



FUTURE CARE CAPITAL



Taking Next Steps to Harness the Value of Health and Care Data

About us

Future Care Capital is a charity which undertakes research to advance ideas that will help shape future health and social care policy and deliver better outcomes for individuals living in the UK. Beginning life as the National Nursery Examination Board in 1945, the charity has evolved throughout its 70-year history and we continue to have Her Majesty the Queen as our Royal Patron. For further information about us, see: www.futurecarecapital.org.uk

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Acknowledgements

This work contains quantitative and qualitative data obtained from primary and secondary research undertaken by Future Care Capital.

It also draws upon discussions involving representatives of

the Academy of Medical Royal Colleges | Aging 2.0 | the Association of Medical Research Charities | the Cabinet Office | the Centre for Data Ethics and Innovation | Connected Health Cities | the Department for Digital, Culture, Media and Sport | Future Agenda | HDR-UK | the Department for Health and Social Care | the Health Foundation | HM Treasury | the Government Office for Science | the Institute of Global Health Innovation | the Office for Artificial Intelligence | the Office for Life Sciences | the Medicines Discovery Catapult | NHS Digital | NHS England | NHS Improvement | NHS Providers | NHSX | the University of Cambridge | the University of Oxford | Use My Data

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Whilst the analysis and views expressed here are those of the authors alone, we have benefited greatly from conversations with broad-ranging stakeholders.

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Executive Summary

We have produced this Discussion Paper about the practical steps needed to better harness the value of health and care data, which reflects upon recent and anticipated policy developments, to stimulate debate about where they might help or hinder progress - in improving outcomes for individuals, critical infrastructure and services, as well as in delivering economic development goals and bolstering the sustainability of health and care provision.

We explore:

- **Demand:** What organisations want data controlled or generated by health and care organisations?
- **Supply:** What data do health and care organisations control or generate? How might the UK harness broad-ranging data, insights and tools not directly controlled/generated by them in order to improve health and care outcomes?
- **Value:** What is the value of data controlled or generated by health and care organisations? If that cannot be determined robustly, what criteria might be applied to determine the 'tipping point' beyond which their depreciation is anticipated? What value is currently 'enclosed' by private entities or, else, deemed to be 'leaking'?
- **Strategy Development:** What should the UK's strategic priorities be regarding harnessing the value of data controlled/generated by health and care organisations as well as other potentially useful data in respect of health and care?

Key Research Findings

Publicly funded and accountable health and care organisations in the UK are not currently required to report data about requests to access or use the data they control for research and/or commercial purposes in a consistent manner. Nonetheless, we found that:

- Acute and Mental Health trusts received up to x10 as many requests to access/use the data they control for research or commercial purposes each year as Ambulance and Care trusts, and Foundation Trusts (FTs) received x2-x3 times as many requests as non-FTs;
- Trusts in the West Midlands, London and the North West received more requests than other regions and demand, generally, mapped to the presence nearby of a Russell Group university; and
- Most recorded requests came from Higher Education Institutions (HEIs) and other NHS organisations rather than commercial entities, although 1/3 of requests resulted in a financial/commercial relationship between the Trust and the requester and Trusts from London, the West Midlands and the North West were most likely to enter into such relationships.

There appears to be a discrepancy in the potential for NHS Trusts of different types and in different places to harness the value of health and care data. Our concern is that this could be at odds with the Government's intention to maximise the value of healthcare data whilst ensuring a fair distribution of associated benefits (Office for Life Sciences, 2018).

In the course of our Discussion Paper, we recommend that Government

- mandates standard returns from health and care organisations so that data supply, demand and commercialisation activities are made transparent;
- pilots innovative approaches to auditing and communicating the demand for data controlled by and/or generated with organisations that might comprise an Integrated Care System - to test their trustworthiness from the point of view of individuals and utility from the point of view of constituent organisations and front-line professionals as well as innovators and commercial entities;
- explores the scope to use its powers at a national level to increase access to and/or the supply of operational data, insights and tools from contractual arrangements entered into by publicly funded health and care organisations and takes a view about the relative merits of such organisations entering into other types of arrangement in anticipation of a value return; and
- tests innovative approaches to better harness the value of operational data, insights and tools generated by and/or with health and care organisations in practical settings to improve clinical, social, economic development and commercial outcomes.

Our understanding of the term 'value' refers to clinical, social, economic development as well as commercial value because, in practice, Government must alight upon a forward plan of action that delivers each type of them if the potential for data-driven innovation is to be capitalised upon 'in the round'. Crucially however, that is not to suggest that each type of value should be afforded *equal weight* in any resultant proposition.

Where data-driven innovation is reliant upon person-identifiable data, Government should commit to upholding and improving established consent mechanisms. It should also pursue a policy of 'radical transparency' in the interests of building and maintaining public trust. Ultimately, individuals should have a say and stake in whether and how the value of health and care data about them is being harnessed via a readily intelligible and trustworthy feedback loop.

Government should also recognise and put in place measures to better harness the benefits that could flow from operational data, insights and tools - which could be

- better utilised in the design, commissioning and delivery of services impacting individuals' care and population outcomes;
- more rapidly, securely and less controversially deployed by public bodies than patient-identifiable data and their derivatives to stimulate innovation and the creation of new businesses and employment opportunities - complete with export capabilities; and/or
- made more accessible to enhance competition amongst existing and prospective suppliers with the potential to realise efficiencies and/or improve productivity.

Discussion Points

- What do we mean when we talk about the ‘fair distribution of benefits’ from data-driven innovation in health and care?
- How might we reconcile the tension between the local use of data to develop intellectual property and the derivation of benefits at a national level?
- How will we ensure individuals are able to understand and have a say and/or stake in whether and how the social, economic development and commercial value of health and care data about them is being harnessed – what might a readily intelligible and trustworthy feedback loop look like in practice?
- How is the control/ownership of operational data, insights and tools treated in the course of procurement exercises undertaken by publicly funded and accountable health and care organisations?
- Is there scope and utility in seeking to introduce national standards for the operational data, insights and tools that are controlled, generated or developed through out-sourcing?
- What benefits could flow from the development of a ‘digital twin’ for health and care infrastructure and services integral to it?
- If the commercial value of data, insights and tools controlled and/or generated by health and organisations cannot be determined robustly, what criteria might be applied to determine the ‘tipping point’ beyond which their depreciation is anticipated?
- What steps does Government intend to take in order to protect, enhance and deploy UK health and care data assets such that the Government maximises their clinical, social, economic development and commercial value as well as guarding against depreciation?

Context

Around the world, governments are exploring how they might make best use of health and care data to transform outcomes for the populations they serve, whilst grappling with an array of country and region-specific challenges (Future Agenda, 2018). Our own work in this regard has involved extensive research and policy development activity in the United Kingdom (UK). In particular, we have sought to better understand how the clinical, social, economic development and commercial value of such data might be harnessed with the express consent, involvement and support of the general public (Future Care Capital, 2017; 2018a; Bagenal and Naylor, 2018). We have also highlighted the lack of interest and investment in data and technology to evolve social care planning and provision in comparison with health (Future Care Capital, 2018b).

Our overarching aim has been to ensure that any benefits flowing from the fourth industrial revolution in health and care are fairly distributed or, better still, serve proactively to tackle inequalities (whether existing or potential). During that time, broad-ranging developments have continued to underline that data-driven innovation harbours significant potential – whether we are talking about turbo-charging the prevention agenda, enabling the development of new treatments and technologies, supporting independent living, empowering the health and care workforce, or seeking to improve productivity in systems and services. Meanwhile, a number of high-profile cases have resulted in calls to bolster the cybersecurity measures that are designed to safeguard health and care services and their users (Ghafur, Grass, Jennings & Darzi, 2019). Others, involving the use and misuse of personal data, have hit the headlines with implications for public trust in data handling by corporate entities – in particular, where social media companies are concerned.

Understandably, the national policy landscape has also moved on apace. Last year, the UK introduced a new *Data Protection Act* (2018) to reflect the key tenets of the European Union’s (EU) *General Data Protection Regulation* (GDPR). The Government established the Centre for Data Ethics and Innovation (CDEI) and placed the National Data Guardian for Health and Social Care (NDG) on a statutory footing – enshrining our call for the UK to blaze a trail in the development of ‘data ethics’ to proactively build trust whilst safeguarding individuals in pertinent national legislation and policy. The Department of Health and Social Care (DHSC) also published a first iteration of its *Code of Conduct for Data-driven Health and Care Technologies*, which laid the foundations for an iterative approach to development of the Code’s core principles (DHSC, 2018). We called for adherence to the Code to be mandated at the time and remain hopeful that Government will require commissioners and providers to uphold its central tenets in due course, although we acknowledge the need to strike a balance between regulation and innovation where the development, testing and roll-out of new technologies is concerned.

Supplementary to Budget 2018, HM Treasury (HMT) published *Getting Smart about Intellectual Property and Intangible Assets* (HMT, 2018). It provides high-level recommendations about managing public sector ‘knowledge assets’ to generate social, economic and financial benefits as a precursor to an implementation study due later this year (HMT, forthcoming). It is, as yet, unclear whether this will result in intangible assets controlled and/or generated by health and care organisations being placed on the National Balance Sheet, in keeping with our call for the

same (Future Care Capital, 2018b), since international agreement upon pertinent accounting standards has failed to keep pace with the development of our increasingly digital economy. We also anticipate challenges in reconciling which knowledge assets generated and/or developed by organisations set to comprise Integrated Care Systems (ICSs) in England should be accounted for at a local level – subject to the parameters of proposed legislation about the same – and whether and how they might then be reflected in the Whole of Government Accounts (WGA). However, at the very least, we would hope to see a commitment to update best value guidance about them in the Green Book integral to the Comprehensive Spending Review later this year.

