

Making NHS data work for everyone

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December 2018

#reformNHSdata

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Acknowledgements

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¹ Reform, 'Making NHS Data Work for Everyone (Panel Event)', Webpage, Reform, 5 June 2018.

² Reform, 'Labour Party Conference: "Making NHS Data Work for Everyone" (Roundtable Event)', Webpage, Reform, 24 September 2018.

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Executive summary

This paper focuses on the use of NHS data by private sector companies. It highlights the different elements that should be considered when the public and private sector partner to build a product or service based on data – i.e. what each side is bringing to the table. It looks at the challenges the NHS might face given the types of partnership that are developing on the ground and recommends a strategic national approach to resolve some of these issues.

Uses of healthcare data

Everyone and everything within the NHS generate data daily, from patients to doctors and nurses, MRI scanners to appointment booking systems. The primary purpose of this data is direct patient care which means that it is used to inform medical decisions about a patient's treatment. Data held and collected by NHS organisations can be used for other purposes such as research by universities or by private sector companies, or for product and service development.

The value exchange

The private sector is an important partner to the NHS and plays a crucial role in the development of healthcare technologies that use data collected by hospitals or GP practices. It provides the skills and know-how to develop data-driven tools which can be used to improve patient care. However, this is not a one-sided exchange as the NHS makes the data available to build these tools and offers medical expertise to make sense of the data. This is known as the “value exchange”. The value exchange is specific to each product and service. The research uncovered that there is a lack of clarity over what a fair value exchange looks like. This is partly because healthcare data is an asset that no one knows how to adequately value. The paper builds a list of factors that have an impact on its value. However, it also highlights that the value exchange between the public and private sector is about more than just data.

Keeping society in the loop

Engaging with the public about how data about them is being used within the NHS is crucial. Various models have been developed to do so. There are, however, no public sector models or examples that allow patients to participate in the conversation about what fair value exchange with the private sector might be. The report recommends that this should change, and people should be given an opportunity to engage in these conversations. This is crucial to build a trustworthy system.

The healthtech ecosystem

To create a strong healthtech ecosystem whilst safeguarding the NHS's constitution and patients' trust, strong guidance and leadership will be needed to make sure the value of healthcare data is optimised.

Letting a thousand flowers bloom?

Research carried out for this report suggests that there is a wide variety of arrangements between the NHS and industry when there is access to data for research and product or service development purposes. However, it is difficult to gain an understanding of what the national picture is as there is no national registry describing data sharing agreements and the various types of commercial models that have developed on the ground. The paper presents the first classification of the different models that can be found.

National strategy

It is crucial for the Department of Health and Social Care to ensure that local bodies are not creating perverse incentives in the system. A commercial model might seem fair at GP practice or Trust-level but could be detrimental at a national level. For example, a hospital could receive a financial revenue from a partnership it has engaged in, because of the way it was structured. This might be fair at a local level, but this increases the risk of some Trusts becoming richer than others. The paper presents a table of various other commercial models that could be explored. All models have advantages and disadvantages, meaning that different models will suit different scenarios. There is no one-size-fits-all solution. Nevertheless, it is crucial that national policy provides a framework for the array of possible models that will not have an adverse effect at the national level.

Access to good quality data

Most data held by NHS organisations is collected for the purposes of direct patient care. This has an impact on its ability to be directly used for research or product or service development purposes. In addition, data within the NHS is fragmented and there can be issues around its quality. It is important for the private sector to have clarity over this before engaging in a partnership. The paper suggests that transparency over data quality could be increased. The speed of access to data can also be an issue for private sector organisations, particularly smaller companies, however, accelerating this process should never come at the price of protecting individuals' privacy. The report suggests that privacy-preserving techniques like synthetic data – a fake version of real data that is sufficiently different so that it preserves a person's anonymity, but sufficiently similar that it can be used for analysis – should be used to speed up access. This would also allow a better understanding of the commercial value of data-led innovations and a more informed conversation about the appropriate type of commercial model that should be developed.

Procurement, partnership, or somewhere in between?

Partnership models seem to offer more flexibility at the early stages of the innovation process and might be a way to alleviate some of the concerns around the potentially ill-fitted nature of current procurement processes for data-driven technologies. However, there might be a need to clarify the boundaries between some commercial partnerships and procurement processes.

Commercial and legal skills

To create a thriving healthcare ecosystem in which the private sector acts as a partner to the public, the public sector will need the right skills to negotiate these partnerships. Having an even distribution of commercial and legal skills at Trust-level would be unfeasible as those skills are a scarce resource within the public sector. They are also an expensive resource. The report recommends that the Department of Health and Social Care should invest in creating a new independent unit with legal and business experts to help NHS organisations negotiate fair and proportionate partnerships.

Recommendations

- 1** The Office for National Statistics should provide a framework and accounting standards for measuring and reporting the value of knowledge assets such as healthcare data.
- 2** The Department of Health and Social Care should in conjunction with Caldicott Guardians, NHS organisations and industry representatives ensure that a dialogue with the public is set at a local level to discuss commercial models. Proportionate governance models provide an interesting avenue for public and patient engagement that could be explored.
- 3** NHS England and NHS Digital should create a register of data sharing agreements between the NHS and commercial organisations. It should include what type of data are being shared and a description of the type of partnership model being used. This would allow for clear understanding of what is happening on the ground and facilitate public scrutiny.
- 4** The Department for Health and Social Care in conjunction with the Crown Commercial Service, Office for Life Sciences and HM Treasury should make sure to include in its formal review of commercial partnerships, a macroeconomic study of the impact that different partnership models might have to avoid reinforcing a postcode lottery or other negative externalities such as exclusive data access.
- 5** The Department of Health and Social Care should include the results of this macroeconomic study in a clear national strategy which should seek to optimise the value of data held by NHS organisations when it is accessed for commercial purposes. It should consult with all stakeholders including industry, patients and NHS organisations as to what a fair apportioning of value might be.
- 6** NHS England should create a 'Data Quality Service', with a tiered-fee system dependent on factors such as company size and global profits, to provide bespoke reports on data quality at the early stages of a partnership discussion between the NHS and industry.
- 7** Procurement rules should include an agreement by digital providers that data generated within clinical applications should also be freely available for and interoperable with clinical information at the patient level, either via personal health records or interchange with appropriate electronic health records.
- 8** Health Data Research UK in conjunction with NHS England, NHS Digital, the National Data Guardian should work on developing the appropriate data governance structures to ensure that Digital Innovation Hubs are safeguarding patient data. This would include developing audit trails which track how data are used to ensure every interaction with personal data is auditable, transparent and secure.
- 9** NHS organisations should offer synthetic datasets, which they can share with private sector organisations for research and product or service development at the early stages of the innovation process. This would enable a better understanding of the commercial value of the innovation and a more informed conversation about the appropriate type of commercial model that should be developed.
- 10** The Department of Health and Social Care should invest in creating a new independent unit with legal and business experts to help NHS organisations negotiate fair and proportionate partnerships. It would ensure that NHS organisations can have access to consistent and necessary advice in order to negotiate fair partnership with SMEs. The negotiation of partnerships should be done by this unit on behalf of Trusts when dealing with Large Enterprise or SMEs whose parent companies are Large Enterprise.

Introduction

There are many benefits that can emerge from the NHS partnering with the private sector for the development of healthcare technologies, such as access to better treatments and increased quality of care.³ However, as highlighted in a recent HMTreasury policy paper on intangible assets, such as data and intellectual property (IP), the UK does not always have a good history in optimising the value of public sector knowledge assets. The document calls for a better understanding of the value of these assets as well as making sure that the frameworks are in place to ensure that value is accrued by the UK.

The Secretary of State for Health and Social Care's vision for the creation of a tech-driven NHS seeks to take a radical approach "to technology across the system" and to lay the foundations for the UK to become a world leader in healthcare technologies.⁴ A key theme developed in the vision is the importance of collaboration and partnerships. The hope is to create "an ecosystem where developers and vendors continuously compete on quality to fill each niche".⁵ There is a lot of debate around the commercial value of data controlled by the NHS and how to ensure that partnerships are beneficial to patients, the NHS and industry.⁶ Patients have a right to object to data being used for purposes beyond direct care, which will increase if they do not have confidence in what will happen to data about them. Protecting patients' privacy and trust will be crucial.

The NHS "holds millions of electronic medical records on the health of the population from birth to death"⁷ as well as extensive administrative datasets capturing, for example, the number of operations being carried out in the operating theatres of a hospital. This wealth of information is extremely valuable for the improvement of the quality of care and patient outcomes.⁸ There is also an "explosion of health care data" being generated outside of traditional healthcare settings thanks to the proliferation of smart healthcare devices and trackers.⁹ However, the value of healthcare data is often trapped as "different kinds of individual-patient data reside in disparate, unlinked silos".¹⁰ Interviews carried out for this paper revealed that accessing, cleaning, validating and linking data, known as data engineering, represents most of the labour involved in creating data-driven technologies, such as artificial intelligence, or new treatments that can be discovered through the analysis of data.

There is a fear that as big tech corporations partner with the NHS they will eclipse SMEs, further reinforcing their position as monopolists. The Department of Health and Social Care (DoHSC) has responded to this by launching a draft code of conduct for technology companies that use NHS data to create products.¹¹ It presents ten broad principles that are supposed to set the rules of engagement and expected behaviours. It is also currently conducting a review of commercial models.¹² Although this a promising start, there is a lack of a national strategy and forum to engage with the public on commercial models. The recent transfer of the Streams App developed for acute kidney injury by DeepMind to

3 Sir John Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector* (HM Government, 2017); Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, Report of Session 2017–19 (House of Lords, 2018).

4 Department of Health and Social Care, *The Future of Healthcare: Our Vision for Digital, Data and Technology in Health and Care*, 2018.

5 Ibid.

6 Lord Parry Mitchell, 'Protect Our Valuable NHS Data from Big Tech', *Financial Times*, 7 February 2018; Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, 88–93; Philip Aldrick, 'If NHS Patient Data Is Worth £10 Billion, Put It on the Balance Sheet and Save Lives Too', *The Times*, 15 June 2018; Philip Aldrick, 'Data Could Be a Huge Source of Funding for the NHS and We Are about to Give It Away', *The Times*, 3 March 2018; *ibid.*; Philip Aldrick, 'NHS Set to Be Offered a "Fair Share" of Data Profits', *The Times*, 5 September 2018; Rebecca Hill, 'Making Good Use of NHS Data "Vital for UK Plc", Says Royal Society', *Public Technology*, 26 April 2017.

7 Peter Border, *Big Data and Public Health* (Parliamentary Office of Science and Technology, 2014), 1.

8 Michael E. Porter, 'What Is Value in Health Care?', *New England Journal of Medicine* 363, no. 26 (December 2010); The Office for National Statistics, 'Quality Adjustment', in *The ONS Productivity Handbook*, 2016, 72–79.

9 Joachim Roski, George W. Bo-Linn, and Timothy A. Andrews, 'Creating Value In Health Care Through Big Data: Opportunities And Policy Implications', *Health Affairs* 33, no. 7 (2014): 1115.

10 Alessandro Blasimme, Effy Vayena, and Ernst Hafen, 'Democratizing Health Research Through Data Cooperatives', *Philosophy & Technology* 31, no. 3 (September 2018): 473.

11 Department of Health and Social Care, *Initial Code of Conduct for Data-Driven Health and Care Technology*, Guidance, 2018.

12 Ibid.

its parent company Google, has sparked up fears around privacy¹³ and ownership of IP.¹⁴ Crucially, it has also brought to forefront the necessity to have a conversation about commercial access to healthcare data and the type of partnership models that are developing on the ground.

This paper will focus on the partnerships between NHS and industry when there is use of data for research and development purposes or to create products and services. It will highlight the importance of clarifying the NHS's value proposition and will depict the current partnership landscape. In the House of Lords report, *AI in the UK: Ready, Willing and Able?*, concerns are raised about "the current piecemeal approach taken by NHS Trusts".¹⁵ There is a lack of an overall strategy considering whether the different partnership models that are emerging on the ground lead to the best possible at a national scale.¹⁶ In addition, it highlights the importance of engaging with the public on the issue of commercial models and the use of data about them.

¹³ Charlotte Jee, 'Google's Decision to Absorb DeepMind's Health Division Has Sparked Privacy Fears', *MIT Technology Review*, 14 November 2018; Madhumita Murgia, 'DeepMind's Move to Transfer Health Unit to Google Stirs Data Fears', *Financial Times*, 13 November 2018.

¹⁴ Alex Ralph and Philip Aldrick, 'Google "Poised to Profit" from NHS Patient Records', *The Times*, 24 November 2018.

¹⁵ Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, 93.

¹⁶ Ibid.

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Uses of healthcare data

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The data collected and controlled by NHS organisations is set in the context of a perpetual evolution.¹⁷ New data are being continuously generated by patients and healthcare organisations through appointment booking systems or the use of X-ray machines. There are improvements in the quality of data collected within the clinical setting thanks to the introduction of better scanners or data from trackers. It is not a static space. However, to produce benefits for the individual and the healthcare system, data needs to be used and shared.¹⁸ This can be done in several ways within the healthcare ecosystem; and there is robust legislation and guidance safeguarding and regulating what can be done to healthcare data.¹⁹ The primary purpose of data collected by NHS organisations is direct patient care. The benefits of granting access to data for this purpose are generally clear: improving the quality of care and the patient experience. Healthcare data can also be used for other purposes, namely secondary uses. These can occur within the NHS – for example monitoring population outcomes (e.g. reduction in the prevalence of diabetes) – or outside the health service, by third-party organisations – like universities or the private sector. Healthcare data might be used for research purposes by both universities and commercial organisations.²⁰ Generally speaking, the purpose of research is to advance knowledge, however, it can sometimes lead to the development of a product or service (see Figure 1). Data collected and controlled by NHS organisations can, within clearly specified parameters, be used directly for product or service development by commercial organisations. There can be clear benefits for the patients and the healthcare system to use data in this way, however, this type of use is more contentious in the eyes of the public²¹ and sometimes rightfully so.²²

1.1 Direct patient care

NHS organisations currently hold millions of electronic healthcare records on the UK population from cradle to grave.²³ Most of these data are produced when individuals interact with healthcare services and are primarily collected for the purposes of direct patient care – meaning that medical professionals use this information to make decisions about care.²⁴ The value of using data in this way is undeniable and immediately measurable as it directly increases the quality of care.²⁵ For example, the type of care a secondary care specialist will be able to deliver if they are able to access a person's GP records will be faster and more accurate than if they are solely relying on the patient's recall.

Although there are clear benefits to using healthcare data to inform medical decision-making, it is not always possible to access these data in a timely fashion. Patients often assume that data between primary and secondary care are digitally shared, however this

¹⁷ See Glossary for definition of data controller.

¹⁸ Hugh Whittall, 'The Use and Reuse of Data', in *Connecting Debates on the Governance of Data and Its Use* (The Royal Society and British Academy, 2016), 14.

¹⁹ Information Commissioner's Office, 'Overview of the General Data Protection Regulation (GDPR)', Webpage, 2017; Information Commissioner's Office, *Guide to the General Data Protection Regulation (GDPR)*, 2018; Information Commissioner's Office, *Guide to Data Protection*, 2017; National Data Guardian for Health and Care, *Information: To Share or Not to Share? Information Governance Review* (Department of Health, 2013); National Data Guardian for Health and Care, *Review of Data Security, Consent and Opt-Outs*, 2016; National Data Guardian for Health and Care, *Impact and Influence for Patients and Service Users* (Department of Health, 2017); Department of Health and Social Care and NHS, 'Information Governance Toolkit', Webpage, n.d.; Department for Digital, Culture, Media and Sport, *Data Protection Bill: Factsheet – Overview*, 2017.

²⁰ Chris Smith, *NHS and Healthcare Data* (House of Lord's Research Briefing, 2018), 2.

²¹ Wellcome Trust, *The One-Way Mirror: Public Attitudes to Commercial Access to Health Data* (Ipsos MORI, 2016).

²² BBC Two, 'Diagnosis on Demand? The Computer Will See You Now', *Horizons*, 5 November 2018; Timothy Revell, 'Google DeepMind NHS Data Deal Was "Legally Inappropriate"', *New Scientist*, 16 May 2017; Jee, 'Google's Decision to Absorb DeepMind's Health Division Has Sparked Privacy Fears'; Naureen Bhatti, 'Seeing a GP on a Smartphone Sounds Wonderful – but It's Not', *The Guardian*, 16 November 2017; Alex P. Burns, 'Where Is the Evidence for Automated Triage Apps?', *British Medical Journal* 360 (February 2018); Margaret McCartney, 'Could Babylon Please Supply Evidence?', *BMJ*, no. 358 (September 2017).

²³ Smith, *NHS and Healthcare Data*, 1.

²⁴ Ibid., 2.

²⁵ Erin Dettrey, 'The Value of Healthcare Data Analytics in an EMR', Webpage, Modernizing Medicine, 13 September 2017; HIMSS, 'The Value of Quality Healthcare Data', Webpage, HIMSS, 16 May 2016; Dave deBronkart, 'The Value of Sharing Data: What Healthcare Can Learn from Oncology', *Future Health Index Blog*, 3 March 2017; Sophie Clark et al., 'Patient-Level Data Linkage across Ambulance Services and Acute Trusts: Assessing the Potential for Improving Patient Care', *International Journal for Population Data Science* 1, no. 1 (April 2017); Dame Fiona Caldicott, 'A Data Opt-out Will Reassure Patients and Improve Care', *The Times*, 13 July 2017.

is often not the case.²⁶ Healthcare records are siloed by the activities (e.g. radiology, laboratory, etc.) performed within NHS organisations (e.g. Trusts, GP surgery etc.).²⁷ Having a single consolidated view of a person's entire healthcare record is the exception rather than the rule. This is not only the result of how data are collected but also due to the lack of interoperability of healthcare IT systems – meaning that systems cannot easily “exchange and use electronic health information” making it difficult to link data together.²⁸

It is important to highlight that individuals can also produce health data outside of the medical setting using wearables and other type of sensors. Measurements with these types of device are continuous and not just confined to a single point in time. In addition, they can be used as a way of gathering data about good health. However, these types of data are not currently integrated in a systematic way to the patient's healthcare record.

