, the costs of on-demand cloud computing and storage are lower, which is supportive of the push for increased access to EHRs, digital health solutions and the analysis of medical data for research purposes.⁴²⁻⁴⁴ NHS Digital has issued a guidance document approving healthcare organisations' use of cloud computing (provided that appropriate safeguards are put in place).⁴⁵ However, local service agreements for cloud have not been standardised, causing confusion regarding the responsibilities of the NHS organisation versus the supplier.

STANDARDS

In recent years there have been positive efforts to improve data quality and define standards. NHS Digital is working to improve data quality through the Data Quality Maturity Index, which provides CCGs with the opportunity to investigate and engage in data quality improvement with providers, and NHS England's Digital Maturity Self-Assessment, which helps providers measure how well they are making use of digital technology.^{46,47} HDR UK has convened a data officers group that brings together expertise from across all UK Health Data Research Alliance members. There has been a concerted effort to drive supplier behaviour to ensure systems support returns and standards. Open standards such as the Fast Health Interoperability Resources (FHIR) have improved interoperability of systems. NHSX and NHS Digital are working to encourage and enforce data and interoperability standards, holding providers to account for implementing standards, and driving usability of systems to increase data quality at source.⁴⁸

Nonetheless, there is still a marked difference in data quality, standard adherence and interpretation, and infrastructure across providers, making it difficult and costly to combine and curate datasets.

CURATION

NHS services see approximately one million patients every 36 hours and almost all

interactions generate some form of electronic record or footprint.⁴⁹ A single patient typically generates close to 80 megabytes of data each year in imaging and electronic medical record data.⁵⁰ Every GP holds electronic records of every consultation, in coded form, many stretching back decades. However, despite significant improvements in collecting near-real time data, such as with the Emergency Care Data Set (ECDS) collected by NHS Digital, accurate **data is very often not captured real-time.**⁵¹ Significant efforts to post-process the data are often required. Curating datasets involves the organisation and integration of data collected from various sources such that the value of the data is maintained over time. This is particularly difficult in the NHS given the variation in data quality and structures.

Across the NHS, there are examples where data curation is done well. For example, NHS Digital's Hospital Episode Statistics (HES), the Clinical Practice Research Datalink's (CPRD) primary care data and the SAIL databank in Wales.⁵²⁻⁵⁴ For years these datasets have been employed for secondary uses, such as academic research, planning health services and informing health policy. A number of individual NHS trusts and CCGs have also invested in the capability to curate data at scale in order to better plan their own services. In addition, many of the 15 Academic Health Science Networks (AHSNs) – established by NHS England to support the adoption and spread of existing innovations at pace and scale across regional networks – have invested in data curation capabilities. The seven Data Research Hubs also have a major focus on data curation.⁵⁵

FUNDING

There are ongoing concerns that the NHS cannot afford to divert funding from direct provision of care towards IT. KLAS Research's Arch Collaborative measured feedback from 200 provider organisations around the world and recommended an annual investment of 3-4% of revenue to run a digitally safe environment.⁵⁶ However, few NHS providers meet this standard and the Information Management & Technology (IM&T) investment survey to look at organisational spend on IT disbanded almost a decade ago.

RECOMMENDATIONS:

1. Enable codified, real-time data to be captured at source, improving data quality in the NHS.

- a. Enforce common standards for data capture across the NHS, signalling as early as possible to suppliers of systems such as EHRs.
- b. Increase digital maturity and shift away from paper-based processes. The Wachter Review (2016) recommended "all NHS trusts to reach a high degree of digital maturity by 2023, after which government subsidies should no longer be made available."²⁶
- c. Ensure that NHS staff that use existing systems are properly trained to do so, improving the quality of data captured in the first instance.

2. Invest in standards-based infrastructure and cloud-based services across the NHS.

- a. Invest in standards-based infrastructure across the NHS with a minimum of availability and reliability. Agreements should also avoid vendor lock-in by ensuring providers can lift and shift data from one cloud provider to another at the end of a contract period.
- b. Outline in local service agreements the scope of cloud services, including who is responsible for what, who holds insurance and who's indemnifying whom.

3. Review the mechanisms for funding IT in the NHS.

For example, encourage a move towards capital funding of Software-as-a-Service (SaaS) solutions, such as cloud, and away from funding on-site legacy technologies.