In Autumn 2018, the Department for Business, Energy and Industrial Strategy (BEIS) launched its Artificial Intelligence and Data Grand Challenge - further demonstrating the Government's commitment to stimulating the use of leading-edge technologies to improve diagnostics and, with them, patient outcomes. Then, in December, the Office for Life Sciences (OLS) published its latest Life Sciences Sector Deal (OLS, 2018). Amongst other things, the Deal points toward the development of a national policy framework to govern commercial relationships between NHS organisations and third parties, – echoing our call for the development of a framework for healthcare information sharing agreements involving NHS bodies to ensure that they conform to nationally agreed standards (Future Care Capital, 2018a). Specifically, the Deal states that any such framework will be underpinned by guiding principles that are currently subject to consultation - namely:

- 1) any commercial use of NHS data must have an explicit aim to improve the health and care of patients in the UK;
- 2) NHS data is an important asset and, in entering into commercial arrangements, NHS organisations should ensure they agree mutually beneficial and fair terms;
- 3) any commercial arrangements agreed by NHS organisations should not undermine, inhibit or impact the ability of the NHS, at a national level, to maximise the value or use of NHS data;
- 4) any commercial arrangements agreed by NHS organisations should be transparent, clearly communicated, and not undermine public trust and confidence either in the NHS or in wider government data policies; and
- 5) such arrangements should fully adhere to all national level legal, privacy and security obligations, including in respect of the National Data Guardian's Data Security Standards.

It also references exploration of the scope to establish a national centre of expertise to provide specialist legal and commercial advice as well as standard contracts to assist NHS organisations. This is in keeping with our recommendation that Government take such steps in order to optimise the value derived from healthcare information sharing agreements entered into with third parties with further details of both the principles and the Centre anticipated later this year¹.

¹ We have consistently championed Principles (1)-(5) but we are concerned at the time of writing that (3), as currently conceived, might introduce a logical and/or legal inconsistency in consideration of both Schedule 4 to the NHS Act 2006 and section 7(2) of the Health and Medicines Act (HMA) 1988 or, at least, require changes in connection with the same. The findings from primary research we outline in Part A of this Discussion Paper speak directly to the challenges the Government faces in delivering (4) and are echoed in our submission to the National Data Guardian's Consultation on Priorities (2019). For further information about the powers and responsibilities of the Secretary of State for Health and Social Care as well as NHS Trusts in respect of developing ideas and exploiting intellectual property, see: Lock, D., and Gibbs, H., *NHS Law and Practice*, pp229-233 [Legal Action Group, 2018].

Elsewhere in Government, a White Paper proposed changes to the 2021 Census, with implications for the future of social care data collection and analysis. The outcome of practical next steps is as yet unknown, but we hope that they will reflect some of the lessons learned from our work with local authorities on the subject (Future Care Capital, 2018b). We also await the Government's Social Care Green Paper which must ensure that investment in data and technology to augment social care planning and provision does not continue to lag behind health - in addition to tackling foundational issues which are, by now, well-rehearsed.

In the interim, DHSC has published the NHS Long-term Plan (DHSC, 2019a) and updated its Code of Conduct for Data-driven Health and Care Technology (DHSC, 2019b). Taken together, they reiterate the Government's commitment to digitisation and herald the introduction of electronic health and care records underpinned by common standards to expedite interoperability in order to modernise health and care service provision and improve direct care. They also elevate user-centric design to its rightful place in our technology-assisted health and care future – for which the new NHSX will be held accountable – and underline the Government's determination to better enable innovation and accelerate access to new treatments and technologies.

Introduction of the National Data Opt-Out and the National Data Guardian's recent Consultation on Priorities helpfully echoed that determination from the point of view of building and maintaining public trust in data sharing, insofar as 'Using Patient Data in Innovation: a Dialogue with the Public' was presented as one of four key priority areas for the forthcoming period. However, moves to harness the value of health and care data – in the broadest possible sense of the term 'value' – extend beyond sector-specific ethical, privacy and security efforts. They will be impacted by policy developments concerning, for example, digital competition and markets (HMT, 2019), data portability provisions (DCMS, 2018) and procurement, as well as the practical implications of Industrial Strategy implementation in adjacent sectors. They will also, doubtless, feature in the forthcoming National Data Strategy being prepared by the Department for Digital, Culture, Media and Sport (DCMS).

The purpose of this Discussion Paper is to reflect upon the implications of recent and anticipated developments to stimulate discussion about where they might help or hinder progress - in improving outcomes for individuals, critical infrastructure and services, as well as in delivering economic development goals and bolstering the sustainability of health and care provision. We also present the findings from research we have undertaken to contribute to these fast-evolving and inter-connected agendas, in respect of which, we believe, coordination across government is now urgently required.

Our findings and the discussion points which flow from them are intended to assist those engaged in the design and development of the National Policy Framework and centre of expertise referenced in the most recent Life Sciences Sector Deal (OLS, 2018), those involved in HMT's Knowledge Assets Implementation Study (HMT – forthcoming) and others, still, with the responsibility for delivering innovation through public procurement (PUBLIC, 2019). We envisage that they will also be of interest to health and care commissioners, providers and entrepreneurs operating in this space. However, we have primarily undertaken this activity in the interests of raising awareness amongst our core beneficiaries, since we refer throughout to data that is either about them or the life-critical infrastructure and services upon which they depend.

Methodology

We believe that data controlled and/or generated by health and care organisations in the UK has the potential to deliver clinical, social, economic development and commercial value and could be better harnessed with all of those ends in mind. Accordingly, in Autumn 2018, we developed a five-step approach to harnessing the value of health and care data, involving:

1. experimental audit and valuation processes;
2. the design and development of protective measures to prevent 'value leakage and/or depreciation';
3. approaches to the enhancement of health and care data - both from the point of view of exercising pertinent policy levers and investing in leading-edge practice;
4. consideration of the terms upon which broad-ranging data assets might be deployed to generate differential value for a range of stakeholders – including, crucially, data subjects themselves; and
5. the generation of options surrounding the investment and recycling of associated revenues – including, but not limited to, the potential to establish what we have termed a Sovereign Health Fund.

We then convened a roundtable event for parliamentarians to test that approach and explored whether and how the Government should seek to maximise the value of health and care data whilst ensuring a fair distribution of associated benefits in keeping with its stated policy position. The event was conducted under the Chatham House rule such that the views expressed by participants are provided in what follows without being attributed to individual contributors.

In particular, we asked attendees about:

1) Auditing health and care data assets - what health and care data does the public sector control and generate; who is interested in which data sets and at what scale/on what terms; what is the relative social, economic development and commercial value of those data sets; what should the UK's strategic priorities be vis-à-vis harnessing the value of that data – who should decide?

2) Protecting health and care data assets – how might we develop pertinent accounting methods and guidance for intangible (knowledge) assets; should government introduce a framework to guide commercial agreements with an information sharing component for publicly funded health and care organisations; how might we ensure measures are in place to protect health and care data in relation to non-EEA data protection regimes post-Brexit; how will government ensure alignment with pertinent trade missions/deals; what other protections may be desirable?

3) Enhancing health and care data assets – what policy levers could be exercised to bring about better 'data quality by design'; how might Government work with service users and front line professionals to build/maintain trust and obtain buy-in to quality improvement measures; how might Government identify and prioritise investment in data clean-up and curation efforts?

4) Deploying health and care data assets – should government establish a dedicated legal and commercial resource to help health and care organisations maximise the social, economic development and commercial value of health and care data when entering into agreements with third parties; what terms should any such resource champion; should the Government's Code of Conduct for Data-Driven Health and Care Technology be more prescriptive and/or mandatory; how else might the Government ensure macro-economic benefits flow from harnessing health and care data for the purposes of research and innovation?

5) Recycling/redistributing/reinvesting proceeds from the deployment of health and care data assets – should government involve health and care organisations in the co-design of a mechanism or mechanisms to apportion data revenues, data-derived IP and associated royalties to local and national entities to ensure that everyone living in the UK benefits from data-driven advancements in a fair and equitable manner?

Since then, we have undertaken primary research and engaged key stakeholders to flesh out our approach. However, each topic merits in-depth exploration, and as the policy landscape continues to evolve, we have opted to take a deep-dive into demand, supply and valuation in this Discussion Paper with a view to offering timely food for thought.

Three types of data are of interest and in scope for our purposes:

1. the data controlled/generated by publicly funded and accountable health and care organisations;
2. the data controlled/generated by organisations which provide pertinent services to health and care commissioners; and
3. the data controlled/generated by private entities whose core business might not be health or care related but which might, nevertheless, have the potential to generate useful insights about a population or individual's health and care.

The first two are addressed, respectively, in Parts A and B of this Discussion Paper whilst the third is referenced in our End Note.

Our aim here is to explore:

- **Demand:** What organisations want data controlled or generated by health and care organisations?
- **Supply:** What data do health and care organisations control or generate? How might the UK harness broad-ranging data, insights and tools not directly controlled/generated by them in order to improve health and care outcomes?
- **Value:** What is the value of data controlled or generated by health and care organisations? If that cannot be determined robustly, what criteria might be applied to determine the 'tipping point' beyond which their depreciation is anticipated? What value is currently 'enclosed' by private entities or, else, deemed to be 'leaking'?
- **Strategy Development:** What should the UK's strategic priorities be regarding harnessing the value of data controlled/generated by health and care organisations as well as other potentially useful data in respect of health and care?

Part A: Auditing demand for data controlled and/or generated by publicly funded and accountable health and care organisations

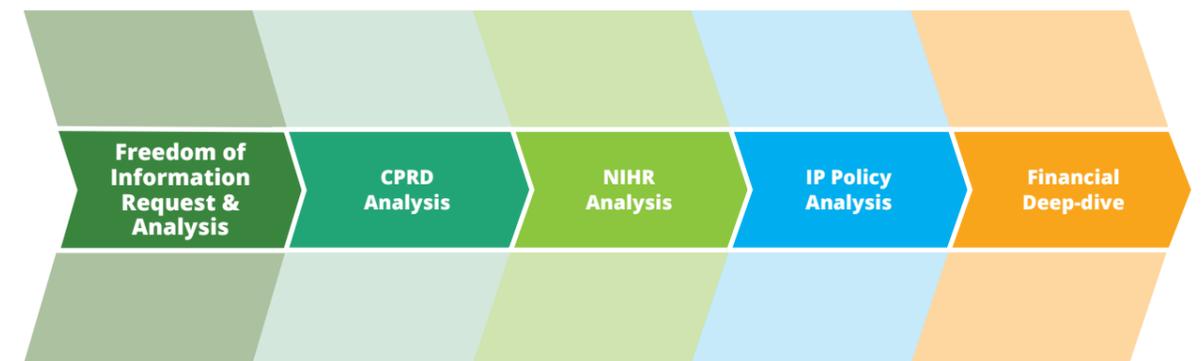
Introduction

Growing recognition of the importance of data and digital innovation for health and care as well as for economic development has spawned broad-ranging initiatives in recent years – including, but not limited to, the establishment of NHS Global Digital Exemplars, NHS Testbeds, Health Data Research UK (HDR-UK), the National Institute for Health Research’s Health Informatics Collaborative and Invention for Innovation (i4i), SBRI Healthcare and, most recently, Digital Innovation Hubs. NHS England has also introduced Local Integrated Health and Care Record Exemplars (LHCRES) to accelerate progress. However, as the Government moves to further encourage the evolution of Integrated Care Systems (ICSs), the challenges surrounding digitisation and the introduction of common standards to bring about interoperability loom large. Simply stated, there are liable to be hundreds if not thousands of data sets controlled and/or generated by publicly funded and accountable health and care organisations in England that are housed in systems which cannot, at present, ‘talk to one another’².