1.2 Secondary uses

Secondary uses of healthcare data that happen within the NHS tend to be less contentious in the eyes of the public than those happening outside and the public benefit can be clearly expressed. For example, clinical commissioning groups (CCGs) use healthcare data to effectively design and deliver services. The Clinical Effectiveness Group in East London, which covers three CCGs, has been using a data-driven approach to systematically improve clinical standards and reduce variation in primary care.²⁹ This has had a positive impact on patient outcomes such as the improvement “in blood pressure control” for patients with certain types of chronic health conditions such as diabetes.³⁰ However, as highlighted by medConfidential the use of healthcare data for secondary purposes is not devoid of contention. It reported that NHS England have granted a legal exemption to pass personal identifiable (see Glossary) data to various commissioning bodies to use for administrative purposes when there is arguably no need to pass identifiable data.³¹

1.2.1 Uses outside of the NHS

Accessing data collected and controlled by NHS organisations for secondary uses outside of the NHS can be hugely beneficial and is also the key to developing a competitive life sciences industry from data-led innovation.³² Harnessing the power of data will mean building relationships with various stakeholders from academia and industry.³³

As shown in Figure 1, a stakeholder's objective will influence the type of output. Research carried out for the purpose of peer-reviewed publication seeks to advance knowledge and is mostly carried out by universities. It is generally transparent in its processes and validated through a rigorous peer-review system. Research carried out for product or service development is rarely openly published due to commercial sensitivity. In addition, product or service development research might not always be carried out with the same rigour as peer-reviewed fundamental or applied research.³⁴ However, there can be interactions between published peer-reviewed research and product development, as one can lead to the other. This paper will focus on the uses of NHS data by commercial organisations.

26 Rebecca Fisher, 'Data Sharing to Improve Care', Webpage, The Health Foundation, 18 May 2018.

27 Eleonora Harwich and Kate Laycock, *Thinking on Its Own: AI in the NHS* (Reform, 2018), 33.

28 Robert M. Wachter, *Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England* (Department of Health and Social Care, 2016), 49.

29 Rebecca Fisher, Ruth Thorlby, and Will Warburton, 'Briefing: Sharing to Improve: Four Case Studies of Data Sharing in General Practice', *The Health Foundation*, May 2018, 4.

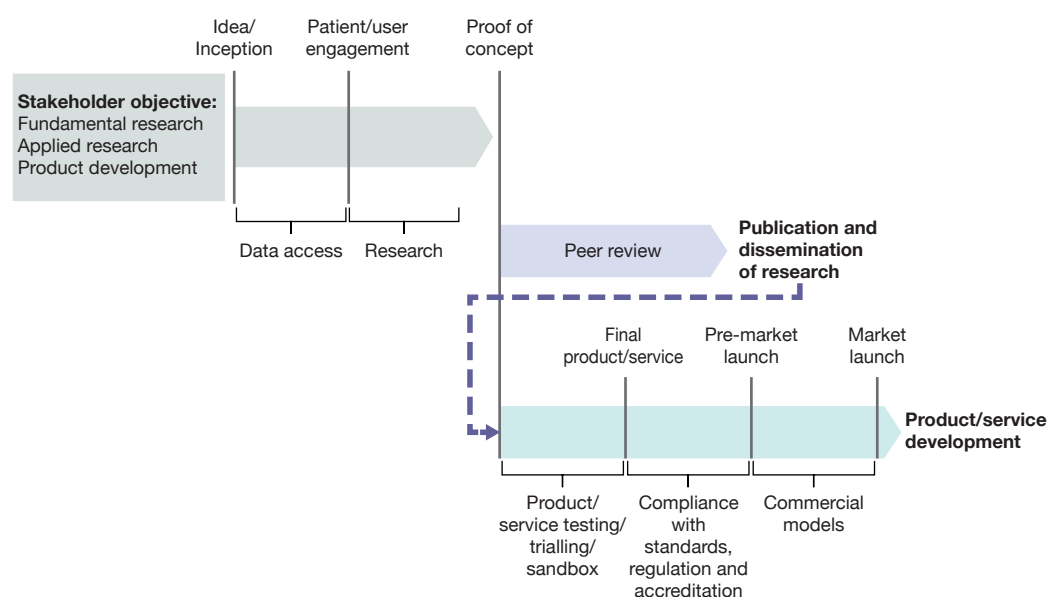
30 Ibid., 6.

31 MedConfidential, 'More Information', Web Page, MedConfidential, 2017.

32 Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*; Department for Digital, Culture, Media and Sport, *UK Digital Strategy 2017*, 2017; House of Lords, *Select Committee on Digital Skills. Summary and Summary of Conclusions and Recommendations*, 2015; Jon Hoeksma, 'NHS England to Establish New Regional Digital Innovation Hubs', Webpage, Digital Health, 12 September 2017.

33 Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*, 50.

34 BBC Two, 'BBC Two – Horizon, 2018, Diagnosis on Demand?'

Figure 1: Stages of research, development and product/service development

Source: *Reform interviews and research.*

Discussions about commercial models arise in the later stages of product development (see Figure 1). It is important to understand the array of available models that could benefit patients, the NHS as a whole – and not just parts of its thousands of local and national organisations – and the private sector.

1.2.2 Access to data

Accessing data held by NHS organisations can be a complex and costly endeavor. Interviews carried out for this paper uncovered that it is often complicated to know what data are being collected at Trust level and consequently what other types of data might need to be collected in order to complete a research project or develop a given data-driven technology or service.

At national level or even at regional level, only a minority of data are organised in neat or ‘clean’ datasets ready for external providers to request access to.³⁵ In addition, these “sources, whilst they may be linked in some cases, do not all currently provide deep, near real-time data for research across multiple care settings as standard.”³⁶ The fragmentation of data across the system and the lack of interoperability of IT systems makes it difficult to access data.³⁷

Interviews also revealed that even when data access requests are compliant with legislation and information governance frameworks (see Appendix) and projects have gone through ethical approvals, there can be delays in obtaining access. Circumstances such as these hinder the entry of smaller businesses with fewer resources from entering the market. NHS organisations, such as NHS Digital have recognised this issue and have “reduced time to completion through the Data Access Request Service to an average of 60 days”.³⁸ However, this is for initial approval once an application is submitted and is not reflective of actual end to end process, which can take much longer.

³⁵ Cliff Saran, ‘NHS Data Not Fit for AI, Lords Select Committee Told’, Webpage, ComputerWeekly.com, n.d.

³⁶ Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*, 56.

³⁷ Wachter, *Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England*; Harwich and Laycock, *Thinking on Its Own: AI in the NHS*, 29–38; Health Data Research UK, ‘Digital Innovation Hub Programme’, Webpage, Health Data Research UK, n.d.

³⁸ Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*, 58.

2

The value exchange

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The DoHSC's code of conduct for data-driven health and care technology highlights that partnerships between NHS organisations and the private sector can and should “deliver benefits to patients, clinicians, industry and the health and care system as a whole.”³⁹ The private sector could be a helpful partner by bringing its expertise and capabilities for research or to develop data-driven technologies and services – including the cost of compliance with standards and regulation for medical devices – as NHS organisations often do not have the necessary expertise or funds to acquire the skills needed to fully develop these in-house.⁴⁰ Despite this the NHS has a lot to bring to the negotiation table such as medical expertise and data. It is therefore crucial that it understands what its value proposition is – defined as the “positioning statement that explains what benefit you provide for who and how you do it uniquely well”.⁴¹ A mutually beneficial value exchange is only possible if there is a discussion and clarity over “what contribution is expected of each party”.⁴² The private sector plays an integral role in the provision of healthcare services in the UK. There are clear advantages for procuring products and services from the private sector such as CT scanners or other medical equipment. However, as revealed by interviews carried out for this paper, the value exchange is not always clear, and the healthcare system lacks people with the commercial skills to engage in these conversations.⁴³

2.1 Improvement for patients and the healthcare system

Arguably, the most important part of the value exchange in a partnership between the NHS and the private sector is demonstrating “how and where the product will add value to people and the health and care system”.⁴⁴ In other words, how will these advances improve patient outcomes whilst safeguarding privacy, population health and the productivity of the healthcare system. This is the legal basis used by most organisations to access data controlled by NHS organisations.

Data-driven technologies can provide support for clinical decision-making by, for example, helping to reduce the risk of morbidity and complications through improved diagnostics. Machine learning algorithms (see Glossary) can interpret mammography scans with high accuracy rates when screening for breast cancer.⁴⁵ This can improve early detection and help doctors better triage patients. Connected Yorkshire has created a new Electronic Frailty Index (eFI), based on routine patient data collected over time.⁴⁶ It helps doctors measure what support elderly people need as they reach old age. Based on the eFI clinicians can make more accurate interventions to avoid elderly patients from falling over or experiencing more acute health problems.

Operational improvements can also be derived from the development and implementation of data-driven products or services on the ground. Predictive analytics can be used to help accurately forecast bed occupancy rates and plan accordingly.⁴⁷ Bradford hospital in collaboration with General Electric is set to create a hub monitoring patients, allowing the hospital to “make better use of scarce resources”.⁴⁸

39 Department of Health and Social Care, *Initial Code of Conduct for Data-Driven Health and Care Technology*.

40 Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, p.88.

41 Michael Skok, ‘4 Steps To Building A Compelling Value Proposition’, *Forbes*, 14 June 2013.

42 Department of Health and Social Care, *Initial Code of Conduct for Data-Driven Health and Care Technology*.

43 Ralph and Aldrick, ‘Google “Poised to Profit” from NHS Patient Records’.

44 Department of Health and Social Care, *Initial Code of Conduct for Data-Driven Health and Care Technology*.

45 Nehmat Houssami et al., ‘Artificial Intelligence for Breast Cancer Screening: Opportunity or Hype?’, *Breast* 36 (December 2017); Alejandro Rodriguez-Ruiz et al., ‘Can Radiologists Improve Their Breast Cancer Detection in Mammography When Using a Deep Learning Based Computer System as Decision Support?’, vol. 10718 (14th International Workshop on Breast Imaging (IWBI 2018), International Society for Optics and Photonics, 2018); Tejal A. Patel et al., ‘Correlating Mammographic and Pathologic Findings in Clinical Decision Support Using Natural Language Processing and Data Mining Methods’, *Cancer* 123, no. 1 (January 2017); L. Hussain et al., ‘Automated Breast Cancer Detection Using Machine Learning Techniques by Extracting Different Feature Extracting Strategies’ (2018 17th IEEE International Conference On Trust, Security And Privacy In Computing And Communications/ 12th IEEE International Conference On Big Data Science And Engineering (TrustCom/BigDataSE), IEEE, 2018).

46 Connected Health Cities, ‘Connected Yorkshire’, Webpage, Connected Health Cities, 2016.

47 Edge Health, ‘Prediction Tool for Critical Care Bed Occupancy – “Critical Planner”’, Webpage, Edge Health, 18 October 2017.

48 Sarah Neville, ‘Bradford Hospital Launches AI Powered Command Centre’, *Financial Times*, 15 October 2018.

At a national level, it is important to consider what the deployment of these data-driven technologies means for the future of the NHS and how these integrate with the NHS's objectives of reducing the health and wellbeing gap (i.e. focus on prevention to improve healthy life expectancy);⁴⁹ and the care and quality gap (i.e. standardise high-quality care).⁵⁰ There might be trade-offs to consider when deciding whether to incentivise data-led technologies in prevention (i.e. avoiding the ailment and need for health system interaction), treatment (i.e. addressing or mitigating the symptoms) or cure. Data-led innovations that focus on prevention may be less immediately profitable than treatment, but have the potential to reduce burden and cost on healthcare systems and might be more socially desirable long-term.

Privacy concerns should also be considered as part of value exchange. Research has found that “machine learning models are vulnerable to a range of cybersecurity attacks that cause breaches of confidentiality”.⁵¹ This has led to some discussion over the nature of these algorithms and how they should be treated (i.e. should they be treated as personal data).⁵² The vulnerability of models to confidentiality attacks raises legitimate questions over the commercialisation of ‘vulnerable’ machine learning algorithms based on UK patient data abroad. Finding the appropriate governance models for the commercialisation of these products or services will be crucial.

2.2 Data

Data collected and controlled by NHS organisations are often described as ‘a gold mine’,⁵³ because the NHS is one of the oldest health services of its kind in the world, with – in theory – a unique national patient identifier.⁵⁴ Some have argued that these data could be harnessed to offer an additional revenue stream for the NHS⁵⁵ or invested into a sovereign wealth fund for the UK.⁵⁶ These ideas can be attractive, however, it is important to remember the financial value of data controlled by the NHS has not yet been established. Valuing data could allow the Government to better understand the relative returns from partnerships with the private sector and therefore ensure that it is optimising the value between patients, the NHS and industry. Several features of data “make them difficult to value within a traditional balance-sheet accounting framework.”⁵⁷ Nonetheless, HM Treasury has recently released a paper on valuation techniques for intangible and knowledge assets (see Glossary) – like data – which makes a few recommendations on what should be considered in future guidance.⁵⁸

2.2.1 What does value in data mean?

There is no single definition of the value of NHS data and no single way of measuring.⁵⁹ This is because the value that is ascribed to healthcare data is dependent on both “the intrinsic characteristics of the data and the environment in which they are used.”⁶⁰ A data

49 NHS England, *Five Year Forward View*, 2014, 10; NHS England, *Next Steps on the NHS Five Year Forward View*, 2017, 9; Department of Health and Social Care, *The Future of Healthcare*; Duncan Selbie, ‘Prevention and the NHS Long Term Plan: 3 Ways We Can Save More Lives’, Press Release, Public Health England, 6 September 2018; Anna Coote, *Prevention Rather Than Cure* (The King’s Fund, 2004).

50 NHS England, *Next Steps on the NHS Five Year Forward View*.

51 Michael Veale, Reuben Binns, and Lilian Edwards, ‘Algorithms That Remember: Model Inversion Attacks and Data Protection Law’, *Phil. Trans. R. Soc. A*, no. 376 (July 2018): 4.

52 *Ibid.*, 12.

53 Aldrick, ‘Data Could Be a Huge Source of Funding for the NHS and We Are about to Give It Away’; Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, 88–89; Mitchell, ‘Protect Our Valuable NHS Data from Big Tech’.

54 In practice, there are duplicates of NHS number and wrong attributions of NHS numbers. See: Sarah Timmis, Luke Heselwood, and Eleonora Harwich, *Sharing the Benefits: How to Use Data Effectively in the Public Sector* (Reform, 2018), 19.

55 Aldrick, ‘Data Could Be a Huge Source of Funding for the NHS and We Are about to Give It Away’; Aldrick, ‘If NHS Patient Data Is Worth £10 Billion, Put It on the Balance Sheet and Save Lives Too’; Mitchell, ‘Protect Our Valuable NHS Data from Big Tech’.

56 Annemarie Naylor, ‘Parliamentary Debate Briefing: This House Takes Note of the Value of NHS and Healthcare Data and How It Could Be Used to Improve the Health of Our Nation.’, *Future Care Capital*, 6 September 2018.

57 Centre for Economics and Business Research, *Data on the Balance Sheet* (SAS, 2013).

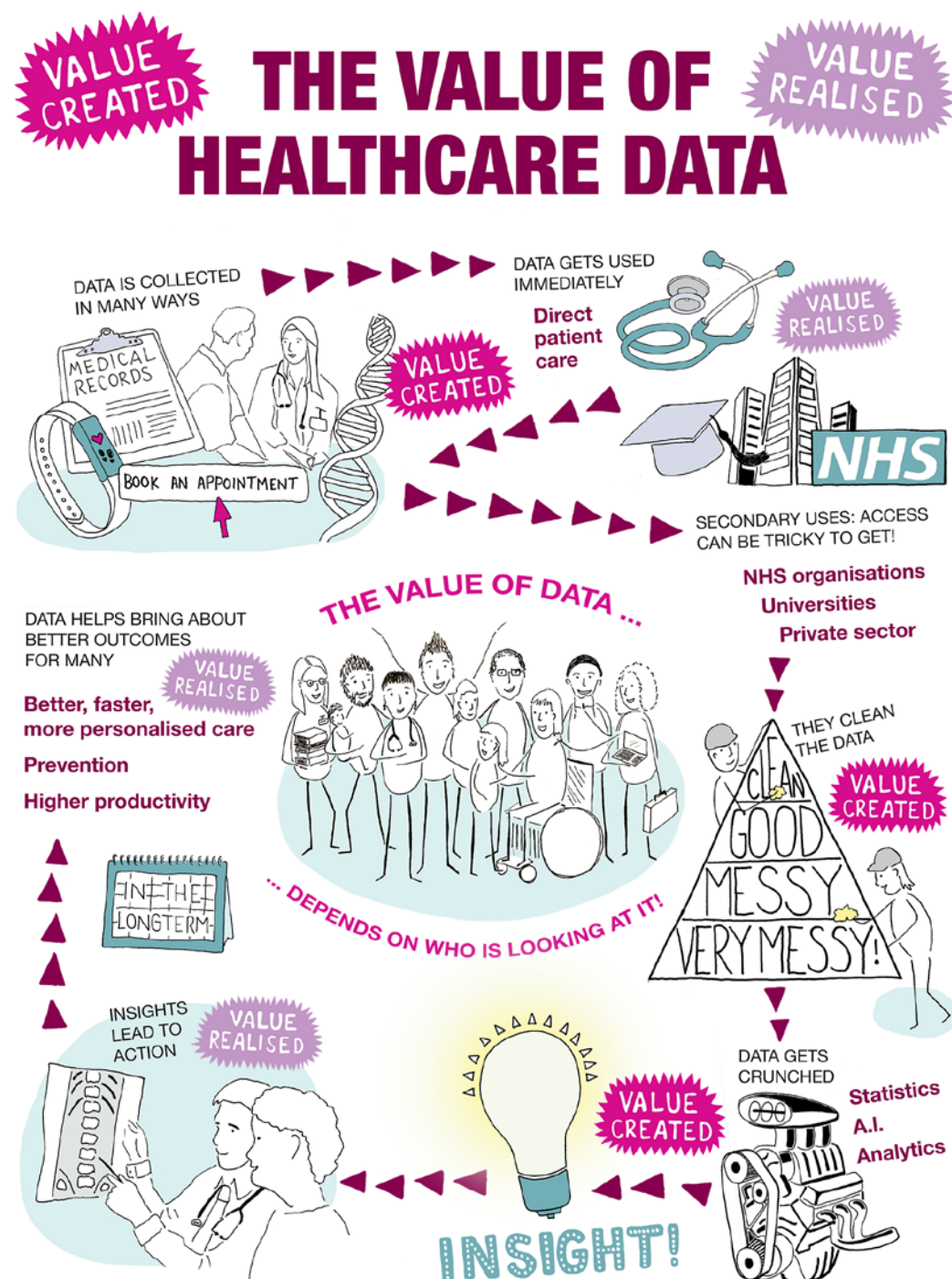
58 HM Treasury, *Getting Smart about Intellectual Property and Other Intangibles in the Public Sector: Budget 2018*, 2018.