4. Capabilities

SUMMARY:

- To maximise the impact of health data, a more effective approach is needed to deliver the recommendations of the Wachter and Topol reviews.
- There are few senior digital leaders in the NHS with the knowledge and skills to deliver large and complex IT programmes.
- There needs to be significant investment to attract data science and engineering talent to the NHS, particularly from the private sector.
- More analysis is required to determine whether the NHS should build capabilities for the curation of data centrally or within local NHS organisations.
- In the short- and medium-term, the NHS could continue to partner with organisations with extensive data science and engineering expertise.

The importance of investing in capabilities and talent to support the digital transformation of the NHS has been articulated effectively.

For example, the Government commissioned a review led by Robert Wachter entitled *Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England* (2016), and Health Education England published *The Topol Review: Preparing the healthcare workforce to deliver the digital future* (2019).^{26, 57} These reviews made recommendations for citizens, healthcare professionals and the health system across emerging fields such as genomics, digital medicine, artificial intelligence and robotics. Amongst the recommendations in The Topol Review was a call to “attract, recruit and retain talented science, mathematics and computing graduates to fulfil leadership roles in ‘bioinformatics’” (including computational genomics, data science and public health informatics).

At present, there are very few senior digital leaders in the NHS who have both the core knowledge and skills to commission or deliver large complex IT programs and the operational experience of having done so. The lack of these leaders in the NHS is simply a direct result of the slow digital transformation of the system over the last decade. In order to scale this

capability at the speed that is required we need to bring in talent from outside the system, and in particular from the private sector.

The NHS has started to take action on the recommendations from the Wachter and Topol Review.

The NHS Digital Academy, launched in 2018 through a partnership with Imperial College London, the University of Edinburgh and Harvard Medical School, provides a year-long programme aimed at Chief Information Officers (CIOs) and Chief Clinical Information Officers (CCIOs) to drive the information and technology transformation of the NHS.⁵⁸ In addition, the NHS Graduate Management Training Scheme includes Health Informatics as one of its six streams, training NHS staff over two years in core areas such as data collection and storage, extraction of data from source systems into data warehouses, clinical coding and standardisation, and information management, governance and security.⁵⁹

A more effective approach is needed to deliver the recommendations of the Wachter and Topol reviews and compete for the talent the NHS needs to maximise the impact of health data. The next five-year cycle will encompass the broadest and most ambitious digital transformation agenda ever undertaken in the NHS with multiple, parallel, complex programs

being implemented. For these to succeed, there needs to be significant investment in data science and engineering capabilities. These are still often seen as overheads rather than essential parts of the organisation that can drastically improve the quality of care and its cost-efficiency. By contrast, tech companies continuously invest huge sums in data science and engineering talent, with many of these individuals being the companies’ most valued and protected employees.

Deciding how and where to build the capabilities the NHS needs, particularly for the curation of data, will be critical. Options include a national centre of excellence, leveraging existing SaaS platforms provided by NHS Digital or other organisations, multiple hubs across the country or the strengthening of expertise locally in every NHS organisation across the country. More analysis is required to determine which approach would be most desirable, but the

Academic Health Science Centre accreditation process and the Global Digital Exemplar programme provide some ideas about how best to both encourage excellence while making sure that all NHS bodies are able to gain from this expertise.

While it develops its own capabilities, the NHS could continue to partner with organisations with extensive data science and engineering expertise, such as research organisations or technology companies. This could be a way for those with clinical expertise (NHS staff) to quickly learn from data scientists. For example, the Beth Israel Deaconess HealthCare system in the US partnered with data scientists at Amazon and Google to deliver 11 artificial intelligence innovations in under two years.⁹ However, such arrangements where significant investment is provided by industry may have an effect on any financial returns.