These, of course, include broad-ranging person-identifiable and/or sensitive data sets as well as pseudonymised and anonymised data about individual data subjects, and the Government’s focus upon them is understandable – whether from the point of view of its aim to improve direct care and population outcomes or to stimulate innovation to generate social and economic development value. At the same time, there are many other data sets which concern critical infrastructure, financial and operational matters, workforce, workflow and transportation (to cite but a few) which, we envisage, could also harbour significant value – and many appear to be ‘locked’ out of reach from service designers and commissioners in the proprietary systems of sub-contractors and third parties at present (see: Part B). There might also be considerable scope to derive insight into the wellbeing of individuals and communities from big data controlled by organisations which do not currently interact directly with health and care commissioners and providers³.

Given these ‘supply-side’ complexities, the limitations of publicly available data and the research methods at our disposal, we did not attempt to undertake a comprehensive audit of ‘available’ data sets. Neither have we developed a typology of the same. Instead, we aimed in the first instance to better understand demand for data controlled and/or generated by one type of publicly funded and accountable health and care organisation: NHS Trusts.

Auditing Demand for NHS Trust Data



² The precise figure is unknown since comprehensive data audits are not currently required of and/or complete where all publicly funded and accountable health and care organisations are concerned.

³ Anecdotally, some estimate that, when seeking to tackle the wider determinants of health, 10% of relevant data is ‘medical’, 30% ‘genomic’ and the remainder ‘social activity’ data.

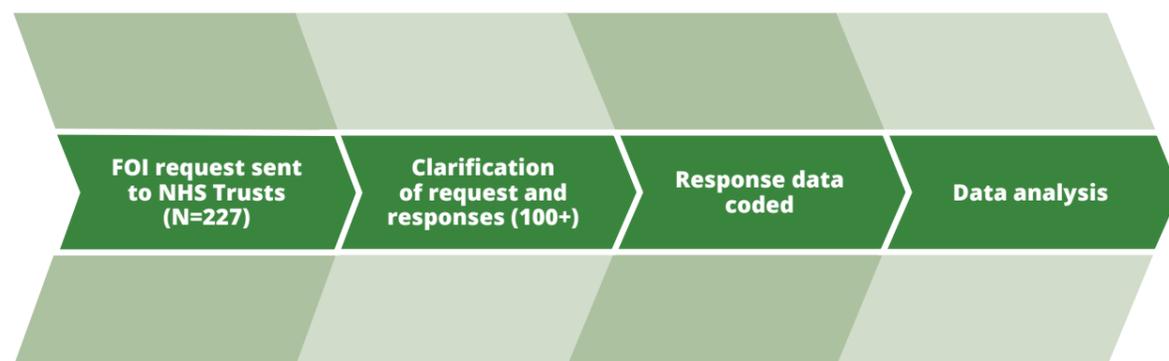
Freedom of Information Request

In December 2018, we issued a request pursuant with the Freedom of Information Act (2000) and asked NHS Trusts in England about any requests to use and/or access data for commercial or research purposes where the Trust is/was a data controller, joint data controller or data controller in common as follows:

- the number of requests made in each of the financial years 2015-16, 2016-17 and 2017-18;
- the percentage of requests that have been accepted, rejected or held pending in each of the financial years 2015-16, 2016-17 and 2017-18;
- a breakdown of the form, size and sector type of the entities that made the requests in each of the financial years 2015-16, 2016-17 and 2017-18; and
- a breakdown of the form, size and sector type of the entities whose requests were successful in each of the financial years 2015-16, 2016-17 and 2017-18; and
- the percentage of those successful requests which resulted in the trust, or its constituent hospitals, entering into a commercial or financial relationship with the requestor or its affiliates in each of the financial years 2015-16, 2016-17 and 2017-18.

We also asked the Trust to:

- confirm whether it, or one of its constituent hospitals, has entered into a commercial or financial relationship with any of the following entities as a result of the requests made in each of the financial years 2015-16, 2016-17 and 2017-18? Google; DeepMind; Sensyne Health; Benevolent AI; Orion Health and/or IBM.
- supply a copy of its intellectual property policy document/s, if any, covering the period 2015 to the present.



Our Freedom of Information request was issued to 227 NHS trusts and we received 192 responses – an overall response rate of 85%. 35 trusts (18%) cited an exemption under Section 12 (s12) of the Freedom of Information Act (2000) - indicating that the cost of compliance would exceed the limit provided for by the Act⁴.

⁴We have made the data we solicited via our request available in full for non-commercial use, re-use and re-mixing via our website in keeping with restrictions imposed by the organisations that supplied it. We have also encouraged the Information Commissioner's Office to consider whether it might be appropriate to introduce an exemption from the existing Section 12 FOIA exemption, where the failure to respond to a request for information could serve to undermine public trust in data protection provisions.

Clarifications and Caveats

We were asked to provide clarification by 100+ Trusts in respect of which we requested information, because:

1. our interest in requests to access/use patient-identifiable data was, in all but one instance, taken for granted – whereas, in practice, we were interested in the range of data they control.
2. the Health Research Authority (HRA) and National Institute for Health Research (NIHR) have clear definitions of the term 'research' and associated processes – where they are concerned with patient identifiable data – and NHS Trusts rightly sought to exclude reference to clinical studies coordinated by the NIHR in which they were/are participating because, technically, they did not receive a request from a third party to access data *controlled* by the Trust but, instead, were invited to participate in a study with a view to *generating* new data.
3. there is currently no standard or accepted definition of what is meant by the term 'commercial' and, therefore, few (if any) trusts maintain records which differentiate between requests made by/for research as distinct from commercial purposes – although we understand the term 'joint working arrangements' is widely used, so we are mindful that the wording of our request might have reaped only a partial response.
4. only a minority of Trusts retains complete records of requests to access/use data they control, such that most are only able to provide confirmation of the numbers that were approved (i.e. it is not possible to obtain a comprehensive picture of demand for data controlled by NHS Trusts from third parties at this time).
5. Trusts which were not used to being approached by third parties did not, in a number of instances, appear to think that the data they control might be of interest/value to others. Here, requests for clarification from Ambulance and Care Trusts were particularly instructive.

Findings and Analysis

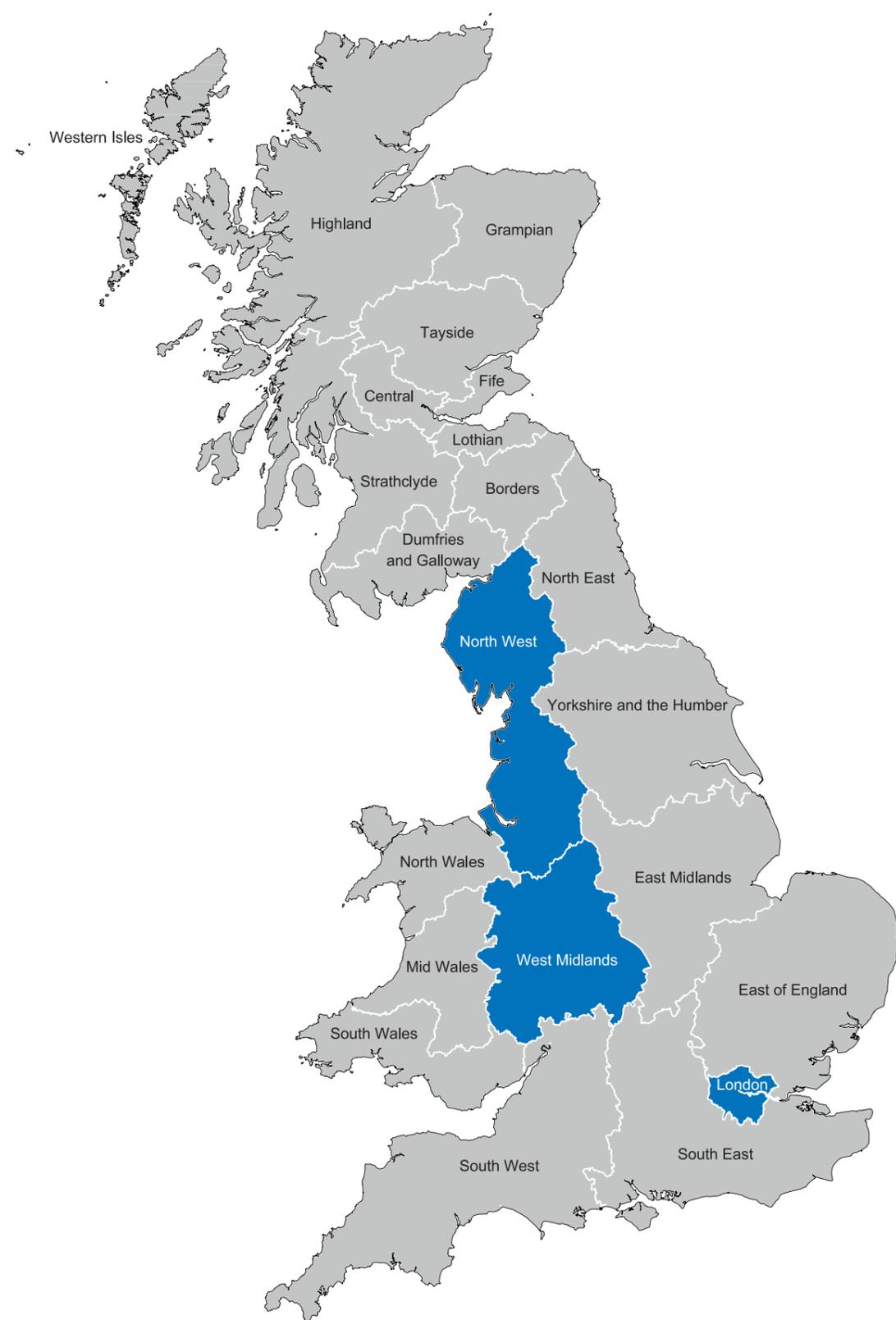
NHS trusts are not currently required to record information about requests to access/use the data they control for research/commercial purposes in a consistent manner for the purposes of reporting to central government. As such, 1/5 Trusts that responded to our request reported not holding any information regarding the number of requests received for research or commercial purposes.