59 *Ibid.*, 8–10; Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, 88–89.

60 Centre for Economics and Business Research, *Data on the Balance Sheet*, 3.

value chain exists “whereby the value increases as data are transformed into information, knowledge and ultimately action”.⁶¹ The exact nature of that value might depend on the type of application and type of data used.⁶² The nature and amount of value ascribed to a particular data-driven product or service “always lie in the eye of the beholder”⁶³ (see Figure 2).

Figure 2: Value(s) of NHS data



Source: Reform interviews and research. Design and animation by Zuhura Plummer.

61 Alan Walker and Philippa Westbury, 'Towards a Successful Data-Enabled Economy: Promoting Trust in Data and Data-Driven Systems', in *Connecting Debates on the Governance of Data and Its Use*, 2017, 40.

62 Ibid.

63 Eric Almquist, John Senior, and Nicolas Bloch, 'The Elements of Value', *Harvard Business Review*, 1 September 2016.

Value is highly complex to define because as shown in Figure 2 different stakeholders might have a different perspective on what value means to them. Value can also be added by cleaning and curating data.

2.2.2 What affects value?

Although healthcare data are part of a broader value chain, research and interviews carried out for this paper have uncovered 10 broad determinants that affect its value (see Figure 3 and Figure 4). The elements presented in Figure 3 describe the supply factors affecting the value of healthcare data – in other words, what makes data in isolation valuable.

Figure 3: Determinants of the value of data – the supply side

Category	Definition
The quality of the data	<p>The better the quality of the data, the greater the value.⁶⁴ This is because of the accuracy of the insights derived from the data. There are several factors which affect the quality of healthcare data: integrity, timeliness, validity, completeness and coverage.⁶⁵ Integrity ensures that data are accurate (e.g. a patient's date of birth is rightly inputted). Timeliness ensures that data are recorded at the time of the event or as close to the event as possible and that a timestamp is added to the "metadata".⁶⁶ Validity ensures that collected data satisfy a set of standards (e.g. making sure that the accepted clinical coding standards are used when coding a diagnostic or procedure). In the NHS coverage is reached if data "have been received from all expected data suppliers."⁶⁷</p> <p>In addition, greater quality data can reduce the cost of the data cleaning process. Data curation is the biggest drain on time when doing research or trying to develop a product or a service using healthcare data. Several interviewees estimated that about 60 to 70 per cent of the time spent on a project is dedicated to data curation. As highlighted by Neil Lawrence, professor at the University of Sheffield, there are different levels of data readiness and stages that need to be passed before data can be analysed by a machine learning algorithm.⁶⁸ Data cleaning processes are bespoke to every use and it is an inevitable process.</p>
The format of data	<p>The format of the data will have an impact on its value. Data in a machine-readable format and accompanied by robust "metadata"⁶⁹ describing the data content is more value than information held in paper files. Secondary care (e.g. hospital Trusts) still heavily relies on paper files.⁷⁰</p>
The ability to link data	<p>The value of a dataset increases when it is linked with another. For example, by combining different datasets on different disease types, new patterns of comorbidity can be discovered.⁷¹ The capacity to link genomic, clinical and diagnostic, medicines, and lifestyle data "forms the powerhouse for personalised medicine."⁷²</p>
The type of data	<p>The type of data can have an impact on its value. For example, the value of patient records can be different to the value of data generated by appointments and booking systems. The value of personal identifiable data (e.g. data including name, date of birth, contact details, etc.) can be different from the value of anonymised data (see Appendix for definition).</p> <p>Although they are not currently common practice, personal healthcare records might be more valuable than medical health records. Instead of collecting information through the silo of healthcare activities (i.e. GP records, lab results, etc.), personal healthcare records allow for the patient to act as the integrator of the data. The data follows them and is no longer siloed by activity. Patients are effectively given an active role as data curators and validators which might have an impact on the quality of this type of data.</p>
The reason for data collection	<p>Most data controlled by NHS organisations is primarily collected for the purposes of direct patient care. It is not collected for other purposes.⁷³ This affects its value for secondary uses as it might not be the exact type of data needed for research or product/service development purposes.</p> <p>Interviews carried out for this paper highlighted that some research projects include an entire process of data collection within an NHS setting as a very specific type of data might be needed for the purposes of research. In several cases, data collected as part of research projects can become long-term databases which can then be used for clinical care, such as disease registries or system-level dashboards.</p>

SUPPLY FACTORS

64 Centre for Economics and Business Research, *Data on the Balance Sheet*, 5.

65 Data Services for Commissioners, *Data Quality Guidance for Providers and Commissioners* (NHS England, 2016); Nicole Gray Weiskopf and Chunhua Weng, 'Methods and Dimensions of Electronic Health Record Data Quality Assessment: Enabling Reuse for Clinical Research', *Journal of the American Medical Informatics Association* 20, no. 1 (January 2013).

66 Walker and Westbury, 'Towards a Successful Data-Enabled Economy: Promoting Trust in Data and Data-Driven Systems', 40.

67 Data Services for Commissioners, *Data Quality Guidance for Providers and Commissioners*, 6.

68 Neil D. Lawrence, 'Data Readiness Levels', *ArXiv*, May 2017.

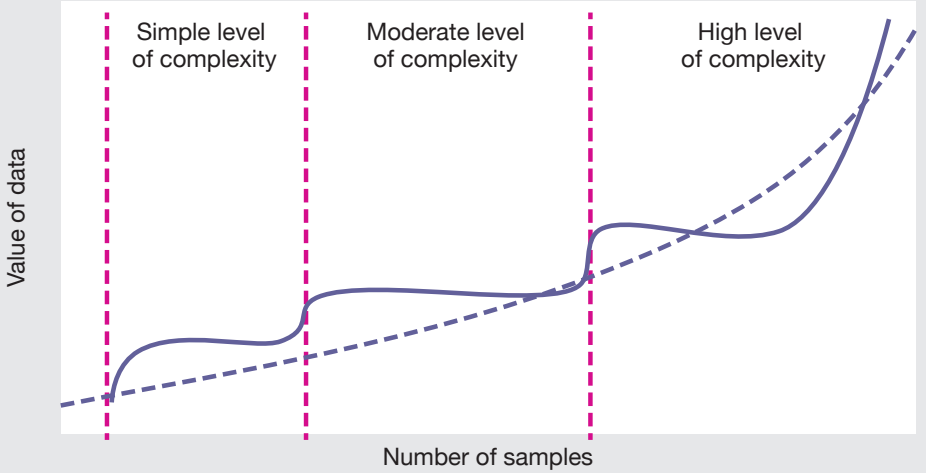
69 Walker and Westbury, 'Towards a Successful Data-Enabled Economy: Promoting Trust in Data and Data-Driven Systems', 40.

70 Wachter, *Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England*.

71 National Institute for Health and Care Excellence, *Data Science for Health and Care Excellence*, 2016.

72 NHS England, *Improving Outcomes through Personalised Medicine*, 2016, 7.

73 Timmis, Luke Heselwood, and Harwich, *Sharing the Benefits: How to Use Data Effectively in the Public Sector*, 17.

Category	Definition
The quantity of data	<p>The quantity of healthcare data has an impact on its value. For example, the value of a single patient record is different to the value of multiple patient records. This is because the smaller the sample size the harder it is to find robust results or to develop system-level products. In the context of machine learning, Posner and Weyl's research provides an interesting visualisation of the value of data, showing that it increases with the amount following a step-wise function.⁷⁴ More data becomes more valuable as it allows for the analysis of more complicated and potentially more valuable problems.⁷⁵</p> <div data-bbox="469 544 1431 1108">  <p>According to Posner and Weyl, the capacity of a machine learning algorithm to solve issues of varying complexity is dependent on the number of samples available.</p> </div> <p>Source: Eric A. Posner and E. Glen Weyl, 'Data as Labor', in <i>Radical Markets</i> (Princeton University Press, 2018), 227-228</p>
The actionability of data	<p>Currently, trade-offs need to be made between the quality and quantity of data as high-quality data are a scarce resource.</p> <p>The contrast in the objectives of the stakeholders highlighted in Figure 1 becomes apparent when looking at the actionability of data. For example, academic researchers might produce excellent research, but it might not have immediate, obvious or realistic real-world applications. However, this type of research might produce value in real-world applications in an indirect way. By advancing fundamental research, this might in turn lead to some practical real-world applications. Another example would be the tension between a data scientist wanting to develop a high-performing model and what might be realistic for the NHS. For example, if the model is good at finding true positives (i.e. the proportion of people with a specific condition who are correctly identified as having that condition by the algorithms) but produces many false positives (i.e. healthy individuals who are told they have a condition when they do not), it can have severe financial implications for the NHS.</p> <p>The ability to produce change on the ground thanks to insights derived from data are essential to derive value. If the insights provided by the eFI did not lead to action, there would be no value generated from data in terms of improved patient outcomes. Making sure that insights are converted into best practice on the ground is not an easy feat.⁷⁶ The production of new clinical evidence around technologies and medicine “does not guarantee its implementation”.⁷⁷</p>

⁷⁴ Eric A. Posner and E. Glen Weyl, 'Data as Labor', in *Radical Markets* (Princeton University Press, 2018), 227.

⁷⁵ Ibid., 227–28.

⁷⁶ L. A. Bero et al., 'Closing the Gap between Research and Practice: An Overview of Systematic Reviews of Interventions to Promote the Implementation of Research Findings', *British Medical Journal* 317, no. 7156 (August 1998); Mark J. Johnson and Carl R. May, 'Promoting Professional Behaviour Change in Healthcare: What Interventions Work, and Why? A Theory-Led Overview of Systematic Reviews', *BMJ Open* 5, no. 9 (September 2015); Stephan U. Dombrowski et al., 'Interventions for Sustained Healthcare Professional Behaviour Change: A Protocol for an Overview of Reviews', *Systematic Reviews* 5 (October 2016); Bhupendrasinh F. Chauhan et al., 'Behavior Change Interventions and Policies Influencing Primary Healthcare Professionals' Practice—an Overview of Reviews', *Implementation Science* 12 (January 2017); Heather L. Colquhoun et al., 'Methods for Designing Interventions to Change Healthcare Professionals' Behaviour: A Systematic Review', *Implementation Science* 12, no. 1 (March 2017).

⁷⁷ Dombrowski et al., 'Interventions for Sustained Healthcare Professional Behaviour Change: A Protocol for an Overview of Reviews', 2.

Figure 4 presents some of the factors which might have an impact on the value of data from a demand-side perspective. In other words what factors might affect an organisation's decision to request data from NHS organisations.

Figure 4: Determinants of the value of data – the demand side

Category	Definition	DEMAND FACTORS
The use of data	The same data could have a different value depending on what it is used for and applied to. Information contained in clinical audits and registries can be both used for monitoring public health outcomes or by commercial organisations for post-market surveillance. In addition, data governance might affect what the data might be used for which might have an impact in its value. ⁷⁸ There can be legislative constraints around what can be done to data.	
The market capitalisation of organisations	The value of a publicly traded private sector organisation might affect its willingness to access different types of data. Organisations with lower market caps, might not be able to afford the time and cost of accessing and cleaning data, thus affecting their willingness to incur the costs of accessing the data.	
The relative cost of getting data elsewhere	It is important to acknowledge that many healthcare systems in the world are preparing for data to be shared with private companies for fundamental and applied research and product/service development. The relative ease and cost with which private sector organisations will be able to access data in other countries might affect the value of the UK knowledge asset.	

2.2.3 How to measure value

HM Treasury's recent report on intellectual property and other intangible assets in the public sector defines public sector data – including healthcare data – as a knowledge asset (e.g. intellectual property, software, data, technological expertise etc).⁷⁹ It argues that better management of knowledge assets is required to release the full value of public sector data.⁸⁰ Ascertaining the value of healthcare data would ensure that this 'national asset' is harnessed for the benefit of society.

Knowledge assets and public sector intellectual property should be protected.⁸¹ In the context of healthcare this should mean benefits are optimised between patients, the NHS and industry. The healthcare system, however, does not have a history of fully harnessing the benefits of innovations it has helped develop. The NHS played a key role in the development of computed tomography (CT), but failed to protect this asset by securing "meaningful financial interest" in the exploitation of that technology.⁸²

However, it is a challenge to measure as data are an intangible asset⁸³ and one for which there is no clear market – although some private sector companies are entering that space and allowing patients to be remunerated for sharing data.⁸⁴ The acquisitions of some healthcare companies have been used as indications for the financial value of NHS data. IBM's acquisition of Merge Healthcare "in the USA for \$1 billion, which netted them five to six million patients' records, might be indicative of the value of the data held by the NHS."⁸⁵ Another example would be Roche who paid \$1.8 billion for Flatiron Health's

⁷⁸ Centre for Economics and Business Research, Data on the Balance Sheet, 6.

⁷⁹ HM Treasury, *Getting Smart about Intellectual Property and Other Intangibles in the Public Sector: Budget 2018*, 3,6.

⁸⁰ Ibid., 12.

⁸¹ Ibid., 16.

⁸² Ibid.

⁸³ Walker and Westbury, 'Towards a Successful Data-Enabled Economy: Promoting Trust in Data and Data-Driven Systems', 41.

⁸⁴ Medicalchain, *Medicalchain Whitepaper 2.1*, 2018; Datum Foundation Ltd, 'Datum Returns Data Ownership to Individuals', *PR Newswire*, 2017; Vasilis Gkatzelis, Christina Aperjis, and Bernardo A. Huberman, 'Pricing Private Data', *Electronic Markets* 25, no. 2 (June 2015); K. T. Pickard, 'Exploring Markets of Data for Personal Health Information', in *2014 IEEE International Conference on Data Mining Workshop*, 2014.

⁸⁵ Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, 88.

health data.⁸⁶ However, healthcare data from the USA is very different to that held by the NHS as it is mostly collected for payment purposes and is very fragmented. An interview carried out for this paper estimated that on average the value of healthcare data can be approximately estimated at £0.45 per feature (e.g. date of birth, weight...) per individual. Financial estimates vary widely and the usefulness of this type of 'market value' measure is limited by the various determinants of value described in Figure 3 and Figure 4.

Healthcare data could be valued by considering the cost of collection and curation.⁸⁷ Nevertheless, this type of valuation assumes that the "cost of data collection can be clearly identified"⁸⁸ and would be a gross underestimation of the value that might be generated from it. Data could be valued "based on a quantification of the earnings and profits from their use".⁸⁹ This is similar to the method suggested in the Treasury's report: "the capitalised net present value of past investment in knowledge generating activities such as research."⁹⁰ Measuring value in this way is difficult because it is complex to estimate what potential earnings data could generate.

In addition, there are both non-monetary and monetary aspects to value. The non-monetary value such as increased quality of care and better health and care outcomes for patients could be measured using traditional instruments such as Quality-Adjusted Life Year (QALYs),⁹¹ which is a measure of the quality and quantity of life generated by a healthcare intervention.⁹²

Given all these measurement pitfalls, the Treasury's report recommends the development of new standards and approaches for measuring and reporting the value of knowledge assets.⁹³ It also suggests registering intellectual property assets with the most commercial potential so that "their value to the UK is maximised".⁹⁴

Recommendation 1

The Office for National Statistics should provide a framework and accounting standards for measuring and reporting the value of knowledge assets such as healthcare data.

The NHS holds a record from cradle to grave of a diverse population. This is a truly unique asset, which could give the UK a competitive advantage on the global stage.⁹⁵ As highlighted, by the House of Lords review on AI, the public are very concerned about companies "making a profit at the expense of both the NHS and patients".⁹⁶ However, there might be a lack of awareness amongst the public about the key role that the private sector plays in the provision of goods and services in the NHS. A fair value exchange should be about optimising the benefits between patients, the NHS and industry.

2.3 Expertise

An important part of the value exchange in the relationship between the public and private sector is expertise. The NHS can provide medical expertise and the insights needed for the research and development of data-driven technologies. It can also provide guidance

86 Roche, 'Roche to Acquire Flatiron Health to Accelerate Industry-Wide Development and Delivery of Breakthrough Medicines for Patients with Cancer', Press Release, n.d.

87 Centre for Economics and Business Research, *Data on the Balance Sheet*, 4.

88 Ibid.

89 Ibid.

90 HM Treasury, *Getting Smart about Intellectual Property and Other Intangibles in the Public Sector: Budget 2018*, 10.

91 HM Treasury, *The Green Book, Central Government Guidance on Appraisal and Evaluation*, 2018, 72.

92 National Institute for Health and Care Excellence, 'Glossary', Webpage, NICE, n.d.

93 HM Treasury, *Getting Smart about Intellectual Property and Other Intangibles in the Public Sector: Budget 2018*, 30–31.

94 Ibid.

95 Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, Report of Session 2017–19 (House of Lords, 2018) p.88; Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*; 'A Revolution in Health Care Is Coming', p.50, *The Economist*, 1 February 2018; Aldrick, 'Data Could Be a Huge Source of Funding for the NHS and We Are about to Give It Away'.