RECOMMENDATIONS:

1. Implement recommendations related to IT and analytical capability in the NHS put forward in the Wachter and Topol reviews, for example:

- a. Develop a workforce of trained clinician-informaticists at NHS Trusts, and give them appropriate resources.
- b. Invest 1% of the £4.2 billion to be spent on digitising the NHS to support workforce development and deployment (these figures might require updating).²⁶
- c. Attract, recruit and retain talented science, mathematics and computing graduates to fulfil leadership roles in bioinformatics.⁵⁷
- d. Attract graduates in data analytics to begin a career in health, to create and implement technological solutions that improve care and productivity in the NHS.⁵⁷
- e. Ensure genomics and data analytics are prominent in undergraduate curricula for healthcare professionals and offer opportunities for healthcare students in areas such as engineering or computer science.⁵⁷

2. Review how IT and analytical talent in the NHS are paid, including salaries and incentive structures, to increase competitiveness with private sector employers.

3. Determine which approach to building data capability (centralised, hubs, local) fits the needs of the NHS.

5. Investment

SUMMARY:

- Despite national investment to improve the digital infrastructure in healthcare, there has not been a true step-change in the value and use of data in the NHS.
- A major increase in government investment is needed to achieve the required improvements in data quality, infrastructure and capabilities.
- Improvement in healthcare data and data infrastructure will unlock opportunities for research and development and enable an innovation ecosystem that attracts billions of pounds in private investment.
- For the UK to maintain its position as a top destination for research and development, clear rules need to be in place along with appropriate incentives for innovators.

Achieving the required improvements in data quality, infrastructure and capabilities will require a significant increase in current levels of investment. Doing so at the speed and scale required to make a difference to patient care and maintain the UK's competitive advantage in this area is imperative. We must also continue to determine which innovation mechanisms, such as public/private partnerships, can create the conditions for innovation to thrive.

Over the past five years there has been significant national investment to improve the digital infrastructure in healthcare. This has included £250 million to set up the Artificial Intelligence Lab through NHSX in 2019,⁶⁰ £43 million to build a cloud first approach to data processing and improve data access at NHS Digital, the funding of the Global Digital Exemplars (2018), Fast Followers (2019) and Local Health Care Record Exemplars programmes,^{62,63} and the establishment of Health Data Research UK (HDR UK), which in turn awarded £22 million to seven Digital Innovation Hubs (through the industrial strategy challenge fund).⁶⁴

However, there has not been a true step-change in the value and use of data in the NHS. Some senior healthcare leaders have identified funding as the main barrier to the digital transformation of the NHS and estimate investment to be in the order of £3 billion.⁶⁵ If deployed effectively, this could pay for

significant improvements to data quality across the NHS, the collection of machine-readable data at source and the technological infrastructure required for curation, storage, manipulation and linking.

The most appropriate source of funding to improve data quality, infrastructure, and capability is likely to be government. The investment will deliver significant public benefit, although more work is needed to quantify the size of the improvement it could bring to direct patient care and system efficiency. Investment from long-term, non-speculative private sector actors based in the UK (for example, insurance companies) might also be an option, but **more work is needed to understand what form of private sector investment would be acceptable to the public.**

By setting out clear priorities for data quality and infrastructure, the NHS can direct industry to focus efforts in these areas. Too often ideas are generated by the private sector, but this supply-led approach means that important areas can be left behind. **The involvement of research organisations or charities may be more acceptable to public opinion.** The registered charity UK Biobank is an example of where funds from the Department of Health in partnership with the Wellcome Trust and the Medical Research Council (MRC) have resulted in world class datasets with widespread public support.⁶⁶ The Biobank has also been able to

leverage in private sector money, for example through partnering with pharma companies to whole genome sequence the samples it holds, to improve the quality of its asset in a way that retains the trust of its participants.

Investment of this magnitude in data and capabilities will unlock significant opportunities for research and development by public and private organisations.

Innovations developed from NHS data could then further contribute to healthcare improvements, but also to economic growth and prosperity in the UK. The life-sciences and technology industries contribute billions of pounds to the UK economy, have an international reputation for health innovation and employ huge numbers of people in the UK (140,000 in the life sciences sector alone).⁶⁷ Both life sciences and artificial intelligence are key priorities for the UK's industrial strategy. With better healthcare data, accessed in an appropriate and publicly approved way, these strategic sectors of the UK economy could further thrive. Research organisations could strengthen their position as global leaders in health research and innovators from all sectors could develop the healthcare interventions of the future.