Of the trusts that had received requests, 1/5 stated that they only maintain records of accepted requests – i.e. they do not hold records of requests that were rejected.

Among Trusts that reported having received requests to access/use data they control:

- Acute and Mental Health trusts received x10 as many requests each year as Ambulance and Care trusts and Foundation Trusts received x2-x3 as many requests as non-Foundation Trusts. This, perhaps, provides some indication as to the potential for data-driven innovation to benefit different facets of the health and care system in the absence of proactive Government intervention to encourage industry engagement. However, this is not something we are able to verify given the limited parameters of our request.

- Trusts in the West Midlands (WM), London and the North West (NW) received more requests than other regions in the three financial years we asked about but demand, generally, mapped to the presence nearby of a Russell Group university.



- Of the Trusts that responded to our audit, 27% said they had not received any requests for data for the purposes outlined in our request. Among those Trusts that did receive requests, the vast majority (87%) were accepted.
- Most respondents were unable to provide a breakdown by sector of parties interested in the data they control, but they were able to say more about the types of organisations which approached them, and the majority of recorded requests were reported as having come from Higher Education Institutions (HEIs). We were unable to confirm the extent to which requests from HEIs led to activity funded by and/or involving commercial entities based upon the responses we solicited and other publicly available information. We, nonetheless, recommend further work be undertaken to help bottom-out the distinction between 'research' and 'commercial' activity as well as to develop a more nuanced understanding of demand for data from technology companies (which seemed under-represented in the responses we solicited)⁵.
- 31% of requests resulted in a financial or commercial relationship between the Trust and the requester. Trusts from London, the West Midlands and the North West were most likely to enter into such relationships. This, perhaps, provides some indication as to the urban/rural/coastal split in associated revenues – although, once again, this is not something that we are able to verify given the limited parameters of our request.

Complexities

Our audit of demand for data controlled by NHS Trusts is, we think, unique, but use of the Freedom of Information Act (2000) limited the utility of the responses we received⁶. We also acknowledge that larger trusts - in particular those belonging to the Shelford Group - are under-represented in our sample. With this in mind, we cross-referenced our findings with information about the demand for primary care data controlled by the Clinical Practice Research Datalink (CPRD) in an attempt to better understand the scale, scope and geography of third-party interest. However, mapping demand for data that is **controlled** by the NHS is not the same as mapping demand for data which is or could be **generated** by the NHS. Interest in generating new data, working with NHS Trusts, is helpfully captured by the National Institute for Health Research (NIHR) in its clinical research study league table, but only where regards patient identifiable data – whereas interest in data generated by activities commissioned from third parties (or the potential for the same) remains something of an unknown quantity at this time. These elements of our audit are outlined below.

The Clinical Practice Research Datalink: Approved Studies

The Clinical Practice Research Datalink (CPRD) provides a portal for access to national, de-identified patient data derived from GP records and a public register of approved studies which make use of the data is available via the CPRD website: <https://cprd.com/protocol-list>

⁵In particular, we suggest information held by UKRI and/or Universities about pertinent doctoral and post-doctoral studentships, patent registrations/transfers recorded by the IPO and data maintained by HMRC and Companies House about mergers and acquisitions is taken into consideration.

⁶Here, it is perhaps worthwhile noting the ways in which the gaps in our findings read-across to those outlined in 'NHS joint working with industry is out of public sight' - BMJ 2019; 364 doi: <https://doi.org/10.1136/bmj.11353> (Published 27 March 2019).

We analysed demand for access to/usage of CPRD data and, in particular, we considered the institution of the principal investigator listed in respect of each approved study:

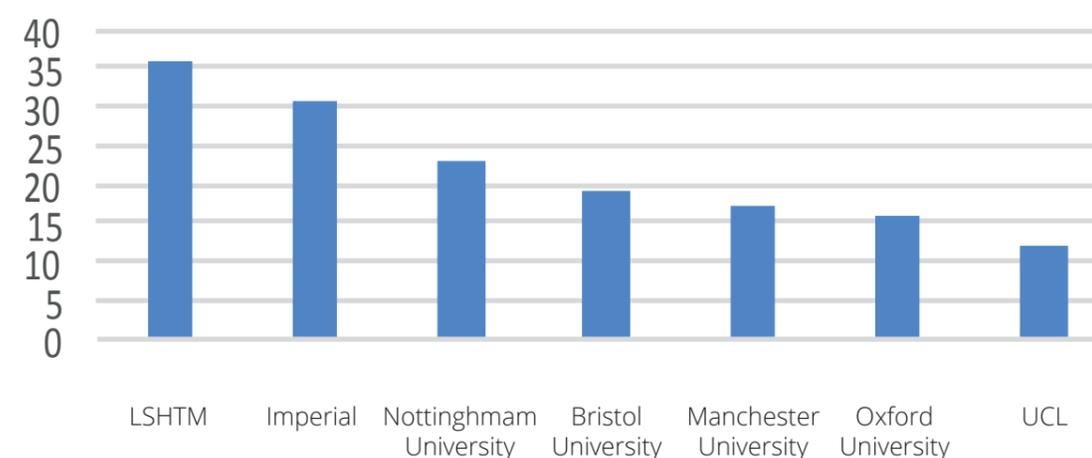
Country of request	Total number of requests 2015-2018	Number of organisations within country
UK	321	From 72 organisations
USA	63	From 27 organisation
Canada	39	Of which 37 from one organisation (McGill University)
Switzerland	21	Of which 18 from one organisation (Basel University)
Netherlands	14	Of which 13 from one organisation (Utrecht University)
Germany	13	Of which 7 from one organisation (Boehringer-Ingelheim)
Belgium	5	From 3 organisations
Sweden	5	Of which 4 from one organisation (Astra-Zeneca)
Singapore	5	From one organisation (Observational and Pragmatic Research Institute)
Denmark	4	Of which 3 from one organisation (Novo-Nordisk)
France	4	From 4 organisations
Australia	2	From 1 organisation
Luxembourg	2	From 1 organisation
Spain	2	From 2 organisations
Israel	1	

Echoing our audit of data requests from third parties of NHS Trusts, the largest proportion of requests to access/use CPRD data originated from HEIs followed by pharmaceutical companies. Although the majority of requests came from within the UK, a not insignificant proportion came from institutions overseas - demonstrating international demand from researchers and commercial entities for well-structured and well-managed databases in health and care⁷.

⁷Most requests came from Higher Education Institutions (321) - followed by pharmaceutical companies (96). Among requests from the UK, 72% came from Higher Education Institutions and 12% from pharmaceutical companies. Among requests from the USA, 41% came from pharmaceutical companies and 27% from Higher Education Institutions.

Notably, the number of approved requests to access/use CPRD data in 2016/17 (168) and 2017/18 (175) compares with **median requests per NHS Trust** of 17 in each year for the 85% of Trusts that responded to our Freedom of Information request – which points toward there being greater demand for the latter than the former; and with potential implications for the commercial value that Trusts might derive from the same⁸.

Organisations in the UK with more than 10 requests 2015-2018



The National Institute for Health Research (NIHR): Clinical Research League Table

The NIHR publishes an annual league table of research activity in NHS Trusts – where the highest ranked is involved in the greatest number of clinical research studies.

In the league tables for 2016/17 and 2017/18:

- all members of the Shelford Group were ranked in the top 15 for each year⁹;
- those non-Shelford Group Trusts in the top ten each year were: Leeds, Nottingham, Barts Health and Southampton; and
- the top 3 trusts in the league table were each involved in 500+ studies.

We cross-referenced the returns from our Freedom of Information request about interest in data controlled by NHS trusts with NIHR rankings and the involvement of Trusts in clinical studies involving the generation of new data (see overleaf).

⁸The CPRD generates circa £4.5m/annum in relation to an average 170 requests to access/use the data it controls, and whilst this is in some very important respects to compare 'apples with pears', one could extrapolate and hypothesise that the 85% of NHS Trusts which responded to our FOI request could be generating circa £85m/annum from access to and usage of data they control, were they to operate on the same full cost recovery basis. However, we are unable to verify as much given the parameters of our analysis.

⁹The Shelford Group is a collaboration between ten of the largest teaching and research NHS hospital trusts in England - together these ten NHS trusts account for over £11bn of the NHS budget, treat over 15 million patients a year, employ over 140,000 staff and account for two thirds of the country's clinical research infrastructure. For further information, see: <http://shelfordgroup.org/>

NIHR ranking in 2017/18	Trust name	Number of requests according to FCC FOIA audit
1	Newcastle upon Tyne Hospitals NHS Foundation Trusts (550)	average 100 requests per year; accepting 20-25%
2	Guy's and St Thomas' NHS Foundation Trust (500)	Cited exemption S12
3	Oxford University Hospitals Foundation Trust (517)	Cited exemption S12
4	Leeds Teaching Hospitals NHS Trust (451)	average 14 requests per year; 33-45% accepted
5	Nottingham University Hospitals NHS Trust (434)	Cited exemption S12
6	Barts Health NHS Trust (429)	No reply
7	University College London Hospitals NHS Foundation Trust (427)	No reply
8	Imperial College Healthcare NHS Trust (422)	No reply
9	Sheffield Teaching Hospitals NHS Foundation Trust (414)	Cited exemption S12
10	University Hospital Southampton NHS Foundation Trust (413)	average 700 requests per year, no info on % accepted
11	Cambridge University Hospitals NHS Foundation Trust (398)	No reply
12	Manchester University NHS Foundation Trust (369)	Cited exemption S12
13	King's College Hospital NHS Foundation Trust (352)	No reply
14	University Hospitals of Leicester NHS Trust (328)	Cited exemption S12
15	University Hospitals Birmingham NHS Foundation Trust (298)	No reply

According to Dr Jonathan Sheffield, Chief Executive Officer - NIHR Clinical Research Network: "The league table is really about giving research opportunities to all patients in the NHS."¹⁰ analysis of the league table reveals that in 2017/18, the top 15 (7%) Trusts each had 300 or more studies attached to them, involving a total of 216,448 participants, while the bottom 70 (30%) Trusts each had 35 or fewer studies attached to them, involving a total of 44,655 participants. As such, the top 7% of Trusts involve almost 5 times as many participants in research as the bottom 30% of Trusts in the league table.