96 Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, 89.

on how to make sense of data that is not primarily collected for the purposes of the research and development of a data-driven technology. In turn, the private sector lends its expertise in fields such as data engineering, artificial intelligence or user centred design to create data-driven technologies. It can also lend its experience and capability in taking a new product or service through development stages, the required regulation, accreditation and standards process (see 3rd arrow at the bottom of Figure 1).

Matt Hancock's vision for the future of the NHS stressed the importance of skills. It raised the need "to recruit and retain" medical and non-clinical professions.⁹⁷ Nevertheless, as highlighted by a few interviews and the research events carried out for this paper, the private sector is acquiring medical expertise by attracting the NHS workforce with higher salaries and has been attracting data scientists for a long time. Putting the NHS's financial constraints aside, it would be impossible for the healthcare system to compete with the salaries in the private sector. The question of staff retention thus will be a crucial one to solve.

2.4 Wider societal impact

Another important element to consider when thinking about the value exchange is the wider societal benefits. Interviews carried out for this paper argued that there is a 'tacit' understanding that when a private sector organisation engages in a partnership with the NHS there is a wider societal benefit expressed through the creation of employment, the payment of taxes and the generations of new technologies and solutions for the market.

There is potentially a need to make a distinction between organisations who are headquartered and pay taxes in the UK and those overseas. It cannot be forgotten that the race for data-driven technologies is a global one.⁹⁸ Having headquarters overseas might allow certain companies to shift profits and not pay their fair share of taxes in the UK. DeepMind's former independent Review Board had called upon the company to clarify its relationship with its parent company Alphabet partly for this purpose.⁹⁹ The company pays its taxes in the UK, however, now that the Streams app (see Figure 12) they developed is moving to Google,¹⁰⁰ the revenue streams generated by this product might not be captured by the UK economy. The Chancellor announced in his 2018 budget a consultation about a UK Digital Services Tax which would seek to target "UK-generated revenues of specific digital platform business models" to make sure that "global giants, with profitable businesses in the UK, pay their fair share towards supporting our public services".¹⁰¹

⁹⁷ Department of Health and Social Care, *The Future of Healthcare*.

⁹⁸ Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*; Ed Fitzgerald, 'International Lessons to Help the NHS Harness Health Data', *The Reformer Blog*, 17 July 2018.

⁹⁹ Martin Bromiley OBE et al., *DeepMind Health Independent Review Panel Annual Report*, 2018.

¹⁰⁰ DeepMind Health, 'Scaling Streams with Google', Website, DeepMind, 13 November 2018; Jee, 'Google's Decision to Absorb DeepMind's Health Division Has Sparked Privacy Fears'.

¹⁰¹ Rt Hon Philip Hammond MP, 'Budget 2018: Philip Hammond's Speech', Speech, HM Treasury, 29 October 2018.

3

Keeping society in the loop

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MIT Professor Iyad Rahman has defined the concept of 'keeping society in the loop' as enabling "society to influence and shape decisions about technology and innovation".¹⁰² Although his concept specifically applies to the design of AI systems,¹⁰³ it is a valuable concept to explore when looking at the types of partnerships people would deem acceptable between the NHS and private sector companies in the data-driven technologies and services industries. Patients are ultimately the producers of that data¹⁰⁴ and will also be on the receiving end as consumers of the products or services being designed.¹⁰⁵ Private sector and NHS organisations need to work on earning patients' trust.¹⁰⁶ Patients and the public need to feel comfortable and able to trust that data is not being exploited¹⁰⁷ and that their privacy is safeguarded.¹⁰⁸ Building a trustworthy system will be key to ensuring patients, the NHS and industry can work collaboratively when using data for research or product and service development purposes.

3.1 Currently not in the loop

While patients have the ability to object to data about them being used beyond direct care,¹⁰⁹ at present patients are not actively involved in partnership discussions. They are given the opportunity to opt-out of data about them being accessed for purposes beyond direct care. In some instances, patients might be asked for their explicit consent when identifiable data about them is being used by NHS organisations, universities or commercial companies for secondary uses. These are the only institutional opportunities for patients to have a 'say'. The model is rather limited by only giving patients a binary option.¹¹⁰ This might not be a sufficient way of engaging on complex issues as there are a number of nuances to patient and public opinion about data uses and in particular commercial access (see Figure 5). These include 'who, what, why, when and how',¹¹¹ indicating that patient opinion will vary from partnership to partnership.

Figure 5: Public opinion

A 2016 study by Ipsos Mori and Wellcome Trust found that people were less inclined to support commercial access to healthcare data, in particular in marketing and insurance industries.¹¹² However, people were generally in favour of commercial access if this was necessary for health benefit.¹¹³ Sixty-one per cent of people in the study would rather commercial companies access data than miss out on research benefits,¹¹⁴ while 25 per cent did not want commercial organisations to access their data under any circumstances.¹¹⁵ It also found that views varied depending on the interaction the

¹⁰² Iyad Rahwan, 'Society-in-the-Loop', *MIT MEDIA LAB* (blog), 12 August 2016.

¹⁰³ Iyad Rahwan, 'Society-in-the-Loop: Programming the Algorithmic Social Contract', *Ethics and Information Technology* 20, no. 1 (March 2018).

¹⁰⁴ Imanol Arrieta Ibarra et al., 'Should We Treat Data as Labor? Moving Beyond "Free"', *American Economic Association Papers and Proceedings* 1, no. 1 (December 2017); Posner and Weyl, 'Data as Labor'.

¹⁰⁵ Department of Health and Social Care, 'New Guidance to Help NHS Patients Benefit from Digital Technology', GOV.UK, n.d.; Kaela Scott, *Data for Public Benefit: Balancing the Risks and Benefits of Data Sharing* (Involve, The Carnegie UK Trust's, Understanding Patient Data, 2018); Accenture, *Digital Consumer Health Engagement 2016 – Global Report*, 2016.

¹⁰⁶ Timmis, Heselwood, and Harwich, *Sharing the Benefits: How to Use Data Effectively in the Public Sector*; Scott, *Data for Public Benefit: Balancing the Risks and Benefits of Data Sharing*; The Caldicott Committee, *Report on the Review of Patient-Identifiable Information* (Department of Health, 1997).

¹⁰⁷ Nick Couldry and Ulises A. Mejias, 'Data Colonialism: Rethinking Big Data's Relation to the Contemporary Subject', *Television & New Media*, September 2018.

¹⁰⁸ Alan F. T. Winfield and Marina Jirotko, 'Ethical Governance Is Essential to Building Trust in Robotics and Artificial Intelligence Systems', *Phil. Trans. R. Soc. A* 376, no. 2133 (November 2018); Graeme Laurie and Emily Postan, 'Rhetoric or Reality: What Is the Legal Status of the Consent Form in Health-Related Research?', *Medical Law Review* 21, no. 3 (September 2013).

¹⁰⁹ National Data Guardian for Health and Care, *Review of Data Security, Consent and Opt-Outs*.

¹¹⁰ Isabelle Budin-Ljosne et al., 'Dynamic Consent: A Potential Solution to Some of the Challenges of Modern Biomedical Research', *BMC Medical Ethics* 18, no. 1 (January 2017); Hawys Williams et al., 'Dynamic Consent: A Possible Solution to Improve Patient Confidence and Trust in How Electronic Patient Records Are Used in Medical Research', *JMIR Medical Informatics* 3, no. 1 (13 January 2015).

¹¹¹ Wellcome Trust, *The One-Way Mirror: Public Attitudes to Commercial Access to Health Data*.

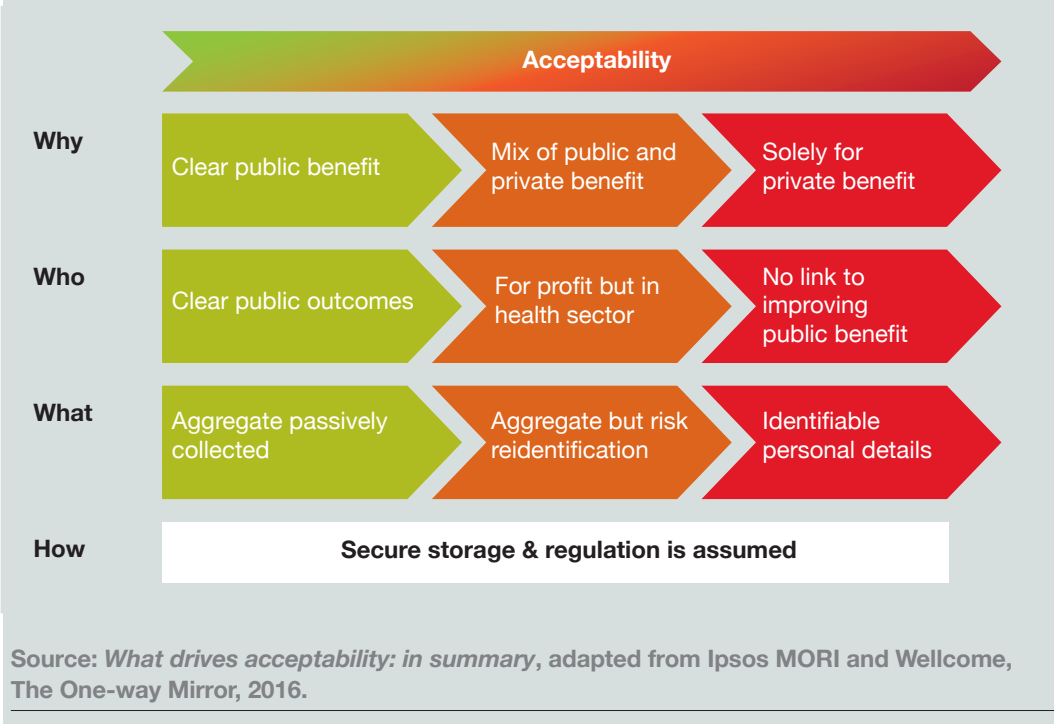
¹¹² *Ibid.*, 91.

¹¹³ *Ibid.*, 97.

¹¹⁴ *Ibid.*, 15.

¹¹⁵ *Ibid.*

individuals had with the NHS. In general, those who interacted more with the NHS were more likely to advocate for data sharing.¹¹⁶ Although, those with severe conditions that are easily identifiable were also worried about the ramifications of sharing data about them.¹¹⁷



Public buy-in will be essential to forming partnerships.¹¹⁸ The care.data programme designed to allow anonymised primary care health records to be shared outside the NHS, is often cited as an example of how policy can go wrong, demonstrating a clear moment where public opinion overturned policy.¹¹⁹ The policy was controversial among the public, who was deeply unsettled by the idea that data about them would be commercialised.¹²⁰ The policy's failure was closely related to a lack of communication and transparency¹²¹ as well as a lack of public confidence in institutions to build fair commercial models.

As shown in Figure 5, on average the public is generally comfortable with commercial access to data if there is an undeniable public benefit. However, when presented with various scenarios levels of acceptability vary.¹²² An interview carried out for this paper described that most commercial partnerships will be along the amber line – partnerships will never be solely for private profit or solely for public benefit – they will be a mix of the two, further demonstrating the need for patients and the public to engage on this issue.

¹¹⁶ Wellcome Trust, *The One-Way Mirror: Public Attitudes to Commercial Access to Health Data*.

¹¹⁷ Ibid., 74.

¹¹⁸ Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*; Lord Freyberg, 'NHS: Healthcare Data – House of Lords Debate Hansard', 2018; Pam Carter, Graeme T. Laurie, and Mary Dixon-Woods, 'The Social Licence for Research: Why Care.Data Ran into Trouble', *Journal of Medical Ethics*, (January 2015); National Data Guardian for Health and Care, *Review of Data Security, Consent and Opt-Outs*.

¹¹⁹ Budin-Ljøsne et al., 'Dynamic Consent'; Carter, Laurie, and Dixon-Woods, 'The Social Licence for Research: Why Care.Data Ran into Trouble'; Roski, Bo-Linn, and Andrews, 'Creating Value In Health Care Through Big Data: Opportunities And Policy Implications'.

¹²⁰ Carter, Laurie, and Dixon-Woods, 'The Social Licence for Research: Why Care.Data Ran into Trouble'; Colin Marrs, 'Care.Data – An In-Depth Check-up on NHS England's Controversial Bid to Join up Health Data', *Civil Service World*, 18 September 2015; Paraskevas Vezyridis and Stephen Timmons, 'Understanding the Care.Data Conundrum: New Information Flows for Economic Growth', *Big Data & Society* 4, no. 1 (June 2017).

¹²¹ Budin-Ljøsne et al., 'Dynamic Consent'; Carter, Laurie, and Dixon-Woods, 'The Social Licence for Research: Why Care.Data Ran into Trouble'; Roski, Bo-Linn, and Andrews, 'Creating Value In Health Care Through Big Data: Opportunities And Policy Implications'.

¹²² Wellcome Trust, *The One-Way Mirror: Public Attitudes to Commercial Access to Health Data*, 9–13.

3.2 Engagement by design

It is essential that society is kept in the loop and feels involved in the data-driven innovation landscape. This goes further than patients engaging in what data are used and by whom, but also involves the partnership and commercial models that exist. *Reform* research suggests that there have been limited attempts to engage the public over this.

As Nicola Perrin, then lead of the Understanding Patient Data initiative, commented in the House of Lord's report, the public "do not like the idea of the NHS selling data, but they are even more concerned if companies are making a profit at the expense of both the NHS and patients".¹²³ This means patients might potentially be less in favour of models such as 'cost-recovery' (see Figure 7) that do not achieve financial value back. The *Life Sciences Industrial Strategy* highlighted that a "strong patient and clinician engagement and involvement, alongside clear permissions and controls, are vital to the success of any health data initiative."¹²⁴

To build a trustworthy system, where patients and the public are engaged, academics such as Mary Dixon-Woods have argued actors, either processing or controlling health data, would need a social licence.¹²⁵ This is different from a legal licence, as it ensures the data processor (see Glossary) or controller consistently acts according to socially defined ethics. A social licence, she argues, would be achieved by acting with 'reciprocity' and 'fairness'.¹²⁶ The former, because the public receives a return from the use of health data (e.g. access to better diagnostic tools) and the latter because the return is equally enjoyed by the public. In order to understand what a fair return might be from the patients' and public's perspectives, private sector and NHS organisations should engage with them to learn about their views. A critical part of this is ensuring that the conversation between patients and private sector stakeholders is continuous. In a field as dynamic as data-driven innovation in the NHS — with constant new patients, new technological potential and a variety of external players, including other government departments¹²⁷ — it is essential that models of engagement are more than a one-off occurrence.¹²⁸

There are various methods for ensuring the continuous nature of the dialogue between patients, the NHS and industry. Connected Health Cities, in association with the National Data Guardian, have used Citizens' Juries to ask "to what extent should patients control access to patient records for secondary use of data".¹²⁹ They found jurors changed their mind over the three days, becoming more positive towards data sharing for public health benefits.¹³⁰ The benefits of this model is that it gives time for patients to form an opinion and have direct contact with experts in the field, while those holding the research can take on patients' opinion and feed it back to governing institutions. To reach more rural areas of the country, such as Cumbria, 'Chatty Vans' have been deployed to explore people's views on various issues to do with health and care.¹³¹ While both examples have been used to engage the public over the governance of health data, these could be more specifically tailored towards commercial models.

There are other ways to platform better governance of data. Until recently, DeepMind Health had an independent review panel, which brought together a group of experts and patient voices to scrutinise the company's behaviour and publish a statement.¹³² Part of this involved assessing the company's approach to engaging patients, as well as

¹²³ Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, 89.

¹²⁴ Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*, 55.

¹²⁵ Carter, Laurie, and Dixon-Woods, 'The Social Licence for Research: Why Care.Data Ran into Trouble'.

¹²⁶ Ibid.

¹²⁷ Timmis, Heselwood, and Harwich, *Sharing the Benefits: How to Use Data Effectively in the Public Sector*.

¹²⁸ Carter, Laurie, and Dixon-Woods, 'The Social Licence for Research: Why Care.Data Ran into Trouble'; Sylvie Delacroix, 'Pervasive Data Profiling, Moral Equality and Civic Responsibility', *UCL Laws and UCL Computer Science*, 17 August 2017; Williams et al., 'Dynamic Consent: A Possible Solution to Improve Patient Confidence and Trust in How Electronic Patient Records Are Used in Medical Research'.

¹²⁹ Malcolm Oswald et al., 'Health Data on Public Trial: To What Extent Should Patients Control Access to Patient Records?', *International Journal of Population Data Science* 1, no. 1 (April 2017).

¹³⁰ Ibid.

¹³¹ HealthWatch Cumbria, *Annual Report 2018*, 2018.

¹³² DeepMind Health, 'Independent Review', Webpage, DeepMind, 2018.

publishing reports with principles for corporate action.¹³³ However, this review panel has been dismantled since DeepMind transferred the “control of its health subsidiary to its parent company Google”.¹³⁴

Proportionate governance offers another alternative to meaningfully engage patients and the public (see Figure 6). This system-wide change, which is government led, could include practical ways of assessing and creating bespoke agreements that use public engagement.

Figure 6: Proportionate governance

In Scotland, the Public Benefit and Privacy Panel for Health and Social Care has been set up to scrutinise applications for access to NHS Scotland data that go beyond direct care.¹³⁵ The idea is to construct a governance model that can be adaptive to each individual research and development application.¹³⁶ Similar to the Independent Group Advising on the Release of Data, which considers external requests for data held by NHS organisations, one of its pivotal assessment criteria for project proposals is whether it has demonstrable public benefit.¹³⁷ The model follows a three-tiered system based on risk. If commercial organisations are involved, the application will immediately go to the second tier where the application is reviewed by a panel of senior experts and Caldicot representatives. If an agreement is not reached about the public benefit, the decision is taken to a third panel made up of members of the public.

As highlighted in the British Academy’s work in partnership with the Royal Society on data governance for the 21st century, access to data as well the governance structures “must consider who reaps the most benefit from capturing, analysing and acting on different types of data”.¹³⁸ Proportionate governance could provide a framework for engaging with the public and keeping ‘society in the loop’ on the types of commercial models that would be deemed fair when there is access to data for research and development or for product or service development. Patient voice and opinion would be included in the governance model by design. This would ensure that commercial agreements are co-produced between industry, health experts, public sector leaders and public representatives through the review process.