Significant improvement in healthcare data and data infrastructure may give rise to an innovation ecosystem able to attract billions of pounds in private investment. It is within this

ecosystem that private funding could make the biggest contribution, while the Government will continue to support research and development directly. This would help grow local health economies and benefit the UK population in two ways: as NHS patients and as taxpayers. This scenario is not unrealistic, and there have been recent examples of public/private partnerships in the life sciences industry. For example, the Government recently invested £79 million in the 'Accelerating Detection of Disease' initiative, which is expected to attract £160 million investment from industry. The collaboration also brings in partners from the NHS and leading charities including Alzheimer's UK, British Heart Foundation and Cancer Research UK.⁶⁸ Moreover, as the public become increasingly interested in - and potentially cautious about - how their data is used, it could provide a new model for securing the active consent of the public to provide their health data for research purposes in exchange for direct health benefits.

However, for the UK to maintain its position as a top destination for research and development, clear rules need to be in place along with appropriate incentives for innovators. First of all, as discussed in previous sections, data access should be structured in a way with which the public is comfortable. In addition, mechanisms should be in place for the NHS, and therefore UK taxpayers, to receive fair value for the data (see next section for more details).

RECOMMENDATIONS:

- 1. Increase government investment in data quality, infrastructure, and capability.** This is likely to require billions of pounds above what is currently invested to achieve a step-change in the value and use of data in the NHS. as the world-leader in this area, building on existing efforts such as the Life Sciences Sector Deals. Greater scale up capital is the most urgent use case.
- 2. Develop a clear UK wide strategy to attract investment specifically in data-driven health innovation with the aim of establishing the UK**
- 3. Focus on significant new opportunities** such as the Accelerating Detection of Disease and other cohort studies that pioneer new models of consent and active patient participation.

6. Value sharing

SUMMARY:

- The NHS should receive fair value for the use of its data, whether financial or in kind; failing to ensure that the NHS is properly compensated may influence public trust.
- There is no best practice for how NHS organisations should respond to health data requests from commercial companies.
- It is unclear who within the NHS should receive the benefits generated from licensing data.
- It is urgent to have a public debate on this topic as many NHS organisations are currently engaging with organisations without central guidance.
- We have provided a framework that describes the different value-sharing arrangements that could be used by NHS organisations. (Table 1)

The NHS should receive fair value for the use of its data, whether financial or in kind, but the question of if and how the NHS should be compensated is often overlooked in discussions. Yet, for years, access to NHS data has been available for a fee, including information on all hospital admissions (HES) and on a significant proportion of primary care interactions (CPRD). These datasets have been available for decades to assist the advancement of health research. Data is shared in anonymised format and according to well-structured processes governed by public agencies, such as NHS Digital, the Medicines and Healthcare products Regulatory Agency (MHRA) and the National Institute for Health Research.^{52, 53}

We believe that NHS data should continue to be made available to innovators in healthcare, including private companies from outside the UK. However, this should happen according to a robust and appropriate set of principles and in a way that the public is aware of, has contributed to and support. Well thought-out and mutually beneficial health data access arrangements can encourage collaboration, whereas pushing forward with ad-hoc licensing arrangements comes with a high risk of undermining public trust in the NHS. Further, a failure to develop these models or adopting inappropriate/

disproportionate models risks industry turning to datasets in other countries, eroding the UK's competitive advantage in this space.

Further, failing to ensure that the NHS is properly compensated may imperil public trust in the medium- and long-term.⁶⁹ During the last General Election, CPRD was in the news under the headline “Patient data from GP surgeries sold to US companies”.⁷⁰ The strength and negativity of the response suggests that current public awareness of these datasets and of how they are shared is very low.

There is no best practice for how NHS organisations should respond to data requests from research or commercial organisations, and many do not have the experience to conceive, structure, and negotiate complex and/or innovative commercial data arrangements. It often comes down to an exchange of data for the promise of free access to products that might be developed. While that may be an appropriate outcome in some cases, in other cases there may be an opportunity to take a different approach. It will be important for the NHS to have personnel who have experience in identifying when NHS data is of particular value and knowledge of the best types of arrangements to license data on a case-by-case basis.