Our analysis points toward a relatively small number of NHS Trusts being more 'data intensive' in their activities than others. Whilst this is not unexpected, this could result in differential impact upon data sharing amongst particular populations; although, here, the extent to which clinical trial participation reflects a Trust specialism, rather than the involvement of patients located in its operating geography, needs to be borne in mind. That pertinent activities of 'data intensive' Trusts should also be less transparent from the point of view of the information they

¹⁰ National Institute for Health Research, What does the league table mean?, <https://www.nihr.ac.uk/research-and-impact/nhs-research-performance/league-tables/what-does-the-league-table-mean.htm>

appear able/willing to make available is, nonetheless, of concern, to the extent that it harbours the potential to do damage to public trust in future. It is also liable to render monitoring of DHSC's Code of Conduct for Data Driven Health and Care Technology and any related centre of expertise's performance challenging unless remedied.

Intellectual Property: Policy Landscape

Given the complexities involved in auditing demand for data controlled and/or generated by NHS Trusts, we opted to explore their Intellectual Property (IP) policies as a 'proxy measure' for interest in R&D – although, we acknowledge that this is, in some respects, to treat Trust employees akin to 'third parties' where they are the instigators of innovation or 'inventors'. We also sought to understand the extent to which the commercial principles outlined in the latest Life Sciences Sector Deal are already adhered to at a local level or, conversely, might be deemed ambitious at this juncture.

We obtained IP policies for 105 NHS Trusts through our Freedom of Information request and further desk research. As such, only 50% of Trusts appear to have developed and/or published one to date – although, we wish to emphasise that it is not our intention here to take a view about their merits (or otherwise).

Trusts in London, the West Midlands and North West (which reported the highest number of requests to access/use data from third parties according to our FOI request) were the least likely to report having an IP policy. However, when looking at types of Trust, Acute and Mental Health Trusts (which receive the highest number of requests by Trust type) were more likely to have an IP policy than Ambulance or Care trusts.

We designed and deployed a framework for IP policy analysis and looked at 1/3 of policies obtained in-depth – a cohort of x32 policies:

- x24/32 policies analysed refer to Department of Health guidance published and not updated since 2002 (by an organisation which no longer exists);
- only x2 policies in total make any explicit reference to data protection or GDPR; and
- x27/32 offer an explicit incentive for employees but amounts vary between different Trusts and within STPs.

Employee Incentives

- x10 Trusts offer incentives of 35% or less - regardless of the revenue generated – and, in almost all cases, this is where profit is split three ways between the Inventor, their Department and the Trust.
- x7 Trusts offer the Inventor 50% or more in respect of relatively low revenues (e.g. up to £25k), then 35-40% for amounts up to £200k, and then a lower proportion thereafter.
- x6 Trusts offer significant incentives – in these trusts, the Inventor is awarded 50% or more of revenues up to £200k (nb: the proportion tends to diminish thereafter).
- x2 Trusts offer the Inventor a share on a case-by-case basis.
- x2 Trusts differentiate between research and non-research staff – in one trust, research staff get no share of revenues at all whereas, in the other, they receive significantly less than non-research staff.

We also analysed IP policies based upon the local Sustainability and Transformation Partnership (STP) to which Trusts belong:

- there were no STPs that were fully covered in terms of IP policies;
- the most covered in the cohort we analysed were Cambridgeshire and Durham, Darlington, Teesside, Hambleton, Richmondshire & Whitby - with 5/6 constituent Trusts covered; and
- the least covered in the cohort we analysed were Somerset - where 0/3 constituent Trusts have a policy - and Norfolk & Waveney - where 0/6 Trusts have a policy.

In some STPs, employee incentives provided for in IP policies are consistent, whereas in others they differ substantially - for example:

- all x3 Trusts in Staffordshire and Stoke-on-Trent STP offer lower incentives to employees; and
- of the x5 Trusts which comprise Cambridgeshire & Peterborough STP, x3 offer significant employee incentives, whereas two offer lower incentives (where profit is split three ways between the Inventor, their Department and the Trust - regardless of the revenue generated).

We are unclear about the implications that might flow from the inconsistencies in the IP policy landscape sketched above. Moreover, our analysis is limited to consideration of those NHS Trusts that comprise STP footprints, whereas, in practice, Integrated Care Systems are expected to incorporate broad-ranging health and care organisations – including, local authorities. Nonetheless, our findings point toward there being merit in any centre of expertise and/or National Policy Framework concerned with maximising the value of health and care data addressing the IP policy landscape, if it is also to ensure a fair distribution of associated benefits.

Notably, when analysed in relation to the guiding principles for commercial deals involving NHS data that were outlined by the Office for Life Sciences in its most recent Life Sciences Sector Deal, none were reflected in the IP policies we analysed - save that 1/3 explicitly (and commendably) stated the Trust's priority or principal aim is to improve the health and care of patients in the UK when engaging in the development of Intellectual Property. They might, then, be characterised as 'ambitious' as currently conceived.

Does the Trust make explicit in its IP Policy that its priority or principal aim is to improve the health and care of patients in the UK?	Does the Trust's IP Policy outline how it will quantify associated benefits?	Does the Trust's IP Policy outline how it will guarantee mutually beneficial and fair terms when entering into an arrangement with an employee and/or third party?	Does the Trust's IP Policy make explicit reference to Board Member responsibilities?	Does the Trust's IP Policy set out how it will not undermine, inhibit or impact the ability of the NHS at a national level to maximise the value or use of NHS data?	Does the Trust's IP Policy preclude exclusive arrangements?	How does the Trust's Policy ensure that arrangements are transparent and clearly communicate them so as not to undermine public trust in wider government data policies?	Does the Trust's IP Policy make explicit mention of the National Data Guardian and/or the National Data Guardian's Data Security Standards?
1/3	No	Yes/No	No	No	No	N/A	No

The Shelford Group - Financial Analysis

We also tested an approach to examine the financial arrangements linking NHS Trusts to income generating Special Purpose Vehicles (SPVs) and spin-outs to garner a picture of equity stakes and/or income generation from 'data deals' involving them. In particular, we hoped to understand the scale of 'data deals' entered into between Shelford Group Trusts and third parties, loosely defined in our methodology as equity stakes (associates, subsidiaries and Joint Ventures), with a focus or particular interest in patient and other health data, to help us address their under-representation in our Freedom of Information analysis cohort.

When we examined Annual Reports with a focus on 'the finances', we looked at:

Information	Utility
Operating income from patient services	this did not prove to be of direct relevance to our question
Other Operating income	this was relevant but is in the range of £100m-£250m across the Shelford Group, without any consistent or clear breakdown of sources at a more granular level than e.g. "R&D £x, PFI Transitional Support £y, Other £z". So, further specific inferences were not possible from the accounts and notes. Relevant revenues will be included in this line but cannot be extracted from the information made available.
Balance Sheet investments in Associates and Joint Ventures	these were listed somewhat consistently, but details in notes were sparse, and this is likely only a small subset of relevant 'deals'. It is, however, worth noting that many investments in Associates were valued at zero – i.e. they are loss-making.
Related Party Transactions which are the in-goings and outgoings from subsidiaries/associates/JVs	this, again, could have some relevance but suffers from the same subset issues for making broad inferences. Notably, most were in deficit - i.e. Trusts invested more money into these than they received from them.
CEOs and Non-Executive Directors and their recorded interests on official registers where available	this raised some interesting connections but did not necessarily indicate an official relationship or contractual arrangement. This is also a very manual exercise and incomplete from this source because the Registers are not necessarily the most up to date and, in some cases, appear to be incomplete.

Ultimately, however, this line of enquiry proved wanting for the lack of consistent and publicly available information - which raises questions about the scope for the NHS to offer a comprehensive audit trail to DHSC and, more importantly, data subjects about how data is being used and/or their value is being harnessed¹¹.

Discussion

We were left with more questions than answers from our audit of demand to access or use health and care data. What is, nonetheless, discernible from our findings is that there appears to be a discrepancy in the potential for NHS Trusts of different types and in different places to harness the value of health and care data. That is, whether we are talking about providing access to existing data that Trusts control to facilitate research and/or innovation, new data that Trusts might work with third parties to generate through participation in clinical trials in pursuit of new treatments and technologies, or having an intellectual property policy and, with that, a transparent approach to commercialisation – it seems, ‘the future is here but is not evenly distributed’.

There might be a tacit or, even, explicit acceptance that some NHS Trusts will engage in and benefit more than others from data-driven innovation as a result of their proximity and ties to Russell Group universities and the R&D ecosystems in which they’re both involved and invested. Then, again, there might not. Our concern is that this could be at odds with the Government’s intention to maximise the value of healthcare data whilst ensuring a fair distribution of associated benefits and, in particular, given Government proposals to introduce new legislation in respect of Integrated Care Systems (ICSs).

For example, it points toward a disparity in the extent to which NHS Trusts may be able to help stimulate data-driven economic development and/or generate revenue from ‘data deals’ and, in future, this could impact local productivity and/or the financial position of Trusts and the Local Authorities with whom they might form ICSs in different places. It could affect the ability of some ICSs to provide access to leading-edge treatments and technologies developed by others to benefit their service-users. It might also be the case that data about some individuals or groups will be used more ‘intensively’ than others without interventions that are designed to ‘level the playing field’ – raising questions about the potential for data bias to impact resultant treatments and technologies as well as the relative merits of a one-size-fits-all approach to the National Data Opt-Out and campaigns designed to inform and build/maintain public trust amongst different populations. This is particularly relevant to the extent that the ‘costs’ and ‘benefits’ of data-driven innovation in health and care are unlikely to attach in equal measure to populations – let alone individual data subjects – with further, implications for inequalities that could be entrenched or new ones that could result.

¹¹ We recognise the limitations and narrow focus of our financial analysis in this section of the Discussion Paper but would wish to emphasise that the lack of information made available by Trusts where their commercial activities is concerned is also liable to render monitoring of DHSC’s Code of Conduct for Data Driven Health and Care Technology and any related centre of expertise’s performance challenging unless remedied. We do, nonetheless, acknowledge the challenges inherent in accounting for investment in / revenue generated from the development and deployment of intangible assets which are clearly articulated in Haskel, J. and Westlake, S., *Capitalism without Capital: The Rise of the Intangible Economy*. [Princeton University Press: 2018].