Recommendation 2

The Department of Health and Social Care should in conjunction with Caldicott Guardians, NHS organisations and industry representatives ensure that a dialogue with the public is set at a local level to discuss commercial models. Proportionate governance models provide an interesting avenue for public and patient engagement that could be explored.

¹³³ Bromiley OBE et al., *DeepMind Health Independent Review Panel Annual Report*.

¹³⁴ Murgia, ‘DeepMind’s Move to Transfer Health Unit to Google Stirs Data Fears’.

¹³⁵ Information Assurance and Governance Team, ‘About the Panel Public Benefit and Privacy Panel for Health and Social Care’, Webpage, Information Assurance and Governance Team, 2015.

¹³⁶ Nayha Sethi and Graeme T. Laurie, ‘Delivering Proportionate Governance in the Era of EHealth’, *Medical Law International* 13, no. 2–3 (June 2013).

¹³⁷ NHS Scotland, *Public Benefit and Privacy Panel for Health and Social Care: Guiding Principles and Policy for Decision Making*, 1st ed., 2015.

¹³⁸ British Academy and Royal Society, *Data Management and Use: Governance in the 21st Century*, 2017, 27.

4

The healthtech ecosystem

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To create a strong healthtech ecosystem in which a “tech company can...have an equal opportunity to deliver”,¹³⁹ whilst safeguarding the NHS’s constitution¹⁴⁰ and patients’ trust, strong guidance and leadership will be needed to make sure the value of healthcare data is optimised. Efforts have been made by the DoHSC to develop a code of conduct to ensure that partnerships “deliver benefits to patients, clinicians, industry and the health and care system as a whole”.¹⁴¹ The DoHSC is also conducting a formal review to assess “commercial models used in technology partnerships”.¹⁴² However, prior to the code of conduct there was no guidance on what partnerships should look like when there is access to data to create a product or service. This has led to a lack of clarity as to what is happening on the ground and a lack of strategic understanding at a national level about the consequences of the current commercial models developing on the ground.

4.1 Letting a thousand flowers bloom?

Research carried out for this report suggests that there is a wide variety of arrangements between the NHS and industry when there is access to data for research and product or service development purposes.¹⁴³ However, it is difficult to gain an understanding of what the national picture is as there is no national registry describing the various types of commercial models that have developed on the ground. There are registries at Trust-level documenting data access requests, but these are generally not made available online. Figure 7 presents the different models that can be currently found on the ground – more details can be found in Appendix.

Figure 7: Current models

Data sharing agreements	Grant-funded collaboration	Licensing	Cost-recovery	Commercial arrangements
Various organisations including private sector companies can access NHS data for a specific purpose with patient-consent for secondary uses or without patient consent for direct care. Profits generated from the secondary uses of that data are retained by the private sector.	Grants can be allocated either by academic or public sector organisations for specific purposes to other organisations including the private sector as long as they can demonstrate evidence of innovative potential. ¹⁴⁴	An external organisation is given or pays a fee to hold a licence to use or access data. In most cases, this fee will cover the cost of maintaining the data. The licence might also stipulate privacy restrictions and ethical regulations. Profits generated from the use of that data is retained by the private sector.	This model often operates using a licence. In this case the data controller cleans the data and provides services in exchange for a fee to organisations hoping to do research or create products or services. There are variations in cost recovery models.	Commercial arrangements include any kind of arrangement where there is an exchange of assets or valuable resources. For example, access to data might be granted to an external organisation for research or commercial purposes and in return the NHS might get a cleaned higher quality dataset back.

Source: *Reform* research and interviews.

¹³⁹ Department of Health and Social Care, *The Future of Healthcare*.

¹⁴⁰ Department of Health and Social Care, *The NHS Constitution for England*, 2015.

¹⁴¹ Department of Health and Social Care, *Initial Code of Conduct for Data-Driven Health and Care Technology*.

¹⁴² Ibid.

¹⁴³ Alexander J Martin, ‘NHS Patients’ Data Was Illegally Transferred to Google DeepMind’, Webpage, Sky News, 3 July 2017; Sarah Knapton, ‘How the NHS Got It so Wrong with Care.Data’, *The Telegraph*, 7 July 2016.

¹⁴⁴ Innovate UK and UK Research and Innovation, ‘Business Innovation: What Funding You Can Get and How to Apply’, GOV.UK, 16 August 2018; Vicki Sellick, Solder Amy, and Rosalinda Baker, *Funding for Innovation* (Nesta, 2018).

The NHS is not a homogenous body,¹⁴⁵ it is a highly fragmented system and, as a result, each Trust has its own protocol for partnerships.¹⁴⁶ Partnerships might differ as some products or services require different types of data. For example, products or services that support the organisation and management of hospitals may need real-time access to admin data.¹⁴⁷ Other products or services that seek to improve direct patient care might need access to patient records. Relationships between private sector companies in the data-driven technology space and NHS organisations can be mostly characterised by data sharing agreements with no definition of a commercial model involving the NHS and/or patients (see Figure 7).

There are, however, examples of datasets held by central NHS organisations that can share data at a national level, with datasets that cover the entire population. For example, NHS Digital has 12 datasets currently available for external research.¹⁴⁸ However, some interviews carried out for this paper have suggested that most access requests for datasets held by NHS Digital have been from other NHS Trusts and academic institutions. In addition, there are also independent data repositories which have been established by a variety of non-profit actors and funded by research, charity or council funding (see Figure 8 and Appendix).

Figure 8: UK Biobank

The UK Biobank is a registered charity that was set up in 2006 by the Wellcome Trust, the Medical Research Council, the Department of Health and Social Care, the Scottish Government and the Northwest Regional Development Agency, with the aim to be a major national and international health resource for improving the diagnosis, treatment and prevention of diseases such as cancer, heart disease, depression and forms of dementia.¹⁴⁹ The data collected thus far has come from 500,000 volunteers between the ages of 40-69 years and is accessible to any organisation that can prove a research need. The only contingency is that the research must be made publicly available.

There are benefits to an 'open access' model as it offers 'value back' to society through delivering positive externalities such as furthering knowledge and innovation.¹⁵⁰ It increases the opportunities to conduct academic research as well as research and development, thus potentially leading to better health outcomes and economic growth. The model is based on a "notion of altruistic donation and the notion that biobanks serve the scientific and public good".¹⁵¹ This model is not cost-free and requires finance from often a variety of actors from government, third sector donors and corporate donors. The UK Biobank receives finance from government and the Wellcome Trust. In addition, the cost of the cleaning up of UK Biobank data for pharmaceutical research, for example, has required a number of corporate sponsors, who will get exclusive rights to the data for the first two years – see Appendix. However, as highlighted in the Treasury's discussion paper on the economic value of data, this 'open access model' may not be desirable in every instance.¹⁵²

The only example known to date of a partnership between the NHS and industry offering a form of direct 'financial' value back to NHS Trusts for product development purposes is the partnership between Sensyne Health, the University of Oxford and the Oxford University Hospitals NHS Foundation Trust, South Warwickshire NHS Foundation Trust, and Chelsea & Westminster NHS Foundation Trust (see Figure 9).

¹⁴⁵ Wachter, *Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England*.

¹⁴⁶ Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*, 58.

¹⁴⁷ Ibid., 50; Edge Health, 'Improving Theatre Productivity with Machine Learning – "Space Finder"', Webpage, Edge Health, 2017; Edge Health, 'Surgical Pathway Demand and Capacity Planning', Webpage, Edge Health, July 2017.

¹⁴⁸ NHS Digital, 'Data Sets', Webpage, NHS Digital, n.d.

¹⁴⁹ UK Biobank, 'About', Webpage, UK Biobank, n.d.

¹⁵⁰ Andrew Turner, Clara Dallaire-Fortier, and Madeleine J. Murtagh, 'Biobank Economics and the "Commercialization Problem"', *Spontaneous Generations: A Journal for the History and Philosophy of Science* 7, no. 1 (2013).

¹⁵¹ Ibid., 72.

¹⁵² HM Treasury, 'The Economic Value of Data: Discussion Paper', August 2018, 11.

Figure 9: Sensyne health

Sensyne Health partnered with three separate NHS Trusts – Oxford University Hospitals NHS Foundation Trust, South Warwickshire NHS Foundation Trust, and Chelsea & Westminster NHS Foundation Trust – which have equity shares of 6 per cent, 3.7 per cent and 3.7 per cent respectively.¹⁵³ NHS Trusts, however, will never own above 10 per cent collectively,¹⁵⁴ so each time an NHS Trust joins, the other Trusts' shares reduce in size. Alongside this, each Trust is offered a “double bottom-line return” which is £5 million worth of shares and a royalty on any product developed using its data.¹⁵⁵ In 2018, the company was floated on the London Stock Exchange and has since raised £60 million, according to the Oxford Academic Health Science Network (AHSN) review.¹⁵⁶

The company uses health data to create a variety of health-tech products; from “validated software applications powered by artificial intelligence including prescribed digital therapeutics [to] hospital systems for clinical care”.¹⁵⁷ One example is the GDM-Health App that helps manage gestational diabetes at home. Thus far, the product has achieved a 25 per cent reduction in clinic visits and a 50 per cent reduction in time spent by the diabetes midwives on clerical administrative tasks. The App uses NHS data as well as collecting more data for future research.

The Sensyne example is commendable for sharing equity with the Trusts involved, meaning the NHS Trusts have a stake in the company and the potential to benefit financially.¹⁵⁸ Nonetheless, it is important to consider the macroeconomic effect of such partnerships.

4.2 The need for a national strategy

There is a risk that if all partnerships operate at Trust-level only the Trusts in question will benefit, leaving other Trusts to miss out on products or services and potentially monetary benefits.¹⁵⁹ In the long run this can create imbalances in the healthcare system as a whole, contradicting the principle that the NHS is meant to “maximise [its] resources for the benefit of the whole community, and make sure nobody is excluded”.¹⁶⁰ This situation echoes the one explored in the Naylor Review: that Trusts built on more expensive land have higher value capital assets leading to inequality between NHS Trusts.¹⁶¹ With the potential for the value of NHS data assets to be similarly variable between Trusts – because of varying quality of data, for example – there is a risk that keeping value at a local level could increase inequality. As shown in Figure 10, which presents a typology of commercial models, there are many options that could be explored with varying advantages and disadvantages.

¹⁵³ London Stock Exchange, ‘Sch 1 – Sensyne Health Limited – RNS -’, Webpage, London Stock Exchange, 3 August 2018.

¹⁵⁴ Clive Cookson, ‘Drayson Floats Medical AI Group Sensyne Health on Aim’, *Financial Times*, 14 August 2018.

¹⁵⁵ Ibid.

¹⁵⁶ Oxford Academic Health Science Network, *Oxford AHSN Year 6 Q2 Report* (Oxford Academic Health Science Network, 2018).

¹⁵⁷ ‘Sensyne Health: AI Powered Clinical Solutions’, accessed 6 August 2018.

¹⁵⁸ London Stock Exchange, ‘Sch 1 – Sensyne Health Limited – RNS -’.

¹⁵⁹ Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, 93–94.

¹⁶⁰ Department of Health and Social Care, *The NHS Constitution for England*.

¹⁶¹ Sir Robert Naylor, *NHS Property and Estates*, 2017.

Figure 10: Typology of commercial models

Name	Description	Brief evaluation
Consortium agreements	This would be a joint venture (contractual or incorporated) between an NHS organisation, industry, research institutes and/or academic institutes to collaborate as partners to develop and commercialise a product.	<p>The company and the NHS organisation will be the recipients of financial benefits through ownership of the company's shares. The amount will depend on the terms of the profit share and the success of the consortium. If an NHS organisation has a say in the consortium's activities this may be very valuable. However, there is a risk at a national level of creating inequalities between Trusts as the NHS organisation involved in the company will be the only one receiving financial benefits.</p> <p>Feasibility: There could be various joint venture entities in which the NHS participates and, as part of which, it would need to contribute its own offering (e.g. funding, IP, know-how) to the consortium and engage in the operation and running of the consortium. This would likely mean a radical change in the way the NHS currently operates. Managing this could also require a significant amount of NHS manpower, which might be unfeasible given the NHS mandate.</p>
Equity shares	An NHS organisation holds a minority stake in the company it collaborates with. The NHS organisation holding the shares would have the right to receive a dividend/capital appreciation and to vote at shareholder meetings.	<p>The company will be the main recipient of the financial benefits from any dividend and capital appreciation in the value of the shares crystallised on a sale of the company. The size of that benefit will depend on the size of equity share and the success of the products or services. The ability to negotiate preferential arrangements for the provision of goods/services to equity investors may also mean better (or cheaper) access to products/services. Individual NHS Trusts who have equity shares will be the only ones that receive financial benefits and there is therefore a risk of creating financial inequalities at a national level.</p> <p>Feasibility: This model will be most appropriate for a company that is young or relatively new. A larger or more established company might struggle to convince existing shareholders to adopt this model.</p>
Grant funding models	Funding from the academic or public sectors is a well-established method for research and development (R&D). ¹⁶² This model can be used for data-driven innovation and might involve competition for funding opportunities and include commercial conditions such as royalties or equity stakes.	<p>There are various models within grant funding, some of which might have conditions that stipulate an equity stake for a government department, independent body or third sector organisation or discounts on products or services. The recipient of the grant will need to prove that their research, product or service has clear societal benefits. Many grants such as those from the Industrial Strategy Challenge Fund (ISCF) will also give finance directly to the NHS or to an SME for them to build the necessary data infrastructure.</p> <p>Feasibility: The model has been used in the life sciences space for a long time. By providing upfront funding, this helps platform R&D and enables organisations to take the risks needed to build data-driven products and services. However, it is unrealistic to expect grants to be the only way data-driven products and services are created. The donor may be a central government entity (as opposed to the NHS or a Trust) and, as a result, the NHS would not directly receive the financial benefit.</p>
Golden share	In a typical scenario a public sector organisation owns 51 per cent of shares giving it majority voting rights, or a much smaller percentage of shares but still has veto or majority voting rights over certain types of decisions. This is the key defining feature of golden share agreements.	<p>The NHS organisation – this may be NHS Digital or an individual Trust – that gets the ultimate say will receive a lot of the benefits,¹⁶³ e.g. profit share, control over the direction of the business and its products. The other shareholders in the company will also receive financial benefits.</p> <p>Feasibility: Despite being suggested in the Life and Science Industrial Strategy,¹⁶⁴ this model may be unattractive for commercial organisations who would not want the NHS to own the majority of the company and/or have veto over every decision made. This model could be perceived as restricting industry from being able to pursue innovation and its business as it sees fit.</p>

¹⁶² Sellick, Solder, and Baker, *Funding for Innovation*, 5.

¹⁶³ Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*, 15.

¹⁶⁴ Ibid.

Name	Description	Brief evaluation
Intellectual property sharing (IP)	IP generated from using the NHS data would be owned (entirely or in part) by the NHS organisation entering into the data sharing agreement. Such NHS organisations would then license this IP to the third-party collaborator in return for payment (e.g. one-off fees, milestones and/or royalties).	Financial benefits could be generated from any foreground IP – this is the IP generated in collaboration during a partnership – that is produced by a partnership with the health sector. This would allow the NHS and the private sector organisation to own parts of the IP. Feasibility: In order to own (in whole or part) IP generated using NHS data, it is likely that the NHS would need to contribute more than just raw data. This would need to be provided alongside know-how/clinical expertise to add value to justify IP ownership. Equally joint ownership of IP may be resisted on the basis that it can be legally quite complex.
Open-access	In this model, the results from the research produced from healthcare data have to be made ‘open access’ or aggregate healthcare data could be made openly available (see Glossary).	Indirect financial benefits would be created through a thriving market for innovation. Some interviewees have argued that this model could generate a lot of value to the wider economy. Feasibility: Making the results from research transparent is key to building good evidence. However, this model does not allow for information to remain proprietary, which might disincentivise the private sector. There is a limit on the type of data that could be made open access because of compliance with regulation which means that the benefits of an open data model in healthcare might be limited.
Profit-sharing/ revenue-sharing	In return for providing data, the NHS organisation receives a share of the profits of any product developed using the data (without any ownership interest in the company or the IP in the product). This would provide an alternative fee structure to a one-off up-front fee.	The NHS organisation will receive financial benefits from whatever product(s) or services reach market – the exact apportioning of the profit or revenue share might vary. Financial benefits will depend on whether the company is a UK-based tax paying company. Feasibility: This is dependent on the share the NHS organisation demands and what the NHS’s contribution is to justify such a share. It should be recognised that multiple arrangements of this nature, each with small percentage shares may generate significant revenue.
Royalty payment	An NHS organisation and a private sector organisation negotiate a right to a fixed percentage of profits from a specific asset or a fixed price per unit that is sold. There can be other ways of licencing royalties.	Direct financial benefits from whatever products or services reach market and there is demand for – the exact apportioning of the royalty might vary. This will not capture the value of any ‘background IP’ – any IP owned before the partnership. Financial benefits will depend on whether the company is a UK-based tax paying company. In practice there is a risk that one NHS Trust could be receiving royalties for another Trust purchasing the product or service. Feasibility: This is dependent on what royalties the NHS organisation demands as it would need to be realistic for it to be feasible. It ensures that a company does not pay any up-front costs for data.
Local Asset-backed vehicles (LABV)	This is a joint commercial venture between NHS organisations and a private sector partner. In this model, the public sector organisation provides an asset and the private partner matches the contribution in liquid assets, skills and experience (generally there is a 50-50 apportioning).	The NHS organisation and its corporate partner will benefit 50-50. Financial benefits will also be received as the venture is commercial and would be dependent on how the venture is structured, but there is high potential for NHS organisations to profit both from new health innovation and in financial teams. Feasibility: There are no examples of data being used as an asset in this way. As discussed in Chapter 2, valuing NHS data is a very complicated process and might make LABV difficult to implement.