Exclusive access to data should not be granted where data has been assembled by the NHS or another government-funded organisation. Granting exclusivity is unlikely to be in the public interest or the interest of science and the Department of Health & Social Care has recently banned NHS Trusts from striking exclusivity deals with the private sector.⁷¹

It is unclear who within the NHS should receive the benefits generated from licensing data, whether it is the individual NHS organisation, the NHS centrally or a separate body set up by the NHS (for example, the idea of a Sovereign Health Fund has been proposed and discussed in Parliament).⁷² More sophisticated NHS organisations are more likely to be willing and able to enter into sophisticated, mutually beneficial data- and value-sharing arrangements with companies. If the benefits are solely captured locally, these organisations will become more prosperous and able to invest in data collection, curation and partnership development. This might result in some organisations being left behind, exacerbating inequalities across the system.

We have provided a framework that describes the different value-sharing arrangements that could be used by NHS organisations (Table 1). Some of these arrangements involve simple transactions (e.g., a one-off payment to license data), whereas others are linked to outcomes and could result in a longer relationship (e.g., equity share). Each arrangement – or combination of arrangements – comes with potential benefits and risks and should be dealt with on a case-by-case basis. Considerations

should be given to the extent to which the data is material, whether the NHS entity is providing other “value-added” services, and whether an equivalent dataset can be easily obtained elsewhere.

It is critical and urgent to have a public debate on this topic. Many organisations have begun engaging with research and commercial organisations on data-sharing but have received no central guidance on how to structure or negotiate these complex arrangements. **In an encouraging sign, NHSX has committed to develop a National Centre of Expertise to focus on this topic and it is hoped that they will take the lead in this space.** The Office for Life Sciences (OLS) are currently drafting a full policy framework, which will provide guidance for NHS organisations to ensure they can enter into appropriate data access agreements for healthcare data with innovators. This is due to be published in the next few months and will underpin the advice provided by the Centre of Expertise. The Centre will “oversee the framework, provide specialist commercial and legal advice to NHS organisations entering data agreements, develop standard contracts and guidance, and ensure that the advantages of scale in the NHS can deliver benefits for patients and the NHS”.⁷³ The creation of this Centre must proceed as a matter of urgency.

RECOMMENDATIONS:

1. **Provide NHS organisations with a clear framework and guidance for entering into value-sharing arrangements when licensing data.** This should come from NHSX's Centre of Expertise mentioned above and can build on our proposed framework below.
2. **Strengthen the support available to NHS organisations for the negotiation of data and value-sharing agreements.** Expertise in structuring complex data-sharing arrangements should be built within the NHS, both at central and local levels.

Table 1: Value-sharing framework for the NHS ^{74, 75}

AGREEMENT	DESCRIPTION	MAIN BENEFITS FOR THE NHS	POTENTIAL ISSUES
No value sharing	The NHS shares data for free.	<ul style="list-style-type: none"> No direct economic benefit for NHS, but there is potential for patient and system wide benefit by openly sharing data for free. 	<ul style="list-style-type: none"> The NHS does not get any share of the economic return on products using the data or access to products.
Free or discounted products	The product developed using an NHS dataset is provided to the contributing NHS organisation for free or at a discount (for a defined or unlimited period of time.) The product might also be offered to the rest of the NHS at a discount.	<ul style="list-style-type: none"> NHS as a whole or an individual organisation gets access to cutting-edge products at no or reduced cost. 	<ul style="list-style-type: none"> No additional value specifically captured from product revenues. Risk that no useful product is developed. If the product is discounted or free only for one organisation, other NHS organisations will still have to pay for it. The provision of a product free of charge would need to be reviewed to ensure no breach of regulatory compliance obligations by industry.
One-off payment	NHS receives a one-off payment in exchange for access to the data.	<ul style="list-style-type: none"> Quick and certain access to funds with no risk or ongoing relationship required. Potential to license same datasets for same uses to multiple parties to maximise revenue. 	<ul style="list-style-type: none"> Depending on the pricing, this could generate limited value for the NHS (e.g., HES). Depending on the fee, this may create a financial barrier to initial access to data, potentially penalising smaller companies.
Royalty/ revenue share	The NHS receives a royalty on revenue from products developed using its data.	<ul style="list-style-type: none"> Potential long term source of income. Likely to generate the most income for the NHS. 	<ul style="list-style-type: none"> NHS would have to pay for tools developed using its data. Risk that no revenue-generating product is developed. Industry may require exclusivity in respect of the data limiting the NHS's ability to deal in the data with third parties.