At the very least, we recommend that Government

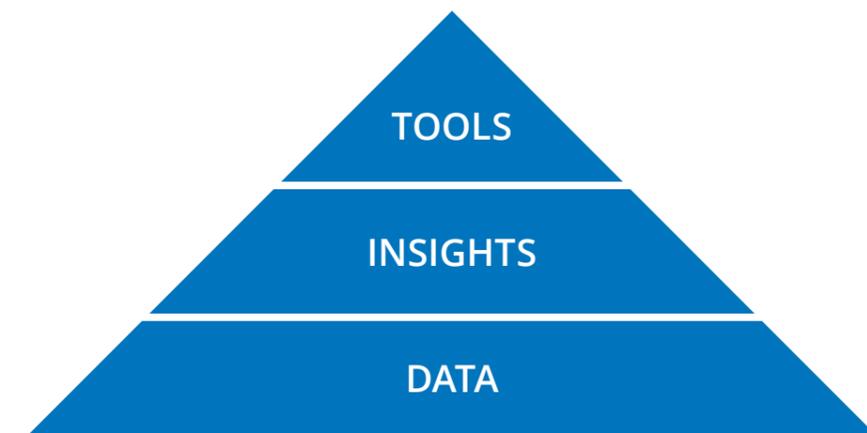
1. mandates **standard returns** from health and care organisations so that data supply, demand and commercialisation activities are rendered **transparent**;
2. considers carefully how to introduce related measures into the already complex landscape for **mapping, managing and accounting** for health and care data and the Intellectual Property it plays a role in developing; and
3. **pilots innovative approaches to auditing and communicating** the demand for data controlled by and/or generated with organisations that might comprise an Integrated Care System - to **test their trustworthiness** from the point of view of individuals **and their utility** from the point of view of constituent organisations and front-line professionals as well as innovators and commercial entities.

We would also encourage further discussion in respect of the following questions:

- **What do we mean when we talk about the ‘fair distribution of benefits’ from data-driven innovation in health and care?**
- **How might we reconcile the tension between the local use of data to develop intellectual property and the derivation of benefits at a national level?**
- **How will we ensure individuals are able to understand and have a say and/or stake in whether and how the social, economic development and commercial value of health and care data about them is being harnessed – what might a readily intelligible and trustworthy feedback loop look like in practice?**

Introduction

In Part A, we explored demand for data controlled and/or generated by publicly funded and accountable health and care organisations, and found that there appears to be a discrepancy in the potential for NHS Trusts of different types and in different places to harness the value of health and care data in the broadest sense of the term. In Part B, we reflect on whether there might be the potential to and utility in taking steps to improve access to 'operational' data but, also, insights and the tools upon which those insights are based - specifically, where they are controlled, generated and/or developed by contractors providing services that are commissioned by publicly funded and accountable health and care organisations.



Our focus flows, in part, from discussions with stakeholders who indicated that some of the ready-digitised operational data, insights and tools controlled, generated and/or developed by contractors could be

- i) better utilised in the design, commissioning and delivery of services impacting individuals' care and population outcomes;
- ii) more rapidly, securely and, potentially, less controversially deployed by public bodies than patient-identifiable data and their derivatives to stimulate innovation and the creation of new businesses and employment opportunities - complete with export capabilities; and/or
- iii) made more accessible to enhance competition amongst existing and prospective suppliers with the potential to realise efficiencies and/or improve productivity.

It also reflects recent developments in national infrastructure, digital competition and procurement policy-making, which appear to lend themselves to measures that are designed to *increase (access to) their supply* - both in the public interest and for public benefit.

Crucially, while we make no claims about the extent to which different types of organisation might be in a position to better harness their value, our intention here is to explore a range of mechanisms that could be adopted throughout the country and irrespective of organisational ties to those local R&D ecosystems referenced in Part A.

Part B: Harnessing the value of data, insights and tools that are controlled, generated and/or developed by contractors providing services commissioned by publicly funded and accountable health and care organisations

Operational Context

Once again, we have not sought to develop a comprehensive typology, but the data, insights and tools with which we are concerned here could flow from outsourced services including:

- data storage / cloud hosting solutions
- construction, estates and facilities management
- utility provision
- plant, machinery and device operation
- transport, logistics and parking
- appointment and referral management
- activity, workflow and workforce rostering management
- legal and financial¹²

The stakeholders we engaged in the course of our research included commissioners and suppliers who encouraged us to explore how the control of operational data and the ownership of related insights and tools is treated by publicly funded and accountable health and care organisations - specifically, from the point of view of procurement and contracting arrangements entered into with third parties.

In truth, we cannot tell because it would entail a detailed analysis of broad-ranging and commercially sensitive agreements, more often than not entered into at the local level and exempt from current Freedom of Information provisions¹³. We were, nonetheless, able to examine a number of potentially pertinent framework agreements (full details of which are made available online).

Government frameworks are agreements between the government and suppliers where the basic terms of use are agreed by both parties after a contract notice is published in the Official Journal of the European Union (OJEU). Buying services through frameworks is intended to be faster and cheaper than entering into individual procurement contracts. However, the number and type of suppliers which make goods and services available in this way differs considerably and, ordinarily, reflects the relative costs and commercial benefits of competing to become involved; notwithstanding the range of Government initiatives intended to 'level the playing field' between SMEs and larger suppliers. Notably, success is also deemed reliant upon access to pertinent data, such that organisations that might wish to compete to provide goods or services for the first time are often deterred - in particular, when having to compete with incumbent suppliers.

¹²In each instance, we accept that the extent to which there may be the potential to better harness value from data, insights and/or tools is liable to differ - the same is true of the type(s) of value that each might harbour. We also acknowledge that taking steps to improve access to some types of operational data might prove more controversial than for others - in particular, where there may be an increased risk of re-identification from anonymised data sets (whether about service users or staff) and/or implications for the intellectual property rights of suppliers.

¹³The Information Commissioner's Office recently published a report: 'Outsourcing Insight: The case for reforming access to information law' (2019) - calling for the Freedom of Information Act's provisions to be extended to suppliers of public services. Were the Government to implement its recommendations, we would not expect it to improve transparency where the Intellectual Property provisions in individual contracts are concerned, since they would continue to be covered by the Act's commercial sensitivity provisions. It is also, as yet, unclear whether Data Audits and Data Protection Impact Assessments required of commissioners and their contractors will be made available in response to FOI requests and/or prove useful in improving transparency about permissions and activities resulting in the harnessing of value from operational data related to health and care organisations.

Facilities Management Services

The framework agreements we analysed included the current Facilities Management Services Framework Agreement, which covers all public bodies, including NHS Trusts (CCS, 2015). References to 'data' and 'intellectual property rights' therein suggest that suppliers are only remitted to provide access to 'management information' from their systems or, else, 'summary data' to enable the contracting authority to respond to Freedom of Information requests - rather than contracting authorities having access to the data, insights and tools controlled, generated and/or developed by suppliers as a result of them delivering the contract.

From the point of view of construction and facilities management services procured by health and care organisations, stakeholders told us that that leads, in some instances, to contracting authorities having access to only very limited information about the land and buildings they own; for example, NHS Trusts can for the most part only access/collect/return the data that is made available in annual ERIC returns which, we are led to understand, is limited both from the point of view of reliability and utility¹⁴.

This could impact the ability of publicly funded and accountable health and care organisations to develop robust capital programme plans - resulting in facilities of a poorer quality than might otherwise be the case, with implications for front-line professionals as well as service users. Tier two suppliers of construction and facilities management services also indicated to us that the resultant lack of access to reliable data hampers their ability to propose potentially more cost-effective and productive service delivery options.

The extent to which these issues hinder efficiency and the potential to reap productivity gains from new ways of working is difficult to estimate but would be worthwhile exploring in more depth as it pertains to health and care commissioning.

Some framework agreements used by health and care commissioners could result in a contracting authority becoming either a Joint Data Controller or a Data Controller in Common by default to improve access to and/or the supply of operational data (back) to them. At a national level, the Information Commissioner's Office (ICO) could, for example, produce a guidance note on the subject for consultation, based upon our reading of infrastructure-related framework agreements, because they include a clause that, in effect, says: in the event of new guidance being issued by the ICO, the agreement is automatically varied and suppliers must comply. We think that this would be in the public interest and could result in public benefit - since it would result in contracting authorities being able to better harness the clinical, social, economic development and commercial value from operational data generated by their activities.

¹⁴The Estates Returns Information Collection (ERIC) is a mandatory collection for all NHS trusts in England. It comprises information relating to the costs of providing and maintaining the NHS Estate including buildings, maintaining and equipping hospitals, the provision of services e.g. laundry and food, and the costs and consumption of utilities. The 2017/18 return involved a data quality assurance exercise in recognition of those issues alluded to above.

There are, nonetheless, other mechanisms already available to health and care commissioners that perceive merit in reaping or 'reclaiming' what would amount to an operational 'data dividend' from contracting arrangements with third parties. For example, the Social Value Act (2012) was strengthened last Autumn. Its provisions could be proactively deployed by commissioners in future to incentivise suppliers that are prepared to offer 'more data' or 'more insight' to benefit the well-being of the populations they serve, on the grounds that that would, in and of itself, harbour the potential to generate 'social value'; they need only make plain that a 'data or insight dividend' for the public sector would be scored as such in the course of procurement exercises. At present, Local authorities and NHS Trusts do not have a particularly good track record in making use of the Social Value Act, in part, because 'social value' is difficult to measure – although, we acknowledge from our conversations with commissioners that this is more readily a function of budget constraints and interpreting 'best value' in strict financial terms; it would be easier if transactions involving improved access to data and/or 'knowledge assets' could be counted in a standard manner towards 'social value' – perhaps, as a result of HMT's ongoing 'knowledge assets review' exercise.

Alternatively, Government's new Supplier Code of Conduct, wherein it states: *"...we expect our suppliers, in delivering goods and services to, or on behalf of government, wherever they operate, to act in a manner that is compatible with public service values, upholds the reputation of government, promotes innovation and expertise, opens up the market to small and medium-sized enterprises, and contributes to growth and prosperity in the UK"* could be rigorously applied and upheld by health and care commissioners to improve access to high quality data from contractors (Government Commercial Function, 2019). Its references to data quality and value are of particular interest in this instance.