It is crucial for national bodies to ensure that local bodies are not creating perverse incentives in the system. A commercial model might seem fair at GP practice or Trust-level, but on aggregate could be detrimental. Concerns have been raised about these types of perverse incentives already happening on the ground with certain healthtech partnerships.¹⁶⁵ The code of conduct argues that the “benefits of the partnerships between technology companies and health and care providers [should be] shared fairly”.¹⁶⁶ However, there seems to be a lack of clarity about whether fairness should be considered at a micro or macro scale, or both.

¹⁶⁵ Bhatti, ‘Seeing a GP on a Smartphone Sounds Wonderful – but It’s Not’.

¹⁶⁶ Department of Health and Social Care, *Initial Code of Conduct for Data-Driven Health and Care Technology*.

The lack of guidance from central government on the type of appropriate commercial arrangements in the data-driven space has also been found to be a key challenge by parts of the private sector. In a recent Academic Health Science Network survey about AI technologies in health and care, 34 per cent of respondents said the lack of clarity over 'appropriate business models for AI development and deployment' was a key factor affecting AI's potential.¹⁶⁷

All models have advantages and disadvantages, demonstrated by Figure 10, meaning different models will suit different scenarios. It is therefore impractical to recommend one model for all circumstances. Nevertheless, it is crucial that national policy provides a framework for the array of possible models that will not have an adverse effect on the national level.

Recommendation 3

NHS England and NHS Digital should create a register of data sharing agreements between the NHS and commercial organisations. It should include what type of data are being shared and a description of the type of partnership model being used. This would allow for clear understanding of what is happening on the ground and facilitate public scrutiny.

Recommendation 4

The Department for Health and Social Care in conjunction with the Crown Commercial Service, Office for Life Sciences and HM Treasury should make sure to include in its formal review of commercial partnerships, a macroeconomic study of the impact that different partnership models might have to avoid reinforcing a postcode lottery or other negative externalities such as exclusive data access.

Recommendation 5

The Department of Health and Social Care should include the results of this macroeconomic study in a clear national strategy which should seek to optimise the value of data held by NHS organisations when it is accessed for commercial purposes. It should consult with all stakeholders including industry, patients and NHS organisations as to what a fair apportioning of value might be.

4.3 Access to good quality data

Access to good quality data that is fair and for clear public benefit will be key to creating a competitive life and sciences industry that is both innovative and dynamic.¹⁶⁸ It is also crucial for different sized companies operating in the life sciences industry to have a level playing field to "compete and have an equal opportunity to deliver".¹⁶⁹ However, as highlighted in Chapters 1 and 2, data within NHS organisations are currently fragmented and of varying quality.

Most data held by NHS organisations is collected for the purposes of direct patient care and not for research or product or service development purposes. When using this data for purposes beyond direct care it is essential to look at how it was generated to understand how it should be cleaned and avoid "using inappropriate data to make decisions".¹⁷⁰ Evidence shows that using data from electronic health records "without consideration to context, can easily lead to biases or nonsensical findings, making it

¹⁶⁷ Melissa Ream et al., *Accelerating Artificial Intelligence in Health and Care: Results from a State of the Nation Survey* (The AHSN Network, Department of Health and Social Care and NHS England, 2018), 32.

¹⁶⁸ HM Treasury, 'The Economic Value of Data: Discussion Paper'.

¹⁶⁹ Department of Health and Social Care, *The Future of Healthcare*.

¹⁷⁰ British Academy and Royal Society, *Connecting Debates on the Governance of Data and Its Uses*, 2017.

unsuitable for many research questions”.¹⁷¹ Data curation is thus an inevitable part of the process for secondary uses of NHS data.

Nonetheless, there is a strong case to be made for increasing data quality to provide better care for patients¹⁷² and potentially provide a more solid basis of data quality for secondary uses. This can be done in various ways such as minimising error at the data collection point¹⁷³ and embedding data quality by design.¹⁷⁴ The design of electronic health record systems can have an impact on the quality of data collected.¹⁷⁵ IT systems used for data collection could flag for potential mistakes when data are being entered. Similarly, systems that have a greater focus on data visualisation “can reveal data quality problems”,¹⁷⁶ which can then be corrected. The use of AI to translate text to clinical code could be explored to reduce the burden on clinical coders.¹⁷⁷

Once data are collected the monitoring of data quality is crucial.¹⁷⁸ NHS Digital has a Data Quality Maturity Index “quarterly publication about data quality in the NHS”.¹⁷⁹ It provides submitters with transparent information about the quality of the data they collect and does so for specific datasets. Understanding the state of data quality at the early stages of partnership discussions with commercial organisations is crucial. This will enable organisations to understand what data engineering capabilities they will need in order to get the data into an acceptable state for analysis.

Recommendation 6

NHS England should create a ‘Data Quality Service’, with a tiered-fee system dependent on factors such as company size and global profits, to provide bespoke reports on data quality at the early stages of a partnership discussion between the NHS and industry.

In addition, the lack of interoperability of IT systems within the NHS creates a situation in which data are locked into multiple fragmented systems. This can have a negative impact on direct patient care as records cannot always be rapidly shared in a digital format. In addition, the difficulty in linking datasets together can put brakes on innovation and limits patient benefits. NHS Trusts in the North East and North Cumbria, the Darlington Borough Council, and GP practices under the umbrella of the Connected Health Cities programme have decided to collaborate in a research project to tackle this problem. They have managed to link-up data from all the stakeholders and provide it in an anonymised and pseudo-anonymised form to researchers to develop evidence on optimal planning and management for urgent care.¹⁸⁰ This project could have not been completed without the linking of datasets.

It is also crucial that when developing data-driven technologies companies ensure that data generated within those applications are made freely available and interoperable. This would avoid vendor lock-in situations and promote competition by allowing NHS organisations to choose different providers.

171 Denis Agniel, Isaac S. Kohane, and Griffin M. Weber, ‘Biases in Electronic Health Record Data Due to Processes within the Healthcare System: Retrospective Observational Study’, *BMJ* 361 (April 2018).

172 Tim Yates, ‘Improving Clinical Data Quality: The Digital Health Challenge’, *BMJ Quality Blog*, 13 December 2016.

173 Amy P. Abernethy et al., ‘Use of Electronic Health Record Data for Quality Reporting’, *Journal of Oncology Practice* 13, no. 8 (July 2017): 530–34.

174 Timmis, Heselwood, and Harwich, *Sharing the Benefits: How to Use Data Effectively in the Public Sector*, 17; Harwich and Laycock, *Thinking on Its Own: AI in the NHS*, 31.

175 Wendy Rollason, Kamlesh Khunti, and Simon de Lusignan, ‘Variation in the Recording of Diabetes Diagnostic Data in Primary Care Computer Systems: Implications for the Quality of Care’, *Informatics in Primary Care* 17, no. 2 (October 2009); Rui Mendes and Pedro Pereira Rodrigues, ‘Main Barriers for Quality Data Collection in EHR – A Review’, *Conference: HEALTHINF 2011 – Proceedings of the International Conference on Health Informatics*, January 2011.

176 Ben Shneiderman, Catherine Plaisant, and Bradford W Hesse, ‘Improving Healthcare with Interactive Visualization’, *Computer* 46, no. 5 (May 2013): 61.

177 Fathom, ‘Fathom – AI to Automate Medical Coding’, Webpage, Fathom, n.d.; dictate.it, ‘Welcome to Dictate.It’, Webpage, dictate.it, n.d.

178 Timmis, Heselwood, and Harwich, *Sharing the Benefits: How to Use Data Effectively in the Public Sector*, 18.

179 NHS Digital, ‘Data Quality’, Webpage, NHS Digital, 2018.

180 Connected Health Cities, ‘Predictive Modelling for Unplanned Care in the North East and North Cumbria’, Webpage, Connected Health Cities, 2018.

Recommendation 7

Procurement rules should include an agreement by digital providers that data generated within clinical applications should also be freely available for and interoperable with clinical information at the patient level, either via personal health records or interchange with appropriate electronic health records.

In the Royal Society and the British Academy's seminal work on data management and use in the 21st century, a key concern is the tension between improving public services through the use of data whilst protecting privacy.¹⁸¹ Risks to patient privacy such as reidentification can compromise the trustworthiness of private companies and NHS organisations seeking to use data for research or product development. Ensuring the auditability, transparency and security of a data access system are not easy feats. Whilst proving compliance is essential, it might also slow down access to data. A few interviews for this paper highlighted that there is a reticence within the NHS to share data with private sector organisations because their objectives are often viewed as antithetical with the idea of public benefit. This does not need to be the case. The *Life Sciences Industrial Strategy* argued that collaboration between NHS and industry can facilitate better care “for patients through better adoption of innovative treatments and technologies”.¹⁸² However, compliance with information governance models is key and clarity over the type of partnerships and commercial agreements is needed.

4.3.1 Digital innovation hubs

The *Life Sciences Industrial Strategy* highlighted the use of ‘Digital Innovation Hubs’ as an opportunity to access healthcare data for research and innovation and reduce the variation “in digital maturity”.¹⁸³ The delivery of this programme is being led by Health Data Research UK.¹⁸⁴ The programme has received £37.5 million in funding from the Industrial Strategy’s Challenge Fund.¹⁸⁵ The Hubs are meant to connect data from GP practices, hospitals, social and community care providers, alongside genetic and biomedical information and other datasets across regions of 3-5 million people safely and securely.¹⁸⁶ The programme aims to improve access to data for “researchers and industry innovators...to help deliver better care and improve health for patients, society and for future generations.”¹⁸⁷ The governance of these hubs needs to be given serious thought but could also present the opportunity to involve patients or patient representatives¹⁸⁸ to engage with decisions about how data about them is being used and what type of commercial arrangements should be put in place.

Recommendation 8

Health Data Research UK in conjunction with NHS England, NHS Digital and the National Data Guardian should work on developing the appropriate data governance structures to ensure that Digital Innovation Hubs are safeguarding patient data. This would include developing audit trails which track how data are used to ensure every interaction with personal data is auditable, transparent and secure.

¹⁸¹ British Academy and Royal Society, ‘B: Priorities for Governance’, in *Data Management and Use: Governance in the 21st Century: Priorities for Data Governance: Discussions at the British Academy and Royal Society Seminar on October 2017*, 2017, 5.

¹⁸² Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*, 3.

¹⁸³ *Ibid.*, 59.

¹⁸⁴ Health Data Research UK, ‘Digital Innovation Hub Programme’.

¹⁸⁵ *Ibid.*

¹⁸⁶ Health Data Research UK, ‘£37.5m Investment in Digital Innovation Hubs to Tackle Britain’s Biggest Health Challenges’, Webpage, Health Data Research UK, 16 July 2018.

¹⁸⁷ *Ibid.*

¹⁸⁸ Delacroix, ‘Pervasive Data Profiling, Moral Equality and Civic Responsibility’; Sethi and Laurie, ‘Delivering Proportionate Governance in the Era of EHealth’.

4.3.2 Synthetic data

Speed of access to data might have an impact on the type of health tech market that will develop, with smaller businesses being more greatly impacted by delays in access compared to bigger companies. Nevertheless, that should never come at the price of good data governance and protection of an individual's privacy. There are however some interesting advances in the privacy-preserving space.¹⁸⁹

Advances in processing capacity have allowed for the production of high-quality synthetic data.¹⁹⁰ By selecting a specific sample of 'real' data, it is possible to create a much larger sample of very realistic fake data.¹⁹¹ This fake data can then be used to train another machine learning model to read and appropriately classify mammography scans, for example. This offers huge future potential in terms of facilitating access to healthcare data.

Synthetic data offers exciting new possibilities in terms of a privacy-preserving technique and lowering barriers to access data.¹⁹² NHS Digital in partnership with the Medicines and Healthcare products Regulatory Agency (MHRA) has received funding from government to develop synthetic datasets.¹⁹³ The fake datasets will "be aimed at increasing the capability to accurately measure the effectiveness of new artificial intelligence algorithms in medical devices in order to validate them and get them to the market".¹⁹⁴ This is an interesting step as one of the regulatory challenges of validating machine learning algorithms is the fact that datasets used to train the algorithm need to be different from those used to validate it. Synthetic data offers the possibility of creating infinite amounts of slightly different datasets.

Public Health England has also recently funded the release of a synthetic dataset for the cancer registry.¹⁹⁵ Having done the initial work around what distribution system for this type of data works others should follow suit. The Hospital Episode Statistics (HES) dataset is linked to the cancer registry,¹⁹⁶ however NHS Digital is the controller of that data, which means they could easily replicate what Public Health England has done and create a synthetic version of HES to be published on their website.

Other NHS organisations should explore the potential of synthetic datasets, by releasing synthetic data that could be used by private sector companies for research and product or services development purposes. This would ensure that patient privacy is preserved as patient data would never be revealed or shared at that stage. In addition, it could allow for a more informed conversation about commercial models and for the potential value from data-driven innovations in healthcare to be realised without having to use patient data in the initial stages of innovation.

Recommendation 9

NHS organisations should offer synthetic datasets, which they can share with private sector organisations for research and product or service development at the early stages of the innovation process. This would enable a better understanding of the commercial value of the innovation and a more informed conversation about the appropriate type of commercial model that should be developed.

¹⁸⁹ MDCIone, 'Synthetic Data', Webpage, MDCIone, n.d.

¹⁹⁰ Dimitrios Korkinof et al., 'High-Resolution Mammogram Synthesis Using Progressive Generative Adversarial Networks', *ArXiv*, July 2018; Arvind Arasu, Kaushik Shriraghav, and Jian Li, 'Synthetic Data Generation', *37th International Conference on Very Large Data Bases*, December 2012.

¹⁹¹ Stefanie Koperniak, 'Artificial Data Give the Same Results as Real Data — without Compromising Privacy', *MIT News*, 3 March 2017.

¹⁹² R. Shamsuddin et al., 'Virtual Patient Model: An Approach for Generating Synthetic Healthcare Time Series Data', in *2018 IEEE International Conference on Healthcare Informatics (ICHI)*, 2018, 208–18.

¹⁹³ NHS Digital, 'NHS Digital Welcomes Funding for Joint Project with MHRA on Creating Synthetic Devices', Webpage, NHS Digital, 5 October 2018.

¹⁹⁴ Ibid.

¹⁹⁵ Public Health England, National Cancer Registration and Analysis Service, and National Disease Registration Service, 'Background on the Simulacrum', Webpage, Simulacrum, 2018.

¹⁹⁶ NHS Health Research Authority, 'Cancer Survival Using Further Data from Audits, RTDS and HES – V2', Webpage, NHS Health Research Authority, 2017.

4.4 Procurement, partnership, or somewhere in between?

The healthtech market operates by using two main models: a partnership model and a procurement model. The procurement model is underpinned by the delivery of a clearly defined good or a service from an external provider, which is bought by the public sector (see Figure 11). The provider must have validated its innovation and be able to establish a business case during competitive tender processes.¹⁹⁷

Figure 11: Example of procurement

DrDoctor has created an application that helps to schedule out-patient appointments which has gone through procurement. The application organises appointments and platforms virtual appointments between patients and doctors. Industry evidence on users of this App shows that users have enjoyed the ease of access to appointment services and healthcare professionals. DrDoctor requires real-time patient data which an algorithm analyses to make suggestions.

In contrast, a partnership will encompass a more complex relationship that does necessitate a transfer of finance (see Figure 12). The latter is more likely to be used for the creation of products or services that need research and trials, while procurement would be used for a finished products or services, such as the DrDoctor App.

Figure 12: Example of partnership

The Royal Free Trust and DeepMind have partnered to create an App known as Streams. The App was meant to alert clinicians, “up to 7 hours earlier”, to acute kidney injury (AKI) in patients. Enabling them to respond faster and avoid kidney damage.¹⁹⁸ The App has a ‘service agreement’,¹⁹⁹ which stipulates that the NHS uses the App for free unless DeepMind’s running costs surpass £15,000.²⁰⁰ This has meant that the App has not gone through a public procurement process as the App is used for free. In 2015, the partners signed an Information Sharing Agreement, and then later a Memorandum of Understanding in 2016, which transferred identifiable patient data from the Royal Free to DeepMind. This transfer was deemed unlawful by the Information Commissioner’s Office.²⁰¹

Recently, DeepMind has announced it will be passing over the Streams App to its parent company Google.²⁰² The company has pledged that patient data remains under the strict control of NHS Trusts “and all decisions about its use will continue to lie with them.”²⁰³ However, the company has been criticised for “betraying patient trust”, and dismantling its Independent Review Panel.²⁰⁴

However, there remain some blurred boundaries. It is unclear how a procurement process could have been triggered in the partnership model presented in Figure 12 if running costs surpassed £15,000 as the Royal Free would have already been using the product.

It is also important to consider at what stage data are being used for products or services development, as it will impact whether procurement or partnership is necessary. Some

¹⁹⁷ Department of Health and Social Care, *Procurement Guide for Commissioners of NHS-Funded Services*, 2010.

¹⁹⁸ Natasha Lomas, ‘DeepMind Health Inks New Deal with UK’s NHS to Deploy Streams App in Early 2017’, *TechCrunch*, 21 November 2016.

¹⁹⁹ DeepMind Health and Royal Free London NHS Foundation, ‘Redacted: Services Agreement between DeepMind Technologies Limited and Royal Free London NHS Foundation Trust’, Contract, 2016.

²⁰⁰ Sam Shead, ‘Google DeepMind Is Giving the NHS Free Access to Its Patient Monitoring App’, *Business Insider*, 24 June 2017.

²⁰¹ Information Commissioner’s Office, ‘Royal Free – Google DeepMind Trial Failed to Comply with Data Protection Law’, Press Release, 3 July 2017.

²⁰² DeepMind Health, ‘Scaling Streams with Google’.