AGREEMENT	DESCRIPTION	MAIN BENEFITS FOR THE NHS	POTENTIAL ISSUES
Profit share	The NHS receives a portion of the profits generated by its industry partner.	<ul style="list-style-type: none"> NHS receives income every year that the company is profitable (irrespective of whether a specific profitable product is created). 	<ul style="list-style-type: none"> NHS would have to pay for tools developed using its data. May be resisted by established partners and therefore adopted by small and medium-sized enterprise (SME) partners which may not be profitable for some time. Industry may require exclusivity in respect of the data limiting the NHS's ability to deal in the data with third parties.
IP ownership share	The NHS owns (alone or jointly) some of the intellectual property generated in the project which uses its data.	<ul style="list-style-type: none"> IP ownership for the NHS. Potential for royalties based on the use of the NHS-owned IP as part of a wider package. Potential to have some control over how the IP is used and exploited (subject to contractual arrangements). 	<ul style="list-style-type: none"> IP ownership does not itself generate revenue. Difficult to manage: will tie NHS into a relationship with the company for as long as it retains a joint ownership interest, creating an administrative burden for the NHS. Unappealing to companies: NHS involvement might complicate decision making and hinder company progress. Unusual for mere provision of data to justify IP ownership; the NHS will likely need to demonstrate a more substantial role in the co-development of any IP e.g. clinical input. Industry may require exclusivity in respect of the data limiting the NHS's ability to deal in the data with third parties.
Equity share	The NHS receives a share of the equity of the company developing solutions from the data.	<ul style="list-style-type: none"> Ownership interest in company developing product and potential to have a say in its activities. 	<ul style="list-style-type: none"> Difficult to decide what a fair share of the equity for the NHS would be. Main return might be capital appreciation on sale (if any) as little or no dividends might be generated for a while. Likely unappealing to established companies. NHS involvement as a minority shareholder might complicate company decision making and be burdensome to manage for the NHS.

AGREEMENT	DESCRIPTION	MAIN BENEFITS FOR THE NHS	POTENTIAL ISSUES
			<ul style="list-style-type: none"> Industry may require exclusivity in respect of the data limiting the NHS's ability to deal in the data with third parties.
Golden share	The NHS receives an equity share which is able to outvote all other shareholders in certain predetermined circumstances.	<ul style="list-style-type: none"> NHS or DH could essentially control the business and therefore require the company to be based in the UK and provide ongoing benefits to the health system. 	<ul style="list-style-type: none"> Restrictive model for industry, giving the NHS or the Government control over strategic decisions. Unclear financial benefit for the NHS; this would result from the direction of the management of the company. This model seems unlikely to be used where the only contribution is data. Rather this (and ownership of IP above) suggests a more integrated development team (e.g., NHS provides clinical test bed, clinical expertise and a strong package of rights in return for industry). Industry may require exclusivity in respect of the data limiting the NHS's ability to deal in the data with third parties.
Multiple one-off fees linked to product sales	NHS receives multiple one-off payments triggered by the licensee achieving certain regulatory and product milestones (e.g., start of clinical trial, regulatory approval, volume of sales, in each case of a product relying on the relevant data).	<ul style="list-style-type: none"> Increased revenue vs one-off payment. Less complex to administer vs other models. More likely to be accepted by industry as payments linked to success. Could reduce the "financial barrier" for smaller companies as mentioned above as larger payments are made when/if a product is successful. 	<ul style="list-style-type: none"> If product is unsuccessful NHS may only receive small sum. Audit may be required to verify if milestones have been met. Total milestone payments may only be a fraction of overall revenues if product is highly successful.
Spin-out	DH sets up a wholly owned business to hold the relevant IP or data asset with a view to obtaining further investment in the company or out-licensing.	<ul style="list-style-type: none"> Would allow DH to ring-fence legally, financially and operationally key assets for commercialisation. 	<ul style="list-style-type: none"> Until a third party investor or collaborator is engaged, this vehicle would not generate any revenue. Might be perceived by the public as a wholesale effort to commercialise data.



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