Ultimately, however, any benefits that might flow from a 'data dividend' are subject to the extent to which:

- i) contracting authorities benefit from the analytic skills and capability to make better use of such data 'in-house' (Health Foundation, 2016; Symons, 2016);
- ii) devolved commissioners that are expert in health and care are deemed 'well-positioned' to determine whether, when and how such data should be made more accessible in the interests of stimulating innovation and local economic development¹⁵; and
- iii) systems and services of particular interest, from the point of view of realising efficiencies and/or productivity gains, are commissioned with a view to securing as much¹⁶.

¹⁵ Local Authorities are perhaps better placed than health organisations in this regard, but this issue draws attention to the need for any centre of expertise to liaise with Local Economic Partnerships (LEPs) – given their role in delivering the Government's Industrial Strategy through the range of Sector Deals – as well as Academic Health Science Networks and Digital Innovation Hubs. Otherwise, it is challenging to see how it might maximise the value of broad-ranging data generated in the course of publicly funded health and care activities from the point of view of stimulating economic development.

¹⁶ The status and use of framework agreements is, in some respects, subject to the outcome of ongoing Brexit negotiations and the parameters of new Free Trade Agreements the UK might enter into in future. In the interim, the NHS England Board recently indicated that it is moving to exempt NHS organisations from The Public Contracting Regulations (2015), such that they will only be required to demonstrate 'best value' in future. At present, best value is the subject of HM Treasury's Green Book which was recently updated. Notably, however, the review did not look at how to value and, where appropriate, treat data as an asset - so far as we're aware - so there is currently a lack of guidance available to public bodies in this regard.

Complexities: Improving Access or Developing Data-Driven Partnerships?

It is important to acknowledge here that increasing access to operational data, insights and the tools upon which those insights are based represent different propositions from a legal standpoint. That is, we provided an example above of services in respect of which it may be both feasible and desirable for health and care commissioners to secure improved access to operational data in broad terms – but, whereas access to raw data is one thing, data structured by a proprietary system, 'insights' gleaned from such data, and the 'tools' used/developed to derive such insights are others still. In short, we begin to stray into the territory of intellectual property rights and associated legal provisions.

The Government has vowed to champion common standards in order to improve interoperability in health and care, with a particular emphasis on enabling the introduction of integrated health and care records. The extent to which such standards will extend to operational data generated by suppliers of out-sourced services is, as yet, unclear, but certainly merits further consideration where commissioners currently lack access to data that could inform infrastructure planning and service improvements or, otherwise, help realise efficiencies and/or improve productivity.

By contrast, one could argue that the 'insights' required of a supplier could (and should) be better specified in contractual agreements, if 'more insight' from out-sourced service provision is of interest to commissioners. The difficulty, here, lies in differentiating between the contractual stipulations a commissioner might require in the course of undertaking a procurement exercise (i.e. 'known knowns'), and the 'unknown unknowns' a commissioner and/or supplier might come across when a contract is operational as well as the ongoing 'value add' proposition.

Example: Community Falls Service

Consider a community falls service with inputs from a local authority and the NHS – where referrals may start with the electronic frailty index used by GPs. A supplier provides a falls risk assessment app extending the frailty index and making it easier to use for multi-disciplinary teams across different settings (from a surgery to home visits). A commissioner might contract to buy a tool or service to gather data and produce actionable information by feeding the data through a known, published, frailty risk model, but that model is improved with data from the commissioner's population, and the newly created predictive value might apply globally and/or locally – affording better prediction in the given population.

The model would, then, have gained new information derived from the data and both the company and the client would gain new value from adapting the software to, for example, improve data capture, risk information presentation and action recommendations and links to other services. Who, then, should own/control those 'value add' insights?

The same holds for the 'tools' used to derive insights from data that are developed by a supplier in the course of delivering a contract - in particular, where it may be difficult to discern or agree upon the extent to which the tool's development was wholly reliant upon access to the data made available as a result a specific contract or, else, required additional investment on the part of the supplier. If we return to our example of a falls risk assessment app, it might be that feedback from the risk assessments undertaken by the falls service is used by the app provider's learning algorithm to learn better risk prediction models - so, not only from the data but, also, from the labours of falls service staff marking up good and bad predictions so the algorithm can learn better models. Who, then, should own/control the 'value uplift' attaching to the improved tool? At the very least, should the commissioner require the supplier to provide access to the training metadata so that it can benefit from better (value) apps and services for frailty management in future?

There is, it seems, a fine - and potentially blurred - line between improved access to data, insights and tools and, for want of a better term, 'data-driven partnerships'.

Discussion

In Part B, our interest in advocating practical next steps to better harness the value of operational data generated in the course of delivering health and care services, could be said to 'rub up against' the thought-provoking arguments articulated in both *The Entrepreneurial State* (Mazzucato, 2011) and *The Value of Everything* (Mazzucato, 2018). There is, then, a grey area where improved access to data, insights and the tools generated in the course of out-sourcing services from the public sector meets the potential for the State to share in any resultant value. Moreover, subject to the type of value in question, the term 'share' is liable to take on very different meanings.

Some will take the view that data generated as a result of the activities of publicly funded and accountable organisations should be 'opened up' and offered 'free-to-air' to help drive innovation as well as competition - where it is deemed compliant with data protection provisions and undertaken in an appropriate manner - whereas any secondary insights or tools developed by third parties ought properly to constitute their intellectual property. Others are liable to vehemently disagree (Collington, 2019).

Others, still, have concluded that such data - in particular, where it pertains to critical infrastructure and related services - should be treated as a sovereign asset and approached as a special category: as 'data of national significance'. Indeed, the National Infrastructure Commission (NIC) made that case in its independent report: *Data for the Public Good* (2017), and we asked stakeholders whether the same principles should apply to life-critical health and care infrastructure/services in the course of our research. Reflecting on the NIC's long-term programme of work to develop a 'National Digital Twin' or computer models designed to help us understand, manage and plan our infrastructure better, we believe there may be merit in improving access to operational data, insights and tools in order to model our health and care infrastructure as well as services integral to it.

There might yet be the scope for something to emerge in between - a mix of national and local 'intangible asset backed vehicles' akin to their tangible counterparts or what might more readily be termed 'data-driven partnerships' - which could enable both the public and the private/

independent sectors to share in any value resulting from them. At present, this is, still, to be determined. Nonetheless, we are persuaded that health and care commissioners' duty of care extends into the digital realm and that, at the very least, practical steps should be taken to mitigate the potential for undesirable and/or unintended consequences where the well-being of individuals but, also, populations depend upon the data, insights and tools associated with life-critical infrastructure and services. Here it is worth considering the extent to which it would be both ethically and legally remiss of such organisations not to have access to life-critical data, insights and tools - for example, an algorithm trained to prioritise ambulance dispatch - in the near-future.

At the very least, we recommend that Government

1. explores the scope to use its powers at a national level to **increase access to and/or the supply of operational data, insights and tools** from contractual arrangements entered into by publicly funded and accountable health and care organisations;
2. takes a view about the relative merits of such organisations entering into other types of arrangement in anticipation of **a value return for contributing** to the generation and development of operational data, related insights and tools; and
3. **tests innovative approaches** to better harness the value of operational data, insights and tools generated by and/or with health and care organisations in practical settings **to improve clinical, social, economic development and commercial outcomes**, then, evaluates them to inform development of the National Data Strategy, pertinent Sector Deals linked to the UK Industrial Strategy and initiatives led by the Government Office for Science.

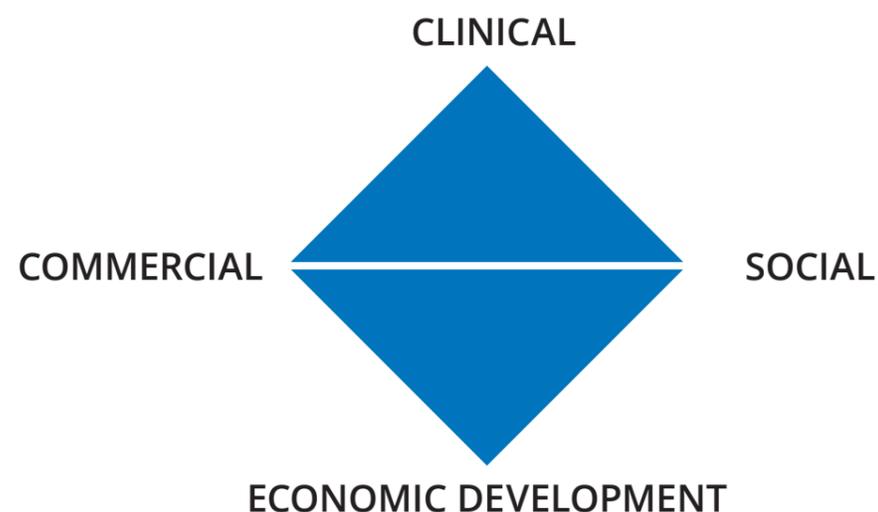
We would also encourage further discussion in respect of the following questions:

- **How is the control/ownership of operational data, insights and tools treated in the course of procurement exercises undertaken by publicly funded and accountable health and care organisations?**
- **Is there scope and utility in seeking to introduce national standards for the operational data, insights and tools that are controlled, generated or developed through out-sourcing?**
- **What benefits could flow from the development of a 'digital twin' for health and care infrastructure and services integral to it?**

Value, Valuation and Strategy

Value

Throughout this Discussion Paper, we have made extensive reference to harnessing the ‘value’ of data, insights and tools. Here, we wish to reiterate that our understanding of the term refers to clinical, social, economic development as well as commercial value because, in practice, Government must alight upon a forward plan of action that delivers each type of value to which we have referred, if the potential for data-driven innovation is to be capitalised upon in the round¹⁷.



Crucially, however, that is not to suggest that each type of value should be afforded *equal weight* in any resultant proposition and that weighting will need to be counter-balanced by pertinent legal as well as ethical and regulatory considerations. Accordingly, we have consistently encouraged an open and honest dialogue with the public to involve them in the design and development of next steps (Bagenal and Naylor, 2018). We have also made plain that coordination across government is urgently required as a result of the inter-connected and fast-evolving policy agendas impacting this terrain.

Valuation

Value should be treated as distinct from ‘valuation’ and, yet, ‘what will it cost and what is it worth?’ are both questions we were frequently challenged to answer in the course of undertaking our research. This is, of course, to assume a narrower focus upon the financial or commercial value of data, insights and tools than we are advocating. However, notably, such questions proved wanting in and of themselves.