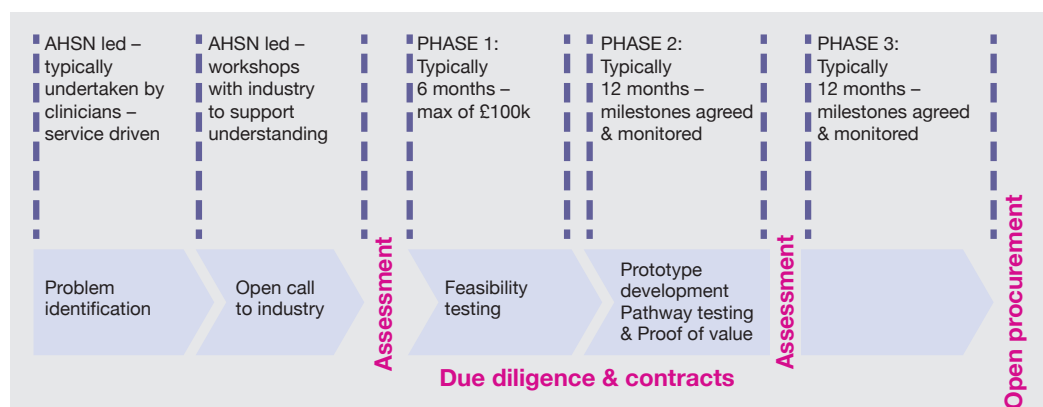
²⁰³ Ibid.

²⁰⁴ Jee, ‘Google’s Decision to Absorb DeepMind’s Health Division Has Sparked Privacy Fears’.

products or services require data for research and development, while other products or services that have been created will only rely on data to run i.e. a product or service that requires the input of live patient data to make real-time decisions. The latter is more suited to procurement, demonstrated by Figure 11. However, often products will require data at both stages, meaning that partnerships might eventually need to go through procurement, once the research and development stage has been finished. In addition, the *Life Sciences Industrial Strategy* highlights that NHS procurement processes can “make it very difficult for SMEs to find a route to market”,²⁰⁵ thus creating an uneven playing field.

There are, however, more structured innovation processes such as the Small Business Research Initiative (SBRI) (see Figure 13). It offers a pathway to connect public sector needs with innovative ideas and solutions from the private sector.²⁰⁶ These are divided by different sectors, the healthcare SBRI is led by the Academic Health and Sciences Networks (AHSN) that have been set up to encourage health innovation across the UK.²⁰⁷

Figure 13: SBRI process



Under this initiative, the NHS can identify a market need and run a competition for businesses to compete for funding in return for providing solutions to health and care needs.²⁰⁸ The programme is aimed at SMEs, as it provides vital assistance to smaller companies in the early stages of creation but is, despite the name, open to all business.²⁰⁹ The advantage of this more structured innovation is that government can have more control over the products or services created with the private sector, ensuring they cater to the demands of health and care. Once a product or service has been created, the public sector has the right to license the subsequent technology, however its IP remains with the company enabling growth and wealth creation for the UK economy.²¹⁰ Thus far, the programme has awarded 211 contracts and managed to bring 22 products to market.²¹¹

However, there are some disadvantages to the SBRI model. As shown in Figure 13 the maximum amount of funding is limited, which might constrain the type of innovation being developed or might necessitate further private finance. In addition, the competition is a one-off, meaning that most other companies that apply will not be supported in any way and will most likely not survive post-competition, as highlighted by one of the interviews for this paper.

²⁰⁵ Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*, 54.

²⁰⁶ Innovate UK and UK Research and Innovation, ‘SBRI: The Small Business Research Initiative’, Webpage, GOV.UK, 26 September 2018.

²⁰⁷ SBRI Healthcare, ‘About Us’, Webpage, SBRI Healthcare, 2017.

²⁰⁸ Ibid.

²⁰⁹ Ibid.

²¹⁰ Ibid.

²¹¹ Martin Leaver, *AHSN Network Impact Report 2017* (The AHSN Network, 2017).

The Government has launched the Industrial Strategy Challenge Fund (ISCF) to support UK science and business innovation and help research and product or service development. Part of this fund makes NHS data available to industry competitors who can offer product solutions for: early diagnosis and precision medicine, healthy ageing, and leading-edge healthcare.²¹² Up to £50 million is available for the creation of Centres of Excellence for healthcare which will be tailored towards helping SMEs test new products that use new technologies such as artificial intelligence within the NHS.²¹³ Alongside the ISCF, as part of the wider Industrial Strategy in the UK,²¹⁴ the Government has recently announced an AI Sector Deal worth £1 billion, £300 million of which comes from private-sector finance, some of which comes from Japan and Canada.²¹⁵ The deal puts into action some of the recommendations in the House of Lords report *'AI in the UK: ready, willing and able?'* and is focused on creating the right ecosystem in the UK for a thriving AI industry.

Partnership models seem to offer more flexibility at the early stages of the innovation process and might be a way to alleviate some of the concerns around the potentially ill-fitted nature of current procurement processes for data-driven technologies. However, there might be a need to clarify the boundaries between some commercial partnerships and procurement processes. In addition, Figure 12 shows the importance of having the legal and commercial skills to negotiate a 'change of control clause' – a provision in an agreement giving "a party certain rights in connection with a change in ownership or management of the other party to the agreement" – in commercial contracts.²¹⁶

4.5 Commercial and legal skills

To create a thriving healthcare ecosystem in which the private sector acts as a partner to the public, Government will need the right skills to negotiate these partnerships.²¹⁷ However, this will require a significant amount of upskilling. This has been recognised in Matt Hancock's vision for the future of the NHS which highlights the need to "build in-house capability to procure data-driven technologies and manage commercial arrangements".²¹⁸

NHS Digital's Capability 2020 review found that there were "gaps in expertise [...and] legal capacity", compared to the banking sector, which can offer higher salaries, being a key competitor for this labour.²¹⁹ It also found "the structure of the workforce is unsustainable with significantly more senior people than junior in commercial, and in procurement not enough senior people."²²⁰ The review concluded that a "bigger inhouse capability" would be necessary to bridge the skills gap in NHS digital for working with the private sector.²²¹

NHS England has sought to address this gap in its workforce through the NHS Digital Academy, a virtual organisation set up to develop a new generation of excellent digital leaders.²²² In partnership with Imperial College London, the University of Edinburgh and Harvard Medical School, it "provides a year-long world class learning programme".²²³ One of its modules specifically seeks to address the gap around commercial skills and procurement. However, it may take some time for this programme to impact the prevalence of commercial and legal skills on the ground, as the first cohort only started in April 2018.

212 Innovate UK, 'Industrial Strategy Challenge Fund – What Is It and How Is It Being Formed?', Webpage, GOV.UK,, 3 February 2017.

213 UK Research and Innovation, 'Up to £50 Million for New Centres of Excellence to Deliver 21st Century Healthcare – Call Open', Web Page, UK Research and Innovation, 2018.

214 HM Government, *Industrial Strategy: Building a Britain Fit for the Future*, 2018.

215 HM Government, *Industrial Strategy: Artificial Intelligence Sector Deal*, 2018.

216 Practical Law, 'Change of Control Clause', Webpage, Practical Law, n.d.

217 Department for Digital, Culture, Media & Sport, Department for Business, Energy & Industrial Strategy, The Rt Hon Greg Clark MP, and The Rt Hon Matt Hancock MP, 'Tech Sector Backs British AI Industry with Multi Million Pound Investment', Press Release, GOV.UK, 26 April 2018

218 Department of Health and Social Care, *The Future of Healthcare*.

219 NHS Digital, 'Fit for 2020 – Report from the NHS Digital Capability Review', July 2017, 37.

220 Ibid.

221 Ibid.

222 NHS England, 'NHS Digital Academy', Webpage, n.d.

223 Ibid.

At the early stage of partnership discussions, NHS organisations will need to be savvy in drawing up contracts, applying the most suitable and proportionate models when negotiating clauses with the private sector.²²⁴ There was a near consensus among interviewees that these frameworks and models will need to be flexible and tailored to a specific context. These might vary depending on the application and size of the company as it is crucial that SMEs benefit from a level playing field.

Having an even distribution of commercial skills at Trust-level would be unfeasible as those skills are a scarce resource within the public sector. They are also a very expensive resource. The Treasury's report on knowledge assets recommends the establishment of a "centre of expertise within government to provide advice and support on the technical, legal and financial aspects for generating and exploiting knowledge assets."²²⁵ Establishing this centre at a national level would avoid issues around vacant positions at a local level because attracting that talent is not easy. Nevertheless, when setting up this 'centre of expertise' it is important that policy makers are aware of the risk of regulatory capture – when a regulatory agency advances the concerns of commercial interest groups rather than acting in the public interest.²²⁶

Recommendation 10

The Department of Health and Social Care should invest in creating a new independent unit with legal and business experts to help NHS organisations negotiate fair and proportionate partnerships. It would ensure that NHS organisations can have access to consistent and necessary advice in order to negotiate fair partnership with SMEs. The negotiation of partnerships should be done by this unit on behalf of Trusts when dealing with Large Enterprise or SMEs whose parent companies are Large Enterprise.

²²⁴ Select Committee on Artificial Intelligence, *AI in the UK: Ready, Willing and Able*, 90.

²²⁵ HM Treasury, *Getting Smart about Intellectual Property and Other Intangibles in the Public Sector: Budget 2018*, 30.

²²⁶ Michael E. Levine and Jennifer L. Forrence, 'Regulatory Capture, Public Interest, and the Public Agenda: Toward a Synthesis', *Journal of Law, Economics, & Organization* 6 (April 1990); Ernesto Dal Bó, 'Regulatory Capture: A Review', *Oxford Review of Economic Policy* 22, no. 2 (July 2006).

Conclusion

The wealth of data collected and controlled by NHS organisations is extremely valuable for the improvement of direct patient care and the productivity of the healthcare system.²²⁷ States around the world, from Israel²²⁸ to South Korea,²²⁹ are heavily investing in digital health programmes as there is huge potential for data-driven innovation in healthcare.²³⁰ With one of the oldest national health services in the world, the UK has a uniquely large and diverse population health-data resource which could give the country a competitive advantage on the global stage.²³¹

Healthcare data are primarily used for the purposes of patient care but can sometimes be accessed by organisations outside of the NHS for research and development or product and service development purposes. Industry access to healthcare data are more contentious in the eyes of the public than access by academic institutions for example.²³² Nevertheless, partnerships with industry are necessary to reap the full benefits of data-driven innovation.

The DoHSC's code of conduct for data-driven health and care technology stipulates that "any benefits from partnerships between technology companies and health and care providers are shared fairly".²³³ However, prior to this code there was no guidance on what partnerships should look like when there is access to data to create a product or service. This has meant that Trusts have been independently building partnerships with the private sector, creating a patchwork on the ground.²³⁴

At a national level, there is both a lack of clarity on developments at a local level as well as a lack of a strategic understanding about the consequences of the current commercial models. What might seem fair at a local level might lead to a poor outcome on a national level such as further entrenching healthcare inequalities. In addition, finding the appropriate ways to engage with patients on the types of commercial models that might be deemed fair is crucial. Patients need to have trust that their data are being used ethically for the public benefit whilst preserving their privacy.

As highlighted by the British Academy and Royal Society "societies can act in advance to create well-founded responses that contribute to bringing the benefits of disruptive technologies into being."²³⁵ The DoHSC needs to develop a clear national strategy that seeks to optimise the value of data held by NHS organisations when it is accessed for commercial purposes. This will ensure that the value of data held by NHS organisations is optimised between patients, NHS organisations and industry for public benefit.

227 Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*; Roski, Bo-Linn, and Andrews, 'Creating Value In Health Care Through Big Data: Opportunities And Policy Implications'; Border, *Big Data and Public Health*; House of Commons Science and Technology Committee, *The Big Data Dilemma – Fourth Report of Session 2015-16*, HC 468 (London: The Stationary Office, 2016); Department of Health and Social Care, *The Future of Healthcare*; Harvey, 'Ready...set...AI – Preparing NHS Medical Imaging Data for the Future'; Harwich and Laycock, *Thinking on Its Own: AI in the NHS*.

228 Yaacov Benmeleh, 'Israel to Invest \$275 Million in Digital Health Project', *Bloomberg*, 25 March 2018; Rahul Dutta, 'A Bit of Israeli Chutzpah – a Way Forward for AI Applications in Healthcare!', *Times of Israel*, 28 October 2018; Max Schindler and Judy Siegel-Itzkovich, 'Israel to Launch Big Data Health Project amid Privacy Concerns', *Jerusalem Post*, 25 March 2018.

229 Richard Staines, 'South Korea Hopes Big Data Will Boost Life Sciences Industry', *Pharmaphorum*, 20 February 2018.

230 Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*; Roski, Bo-Linn, and Andrews, 'Creating Value In Health Care Through Big Data: Opportunities And Policy Implications'; Border, *Big Data and Public Health*; House of Commons Science and Technology Committee, *The Big Data Dilemma – Fourth Report of Session 2015-16*; Department of Health and Social Care, *The Future of Healthcare*; Harvey, 'Ready...set...AI – Preparing NHS Medical Imaging Data for the Future'; Harwich and Laycock, *Thinking on Its Own: AI in the NHS*.

231 Select Committee on Artificial Intelligence, AI in the UK: Ready, Willing and Able, Report of Session 2017–19 (House of Lords, 2018) p.88; Bell, *Life Sciences Industrial Strategy – A Report to the Government from the Life Sciences Sector*; 'A Revolution in Health Care Is Coming', p.50, *The Economist*, 1 February 2018; Aldrick, 'Data Could Be a Huge Source of Funding for the NHS and We Are about to Give It Away'.

232 Wellcome Trust, *The One-Way Mirror: Public Attitudes to Commercial Access to Health Data*.

233 Department of Health and Social Care, *The Future of Healthcare*.

234 Ream et al., *Accelerating Artificial Intelligence in Health and Care: Results from a State of the Nation Survey*, 6.

235 British Academy and Royal Society, *Data Management and Use: Governance in the 21st Century*, 27.

Appendix

Year	Parties involved	Summary of research project or product/ service	Terms of agreement
2015 - present	<p>DeepMind and Royal Free NHS Foundation Trusts</p> <p>Has since been rolled out in Imperial; Tauton and Somerset; and Yeovil Trusts.²³⁶</p> <p>DeepMind has recently announced the App would be scaled up by Google, out of the company's control.</p>	<p>The Streams App can alert clinicians to acute kidney injury in patients “up to 7 hours earlier”,²³⁷ enabling them to respond faster and avoid kidney damage.</p> <p>Eventually, it is supposed to become an AI assistant to help with diagnosis.²³⁸ However, it is currently used to help doctors communicate by sharing real-time patient data with doctors.</p>	<p>A redacted version of the ‘Service Agreement’ can be found online:²³⁹</p> <ul style="list-style-type: none"> > The Trust is the data controller acquiring data processing services from DeepMind to ‘support direct care of patients’ > DeepMind own all the IP of any product, as well as a licence to use the Trusts’ background IP > The Trust is entitled to no commercial benefit; it is being supplied a service, not a product > The App provides ‘direct care’ and therefore there is ‘implied patient consent’ > If DeepMind’s running costs surpass a threshold of £15,000, the NHS trust may have to cover extra costs for the service.²⁴⁰
2016 - present	Moorfields Eye Hospital NHS Foundation Trust and DeepMind ²⁴¹	<p>The partnership is a research collaboration between DeepMind and Moorfields Eye Hospital. AI is used to diagnose and detect eye disease, potentially faster and more accurately than doctors can.</p> <p>Results found that the machine learning algorithm made the correct diagnoses 94.5 per cent of the time.</p>	<p>Specifics of the agreement:</p> <ul style="list-style-type: none"> > Data security is ensured by DeepMind > The agreement lasts five years with the possibility of renewal > DeepMind accesses pseudonymised and/or anonymised data, therefore they do not need direct patient consent > Once the agreement comes to an end, all the data collected will be destroyed – unless a new agreement is negotiated > The algorithms used are owned by DeepMind

²³⁶ DeepMind Health, ‘DeepMind Health and the Royal Free’, Webpage, DeepMind, 2017.

²³⁷ Ibid.

²³⁸ Jamie Condliffe, ‘Is DeepMind’s Health-Care App a Solution, or a Problem?’, *MIT Technology Review*, 22 November 2016.

²³⁹ DeepMind Health and Royal Free London NHS Foundation, ‘Redacted: Services Agreement between DeepMind Technologies Limited and Royal Free London NHS Foundation Trust’.

²⁴⁰ Shead, ‘Google DeepMind is giving the NHS free access to its patient monitoring app.’

²⁴¹ Aliya Ram, ‘DeepMind Develops AI to Diagnose Eye Diseases’, *Financial Times*, 4 February 2018.

Year	Parties involved	Summary of research project or product/ service	Terms of agreement
2006 - present	UK Biobank and various commercial and non-commercial actors ²⁴²	<p>The UK Biobank is a major national and international resource open to a variety of stakeholders (e.g. universities, private sector). Its aim is to improve prevention, diagnosis and treatment of life-threatening illnesses.</p> <p>The data from various blood, urine, and saliva samples, and detailed information from 500,000 people, is used primarily for research.²⁴³</p>	<p>Data are licenced to external organisations who can prove that their research will have a positive impact on health. The terms of such agreements:</p> <ul style="list-style-type: none"> > Applicants will be expected to pay for access to the resource on a cost-recovery basis, with a fixed charge for managing the application review process and a variable charge depending on how many samples, tests and/or data are required for the approved research project > UK Biobank will remain the controller of the database and samples but will have no financial claim over any inventions that are developed by researchers using the resource > All users will be required to publish their findings and return their results to UK Biobank so that they are available for other researchers to use for health-related research that is in the public interest²⁴⁴
2018 - 2020	UK Biobank and a consortium of pharmaceutical companies such as: Regeneron, AbbVie, Alnylam, AstraZeneca, Biogen and Pfizer ²⁴⁵	<p>Regeneron et al. and UK Biobank data are being cleaned and used for research and drug testing.</p> <p>The pre-competitive consortium will fund the creation of genetic exome sequence data (500,000 genetic data records linked with other measures such as brain, heart, body imaging) for research.</p> <p>The main aim is to find and create new treatments.</p>	<p>Terms for partnership:</p> <ul style="list-style-type: none"> > All contributing \$10 million each to the sequencing project > The dataset will eventually be open access, but the consortium will get exclusive access until the end of 2020.

²⁴² UK Biobank, 'About'.

²⁴³ Ibid.

²⁴⁴ UK Biobank, 'Researchers', Webpage, UK Biobank, 28 November 2018.

²⁴⁵ UK Biobank, 'About'; Richard Staines, 'Regeneron: Biobank Project Offers Hope for Alzheimer's R&D', *Pharmaphorum*, 15 January 2018.

Year	Parties involved	Summary of research project or product/ service	Terms of agreement
2016 - present	Babylon Health	<p>The GP at Hand App is for patients to seek medical help online. The platform connects GPs with patients; so they can either have a consultation over the phone or book one online. This is supposed to cut waiting times and save GP time.</p> <p>It is also hoped that the App will be able to diagnose using AI. The company claimed that its diagnosing systems were on par with doctors.²⁴⁶</p>	<p>The App has been commissioned by the NHS Hammersmith and Fulham CCG under a General Medical Services (GMS) contractual agreement.²⁴⁷</p> <ul style="list-style-type: none"> > The App is free at the point of access, but patients will need to live within proximity to the GP at Hand's surgeries or live and work in London zones 1-3 > The App has other restrictions on access e.g. people who are under 16 or with complex needs > Patient data they collect can be shared back with the NHS > Data are also kept for Babylon's own research. They write: "We may also retain your data for medical regulatory purposes, as legally required. On a fully anonymised basis, we may use the data for research purposes and to improve the services we deliver to all patients" > The App is still under trial, and progress in the Hammersmith and Fulham CCG will be monitored before thinking of scaling-up use <p>The expansion of the App outside of London was recently blocked by NHS leaders for safety concerns.²⁴⁸</p> <p>The App exists outside of the NHS, and here Babylon collects health data through the App. It also has a relationship with Bupa, where it charges them £25 per appointment.²⁴⁹</p>

²⁴⁶ BBC Two, 'BBC Two – Horizon, 2018, Diagnosis on Demand?'

²⁴⁷ NHS England, 'GP at Hand – Fact Sheet', Webpage, NHS England, n.d.

²⁴⁸ National Health Executive, 'NHS England Blocks Expansion Plans for "GP at Hand" App Citing Safety Fears', Webpage, National Health Executive, August 2018.

²⁴⁹ Data Services for Commissioners, *Data Quality Guidance for Providers and Commission*

Year	Parties involved	Summary of research project or product/ service	Terms of agreement
2017 – present	Sensyne Health, University of Oxford and Oxford Hospital Foundation Trust, initially – Chelsea and Westminster Hospital NHS Foundation Trust and South Warwickshire NHS Foundation Trust are now also involved ²⁵⁰	<p>Sensyne Health is a healthcare technology company using AI and data science to develop new medicines and improve patient care.</p> <p>For example, the GDM-Health App, which is providing digital therapeutic management for diabetes during pregnancy, has been particularly successful. 98 per cent would recommend it to friends and family. It has also significantly reduced caesarean sections. The company estimates a cost saving of £230 per patient.²⁵¹</p> <p>The company hopes to become an example of how a commercial company can partner with an NHS organisation.²⁵²</p>	<p>The company has a partnership and a Memorandum of Understanding with NHS Trusts – the first being Oxford University Hospital Foundation Trusts and the University of Oxford.</p> <p>The commercial model involves equity shares:</p> <ul style="list-style-type: none"> > Oxford University Hospitals NHS Foundation Trust, South Warwickshire NHS Foundation Trust, and Chelsea & Westminster NHS Foundation Trust, have equity shares of 6 per cent, 3.7 per cent and 3.7 per cent respectively²⁵³ > It appears that NHS Trusts will own 10 per cent collectively,²⁵⁴ so it is assumed that each time an NHS Trust joins, the other Trusts' shares reduce in size > Each Trust is also offered a “double bottom-line return” which is £5 million worth of shares, as well as a royalty on any product developed using its data²⁵⁵ <p>Sensyne was originally known as Drayson Health when it first started in 2017 – it became Sensyne Health only in 2018, when it registered on the London Stock Exchange.</p>
2016 – present	Adler Hey Children's NHS Foundation Trust, IBM Watson and Science and Technology Facilities Council (STFC)	<p>In 2016 Alder Hey announced a new 'Cognitive Hospital' which would use IBM Watson technology to harness the power of Big Data.²⁵⁶ According to IBM, the partnership will improve the patient experience, direct care and potentially create efficiency savings.²⁵⁷ One recent product development is the Alder Play App, an AI powered patient App and webpage. It allows incoming patients to ask a chatbot questions and helps improve children's experiences of hospitals by helping them earn rewards for visiting parts of the hospital.²⁵⁸</p>	<p>IBM Watson services have been procured through the Technologic Facilities Council for Adler Hey Children's NHS Foundation Trust.</p> <ul style="list-style-type: none"> > IBM Watson technology is used by the hospital to exploit its own data asset, meaning IBM has no need to access NHS data > IBM is contributing £200m, and the government £115m, for research into 'Big Data' applications²⁵⁹ > The Alder Play App collects data to identify patterns such as food queries, but does not collect any personal data other than email addresses.²⁶⁰

250 Sensyne Health, 'Sensyne Health: AI Powered Clinical Solutions'.

251 Sensyne Health, 'Research & Discovery Powered by AI', Webpage, Sensyne Health, n.d.

252 Sensyne Health, 'Sensyne Health – Placing and Proposed Admission to Trading on AIM', Webpage, London Stock Exchange, August 2018.

253 Ibid

254 Cookson, 'Drayson Floats Medical AI Group Sensyne Health on Aim'.

255 Ibid.

256 IBM, 'Alder Hey Children's Hospital Set to Become UK's First "Cognitive" Hospital', Webpage, IBM, 11 May 2016.

257 Ibid.

258 Stephen Armstrong, 'Alder Hey's "Cognitive Hospital" Aims to Turn NHS Use of AI on Its Head', *BMJ* 362 (10 September 2018).

259 Clive Cookson, 'Alder Hey Hospital to Use IBM's Watson to Comfort Patients', *Financial Times*, 10 May 2016.

260 Armstrong, 'Alder Hey's "Cognitive Hospital" Aims to Turn NHS Use of AI on Its Head', 1.

Year	Parties involved	Summary of research project or product/service	Terms of agreement
2017 - 2018	NHS Digital and various commercial companies such as: Northgate Public Services Ltd; Capita; IQVIA Solutions UK Ltd; HEALTH IQ Ltd; Method Analytics Ltd; Meditrends Ltd; Lightfoot Solutions; Harvey Walsh Ltd; Device Access UK Ltd ²⁶¹	Each company will be using different datasets for different purposes, such as research and development.	<p>Data sharing agreements effectively give a third party (e.g. university or private-sector company) a licence to use the data:</p> <ul style="list-style-type: none"> > Users pay a fee for the licence to cover the cost for NHS Digital, which costs £1,000 for set-up and the first year's service. There is an Annual Service Charge of £1,000 > The owner of the licence can sublet this agreement > If NHS Digital feels that the agreement has been breached, it will charge the user up to £15,000 for an audit if it is found to have breached the terms.
2012 - present	Clinical Practice Research Datalink (CPRD)	CPRD collects and links de-identified patient data from a network of GP practices and other health-related longitudinal data such as HES controlled by NHS Digital. Data are provided for research that will bring about health benefits and medical advancement.	<p>A licence to use data is granted by the Independent Scientific Advisory Committee which independently reviews research requests to access data from CPRD.</p> <p>The CPRD has two main types of licences:</p> <ul style="list-style-type: none"> > An Individual Study Licence for one-off study > An Unlimited Licence for an annual subscription <p>It has a three-tiered pricing model for:</p> <ul style="list-style-type: none"> > Non-commercial customers (academic, government, charity) > Commercial mid-tier customers (single entity commercial organisations), and > Commercial multi-affiliate organisations <p>The price of an Individual Study Licence for most of CPRD's link data is £4,000 irrespective of the customer sector. The Individual Study Licence for primary care data is £15,000, £30,000 or £60,000 for each tier, respectively. A Multi-Study Licence for primary care data is approximately 5 times the price of the Individual Study Licence.</p> <p>The review process for each licence has multiple stages. The priority is ensuring the owner of the license is a reputable bona fide research organisation which is going to use the data to conduct research for public benefit – it is expected that all research and results will be published.</p> <p>The terms of the licence include:</p> <ul style="list-style-type: none"> > Restrictions preventing the owner of the licence from merging the data with other data sources; transferring the data to third parties other than as strictly permitted through the customer's licence; or selling the data or incorporating it in to a product. Crucially, however, the results of the research using the data are owned by the licensee and not further restricted > All CPRD data must be destroyed on the completion of the study and/or licence term; the data cannot be used to measure effectiveness of sales or advertising campaigns.

261 For more information, <http://theysolditanyway.com/> website has a further examples of NHS Digital data release register.

Year	Parties involved	Summary of research project or product/ service	Terms of agreement
2015 - present	DrDoctor and various health Trusts, such as Guy's Foundation Trust ²⁶²	An App that helps patients make appointments and reminders. The Trusts are expected to make a £2.5 million to £3.5 million return from the App. Outcomes thus far: Improve referral-to-treatment time; increase attendance by over 15 per cent; reduce non-attendance by 47 per cent.	This example follows procurement via the G-Cloud framework. Alongside this, it has had to make separate data sharing agreements with each Trust, sometimes a costly experience for DrDoctor.
2017 - present	Ultromics ²⁶³ a spin out from the University of Oxford and now partnered with 20 NHS hospitals ²⁶⁴	Creating new diagnostic aids for cardiologists using AI. Initial findings indicate the AI could increase the accuracy of diagnoses by 80-90 per cent.	The trial agreement: > Ultromics have access to NHS data across various wards and use data to run algorithms to diagnose heart disease > It has said publicly that whatever diagnostic products it creates would be shared for free with the NHS > The company have said that the products could potentially save the NHS £300 million a year by reducing the number of people who are incorrectly diagnosed ²⁶⁵ The company intends to bring technology to the USA and UK markets. ²⁶⁶
2002 – present	National Joint Registry (NJR) and various commercial companies	Most companies use the data to judge the success of their hip or joint replacements and other health products/services associated with joints. ²⁶⁷	The NJR has different costings for different stakeholders. The principle of the subscription rate is that 'you pay what you can'. It is a cost-recovery model: > The data comes from the NHS web portal. The NJR will clean and analyse the data – which the NHS will get back for free > Commercial companies will pay a subscription of £3,500 per year, large companies pay more > Data comes with analytical report – but a report or bespoke data will cost extra.

262 DrDoctor, 'Home', Webpage, 2018.

263 Ultromics, 'Revolutionising Cardiovascular Diagnosis', Webpage, Ultromics, n.d.

264 Leontina Postelnicu, 'Start-Ups Leveraging AI to Improve Outcomes and Put Patients in Control of Their Care', Webpage, MobiHealthNews, 2 October 2018; Pete Hughes, 'JR AI to Detect Heart Disease Could Be Rolled out across the UK', *Oxford Mail*, 4 January 2018.

265 Owen Hughes, 'Ultromics AI Platform to Expand Trials to 20 NHS Hospitals', Webpage, Digital Health, May 2018.

266 Ibid.

267 Understanding Patient Data, 'Monitoring Joint Replacement Surgery', Webpage, Understanding Patient Data, n.d.

Year	Parties involved	Summary of research project or product/service	Terms of agreement
2016 - present	Kheiron Medical, several universities, the NHS and seed funders	Kheiron Medical, a machine learning company focused on supporting radiologists to tackle breast cancer. The company brings together experts from academia (Oxford, Cambridge, Edinburgh, McGill, KTH, University College London [UCL] and Imperial College), and clinical experts. ²⁶⁸	<p>Kheiron has a partnership with the NHS platformed by grant funding and data sharing agreements:</p> <ul style="list-style-type: none"> > Grants have been provided by various UK and EU organisations. One example is the NHS England Wave 2 Test Bed project with the East Midlands Radiology Consortium (EMRAD), which Kheiron was awarded in a competition²⁶⁹ > Kheiron is also involved in two out of the five ISCF Centres of Excellence for AI in digital radiology and pathology <p>Some of these public-sector grants also provide money to the NHS partner to produce the resources the SME needs to develop products or services</p> <p>The company has also published on its website that it hopes to create a commercial strategy with the NHS.²⁷⁰</p>
Spring 2017	Skin Analytics Ltd and Imperial College Health Partners AHSN ²⁷¹	Currently in development, the partnership is pioneering two new technologies which should enable cost-effective population-based screening for skin cancer. The company has already built two AI melanoma screening tools for assessing pigmented lesions in primary care and earlier. Some can be used at home on a personal mobile. The two extra products under development will be used in addition to the others.	<p>The partnership is platformed by the SBRI healthcare initiative.</p> <ul style="list-style-type: none"> > Skin Analytics has won competition as part of the ISCF data to early programme. The funding will help them support the development of two products for the diagnosis of skin cancer.²⁷² > The project has thus far received £99,941 from government funding <p>Prior to the partnership, the company had received private funding for a start-up. One product was initially priced at £40 and aimed at families and consumers, rather than medical professionals.²⁷³</p> <p>The company is also conducting research with 7 NHS hospitals, led by the Royal Free. It is the first prospective study for AI and melanoma, and the company promises to share the research results in early 2019.²⁷⁴</p>

268 Kheiron Medical, 'About Us', Webpage, Kheiron Medical, 2018.

269 Kheiron Medical, 'NHS Code of Conduct for Data-Driven Health and Care Technology', Webpage, Kheiron Medical, 2018.

270 Ibid.

271 Skin Analytics, 'Pioneering Research', Webpage, Skin Analytics, 2018.

272 SBRI Healthcare, 'Skin Analytics Ltd', Webpage, SBRI Healthcare, 2017

273 Laura Rosbrow-Telem, 'Skin Analytics' Smartphone Lens Screens for Skin Cancer', Webpage, Geektime, 16 October 2015.

274 Skin Analytics, 'Pioneering Research'

Glossary

Anonymised data: data “about individuals but with identifying details removed”.²⁷⁵

Artificial intelligence: any manmade agent (i.e. computer programme or robot) that exhibits intelligence. Intelligence is defined as an “agent’s ability to achieve goals in a wide range of environments.”²⁷⁶

Audit trail: a record of everyone who has looked at or changed a record, why and when they did so and what changes they made.²⁷⁷

Consent (and its different forms): “approval or agreement for something to happen after consideration. For consent to be legally valid, the individual must be informed, must have the capacity to make the decision in question and must give consent voluntarily.”²⁷⁸

Explicit Consent: “It can be given in writing or verbally, or conveyed through another form of communication such as signing.”²⁷⁹ **Implied consent:** “applicable only within the context of direct care of individuals. It refers to instances where the consent of the individual patient can be implied without having to make any positive action, such as giving their verbal agreement for a specific aspect of sharing information to proceed.”²⁸⁰

Data architecture: this is the overall environment of data and includes frameworks, models, standards, policies, data management, data quality, unstructured data etc.

Data controller: “a person who (either alone or jointly or in common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed.”²⁸¹

Data-driven technologies: in this paper the term will describe any technology that uses data as part of its creation and not just or solely as part of its functioning. An example would be a machine learning algorithm which needs data to be trained on.

Data processor: “any person (other than an employee of the data controller) who processes the data on behalf of the data controller.”²⁸²

Data subject: “an individual who is the subject of personal data”.²⁸³

Data standards: the rules by which data are described and recorded. In order to share data properly, the format and the meaning of the data must be standardised.

Information governance: the way in which organisations management the way information and data are handled to ensure it is legal, secure, efficient and effective.²⁸⁴

Intangible asset: a “non-monetary asset without a physical substance”. An asset is defined as “any resource controlled by a company which generate future economic benefits and has an associated cost or value which can be reliably measured.”²⁸⁵

Knowledge asset: a type of intangible asset. It defines a wide-range of intellectual resources such as intellectual property (IP), software, data, technological expertise, organisational know-how, etc.²⁸⁶

²⁷⁵ NHS Digital, ‘How We Look after Information’, Webpage, NHS Digital, 2017.

²⁷⁶ Shane Legg and Marcus Hutter, ‘A Collection of Definitions of Intelligence’, *Frontiers in Artificial Intelligence and Applications* 157 (June 2007): 8.

²⁷⁷ National Data Guardian for Health and Care, *Information: To Share or Not to Share? Information Governance Review*.

²⁷⁸ Health and Social Care Information Centre, *A Guide to Confidentiality in Health and Social Care*, 2013, 7.

²⁷⁹ Ibid.

²⁸⁰ Ibid.

²⁸¹ Information Commissioner’s Office, *Guide to Data Protection*.

²⁸² Ibid.

²⁸³ Ibid.

²⁸⁴ National Data Guardian for Health and Care, *Information: To Share or Not to Share? Information Governance Review*.

²⁸⁵ Centre for Economics and Business Research, *Data on the Balance Sheet*, 2.

²⁸⁶ HM Treasury, *Getting Smart about Intellectual Property and Other Intangibles in the Public Sector: Budget 2018*.

Machine learning: a subset of AI that allows computer systems to learn by analyzing huge amounts of data and drawing insights from it rather than following pre-programmed rules.²⁸⁷

Metadata: information that describes other data by providing a description of its content.²⁸⁸ For example, a digital image may include information on its size, resolution, when the image was created etc.

Personal identifiable data: data “containing details that identify individuals”.²⁸⁹

Pseudonymised data: data “about individuals but with identifying details (such as name or NHS number) replaced with a unique code.”²⁹⁰

Population/aggregate data: “anonymised information grouped together so that it doesn't identify” individuals.²⁹¹

²⁸⁷ The Royal Society, *Machine Learning: The Power and Promise of Computers That Learn by Example*, 2017, 20.

²⁸⁸ Richard Kemp, Paul Hinton, and Paul Garland, ‘Legal Rights in Data’, *Computer Law & Security Review* 27, no. 2 (April 2011): 142.

²⁸⁹ NHS Digital, ‘How We Look after Information’.

²⁹⁰ Ibid.

²⁹¹ Ibid.

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- — —. *Data Management and Use: Governance in the 21st Century*, 2017.
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