That is, whereas public and private investment used to be mostly physical or tangible, it is nowadays, increasingly, intangible – in, for example, knowledge-related products, R&D, design and new business processes – and approaches to as well as standards for measuring

¹⁷We are, also, increasingly, conscious of calls to champion individual ‘data ownership’, linked to health data brokerage platforms and services, but have opted not to explore them in more depth in the context of this Discussion Paper to the extent that they remain new and/or emergent at present.

intangible-intensive economies (both inputs and outputs) remain contested territory at this time (Haskel and Westlake, 2018). Moreover, the demand and supply-side complexities outlined in Parts A and B are such that related factors cannot be used to straightforwardly assess their commercial value – in particular, when coupled with the absence or relative nascence of related markets, and growing interest in the use of synthetic data which might also challenge commercial conventions in the near future.

The stakeholders we engaged in the course of our research were, nonetheless, convinced that there is the potential to better harness different types of value from the data, insights and tools with which we are concerned here – implying that there could well be a cost associated with doing nothing, too little or ‘too late’ – and, especially, in view of related steps being taken by governments, investors and industry around the world at present. They were, also, in many instances, insistent that broad-ranging protective measures are urgently required to guard against ‘value leakage’ as well as ‘asset depreciation’. We have taken the view that these concepts need to be unpacked in more depth and, accordingly, the design and development of protective measures is beyond the scope of this Discussion Paper.

We were, however, interested to learn in the course of our research that adjacent approaches applied by experts in the economics of ‘natural capital’ are well-versed in analysing and accounting for so-called ‘tipping points’ – beyond which, access to natural assets such as fresh-water resources, climate regulation and fertile soils, together with the life-critical benefits with which they are associated, will be ‘irrevocably damaged’ and/or ‘lost’. Clearly, the data, insights and tools we have explored differ in a number of critical respects from their natural counterparts. It did, nonetheless, lead us to consider whether there might be merit in exploring what criteria might be applied to determine the ‘tipping point’ beyond which their damage (depreciation) or irrecoverable loss (of their value) might be anticipated, since their commercial value cannot be determined robustly to establish a more conventional case for action and investment in their protection at this time, and we are entirely in agreement that such measures are required.

The stakeholders we engaged with noted the impact that might flow from:

- a growth in the supply of pertinent data, insights and tools over the next three to five years as a result of international developments in relevant fields;
- increased use and/or access to synthetic data sets - impacting overall demand as well as the scope to innovate at pace where their use may be better ‘insulated’ from established privacy considerations;
- access or the lack thereof to data about people post-mortem and, by contrast, constant improvements in diagnostics and technology which improve the quality of data, such that older data sets have lower fidelity and may not be able to be used continuously with newer sets and thereby render them, progressively, less valuable.
- a lack of pace and/or investment in digitisation, the development of related infrastructure and the skills needed to make full use of them in the short-term (although, the skills requirement will of course continue to evolve over time); and
- investment in the ‘wrong’ infrastructure and/or ‘ahead of time’ – which could enable ‘leap-frogging’ on the part of ‘competitors’ or, else, redundancy in the eyes of new/emergent industries in the medium-term.

We would wish to emphasise that this list is, by no means, exhaustive. Instead, it is intended to point toward the merits of further discussion about the potential to distil protective measures from so-called 'depreciation' and/or 'tipping point' criteria.

Strategy

We have consistently supported calls for a national strategy or policy framework to better harness the value of data, insights and tools flowing from the activities of publicly funded and accountable health and care organisations in the UK (Reform, 2018). Any such strategy or framework must be underpinned by a recognition of 'value' in the broadest possible sense of the term. It will also need to provide a rationale for any *weighting* that decision-makers might be expected to attach to each of those drivers, if all stakeholders are to be convinced and supportive of its priorities and guiding principles.

Agreement upon priorities is critical because they appear, at present, to be geared towards those which flow from the Industrial Strategy into the Life Science Sector Deal – resulting in an emphasis upon public engagement and infrastructure investment in respect of data-driven innovation in *health*. By contrast our own work points toward the need to also stimulate interest, investment and activity in respect of care planning and provision (Future Care Capital, 2018b) as well as healthy longevity¹⁸.

Where data-driven innovation is reliant upon person-identifiable data, any strategy or policy framework should commit Government to upholding and improving established consent mechanisms as well as radical transparency in the interests of building and maintaining public trust - in keeping with the recommendations outlined in Part A. However, there should, also, be a recognition of the benefits that could, potentially, flow more rapidly and more 'evenly' from the operational data, insights and tools we explored in Part B. There could be additional value in the data, insights and tools controlled by private enterprises whose core business is not, currently, health and care service provision – which we touch upon in our end-note – but that will depend upon policy developments in digital competitions and markets and/or the appetite amongst private enterprise to contribute them on a philanthropic basis in the public interest and for public benefit.

Finally, it would make sense, from the point of view of the stakeholders we engaged, for any strategy or policy framework to try and anticipate what data, insights and tools we are liable to need five and ten years from now – to underpin a business case for public investment as well as to afford sufficient time to develop associated infrastructure and workforce capability. We imagine that this is liable to prove challenging, to the extent that industrial developments continue to outpace Governments, but it is also to look toward the future and try to imagine and plan for the health and care treatments, technologies, products and services of tomorrow.

¹⁸ Future Care Capital is a partner of Longevity International – a social enterprise bringing together start-ups, industry, academic and governmental stakeholders to provide a unified voice and coordinating vehicle for positive discourse and change to ensure the 'longevity dividend' is accessible to everyone and the secretariat for the All-Party Parliamentary Group for Longevity in the UK: <https://www.longevityinternational.org/>

Discussion

In this section of our Discussion Paper, we have endeavoured to make plain our understanding of the term 'value' and the difference between harnessing value and 'valuation'. We have, also, reiterated the need for a national strategy or policy framework with guiding principles in respect of data-driven innovation which affords the data, insights and tools related to health and care 'parity of esteem' as well as making plain that this agenda is not solely about person-identifiable data. Ultimately, we need to know whether and how the Government envisages the public sector 'sharing' in any value that might result from arrangements it enters into with commercial entities. To that end, we advocate engaging and involving the public in a discussion about the ways in which 'returns' on their 'investment' of data could be deployed and fairly distributed. There is, in the interim, a great deal of work to do and we acknowledge that the Government must start somewhere.

Here, we would encourage further discussion in respect of the following questions:

- **If the commercial value of data, insights and tools controlled and/or generated by health and organisations cannot be determined robustly, what criteria might be applied to determine the 'tipping point' beyond which their depreciation is anticipated?**
- **What steps does Government intend to take in order to protect, enhance and deploy UK health and care data assets such that the Government maximises their clinical, social, economic development and commercial value as well as guarding against depreciation?**

End Note

Data controlled and/or generated by health and care organisations in the UK has the potential to deliver significant value – for individuals and their families, front-line professionals, commissioners and providers as well as entrepreneurs and long-standing suppliers to health and care organisations in the UK. It could, nonetheless, be better harnessed with a concerted effort on the part of Government to coordinate broad-ranging and fast-evolving agendas.

A determination to explore the potential that health as well as care data harbours is essential. We have also sought to underline what more could be done to unleash the benefits operational data could help organisations to realise.

There may be further value in data controlled by private enterprises whose core business is not, currently, health and care service provision, although we have not looked at this type of data in-depth. Is there scope for Government to both regulate and derive benefit from working in partnership with broad-ranging ‘data monopolies’ in this regard? How might our efforts to reduce obesity be augmented by data from transport providers or supermarkets? Is there an appetite to make better use of banking data to identify and offer support to unpaid carers? What benefit might be derived from petrol stations and/or motor mechanic chains in society’s bid to tackle air pollution? How could data and inferences from smart cities, telecoms or wireless network operators improve our understanding and efforts to reduce the incidence of mental ill-health? We envisage that such data could be appropriately and securely ‘liberated’ in the public interest as well as for public benefit – perhaps, in the course of making radical changes to planning and licensing regimes so that they are fit for purpose in our digital age, or in offering incentives to private enterprises that are prepared to approach corporate social responsibility in new ways – and would hope to see mention of the same in the National Data Strategy in due course.

In the interim, key decision-makers must take heed of hard lessons learned from the shortcomings of past endeavours and commit themselves to radical transparency. Our research highlights the extent to which current arrangements are at best opaque but, more readily, serve to obscure how the value of data about individual data subjects is being harnessed.

We must also support those at the front-line to think beyond getting the basics right and to talk more openly about value in all senses of the term – its protection from leakage but also depreciation; its enhancement using considered policy levers as well as through investment; and the most appropriate means of ‘capture’ through the deployment of data in different circumstances using different models. Ultimately, individual data subjects should be able to understand and, ideally, have a say and/or stake in how the value of data about them is being harnessed and we would encourage further exploration of pertinent mechanisms at this time.

Having developed our own five-step approach to harnessing the value of health and care data, we opted to take a deep-dive into our first proposed step in this Discussion Paper, in the interests of offering timely ‘food for thought’. While we have made high-level recommendations, it has been our intention throughout to provoke further discussion – notwithstanding attendant and entirely appropriate sensitivities as well as a recognition of economic development and commercial interests throughout. That is, we take the view that a considered conversation must be entered into if the UK is to take a lead in championing data-driven innovation in health and care whilst blazing a trail in the development of robust ethical

and regulatory frameworks, because any resultant value proposition must ultimately satisfy individual data subjects, front line professionals working in health and care organisations and government as well as innovators and commercial entities.

Our research and iterative approach to the development of discussion points outlined in this document have afforded us welcome opportunities to inform pertinent policy-making efforts as well as nascent service design activities. They have also laid bare the challenges that those involved on a day-to-day basis face in navigating what is in many respects uncharted territory – and at a time when industrial developments continue to make bigger waves than less agile ships were, perhaps, designed to handle.

We are publishing this Discussion Paper, a related slide-deck and comprehensive data tables online – all of which, we hope, broad-ranging stakeholders will find of interest/use. We are also disseminating the report to parliamentarians, senior officials and key stakeholders in a bid to continue this vitally important conversation. Crucially, we look forward to opportunities to engage with our beneficiaries, commissioners, providers and contractors to better understand their views about the Discussion Points we’ve raised in the context of beginning to think about our own next steps.

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