



House of Commons Public Accounts Committee

July 15th 2019

Written Evidence

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 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.

Our work to enable key stakeholders to better harness the value of health and care data has involved extensive research, policy development and advocacy activity - related publications include: [Intelligent Sharing](#), [Facilitating Care Insight](#) our [parliamentary briefing](#) for the House of Lords as well as our recent Discussion Paper about [Taking Practical Next Steps](#).

Evidence: Executive Summary

FCC's submission to the Public Accounts Select Committee focuses upon the National Audit Office's recent report concerning the [Challenges in Using Data Across Government](#) and, in particular, endorses the view of the NAO that

- data controlled and/or generated with government should be treated as a strategic asset and protected, enhanced and deployed accordingly;
- data, insights and tools controlled and/or generated by publicly funded and accountable bodies should be subject to a balance sheet review and feature on the National Balance Sheet and/or in the Whole of Government Accounts;
- government has done too little to incentivise 'data quality by design' but must, also, increase investment with a view to enhancing data assets of national significance if the UK is to remain competitive from a global perspective;
- there has been a lack of leadership but, also, cross-government coordination with a view to harnessing the value of data assets generated by or with publicly accountable bodies.

We also encourage Members of the Public Accounts Select Committee to consider how any National Data Strategy will ensure that the Government harnesses the value of data it controls and/or generates both in the public interest and for public benefit – the better to enhance trustworthiness of its handling through transparency and fairness.

Evidence: Detail

Government Data as Strategic Asset

1.0 We agree with the NAO's finding that data is not currently treated as a strategic asset whereas, "...by contrast, for government property there are long-term funding plans, with

publicly available strategies for the whole of government collectively and individual departments”. We also agree with its finding that, “...if government is serious about data being one of its most important assets, it is long overdue a balance sheet review”, although we would emphasise the need to harness the value of data, insights and tools controlled by and/or generated with publicly funded and accountable bodies.

- 1.1 Our charitable objects are such that the focus of our work in this instance is limited to health and social care data. We have, nonetheless, consistently called for the development of a national health and care data strategy in contributing to pertinent [reports](#), a **mandatory** policy framework for data-driven innovation underpinned by clear commercial guidance, as well as the establishment of [a national centre of legal and commercial expertise](#) for publicly funded and accountable health and care organisations to assist in optimising the value of their data assets whilst, also, ensuring a [fair distribution of associated benefits](#).
- 1.2 In December 2018, we coordinated a roundtable for expert parliamentarians who expressed strong views about the urgent need to introduce broad-ranging ‘protective measures’ in relation to health and care data assets. We share their concerns that government has, for the most part, neglected to act at a national level to prevent ‘value leakage’ from health and social care data controllers – whether through ‘barter deals’ between individual NHS Trusts and commercial entities (e.g. the Royal Free Hospital/Moorfields Eye Hospital and Google’s DeepMind) or [anticipating new trade deals](#) to be entered into post-Brexit with non-EEA countries (in particular, with the USA) – a concern which was echoed only recently in a related House of Lords [debate](#).
- 1.3 Our [audit](#) of demand for health and care data by third parties in England, conducted earlier this year, further underlined the need for action at a national level to address the scope for a significant disparity in benefits to arise from data-driven innovation in different parts of the country. We also highlighted that the public sector lacks access to operational data, insights and tools generated with third parties under contract – and [recommended](#) that steps be taken to increase access to the same on the grounds that the state’s duty of care and responsibility to ensure value for money must extend into the digital realm.
- 1.4 Health and social care data harbours clinical, social, economic development as well as commercial value. We also acknowledge that valuation of data assets along such lines remains challenging. We are, therefore, engaged in early discussions about the scope to develop and test a related ‘value framework’ working with frontline professionals in health, and we are mindful that other experts are taking forward [pertinent activity](#). Ultimately, however, an approach to accounting for data, insights and tools generated by or with public bodies must be agreed upon – perhaps, integral to HMT’s ongoing knowledge assets review - and result in them featuring on the National Balance Sheet and/or in the Whole of Government Accounts, if the value inherent in them is to be stewarded in a manner that is consistent with the treatment of tangible assets.

Enhancing Data Quality

- 2.0 We agree with the NAO’s finding that “...there is a culture of tolerating and working around poor quality data...evidence-based decision-making is a necessary condition for achieving value for money in public spending”. We also agree that “...good data is not a ‘free good’ and government needs a structured approach to investing in improving and using data”

- 2.1 In our report, [Intelligent Sharing: Unleashing the Potential of Health and Care Data](#), we recommended government streamline information governance modelling for Local Integrated Health and Care Records to expedite data sharing at the local level across publicly funded and accountable health and care organisations based upon qualitative research undertaken with frontline professionals. We also called for an increase in investment for data controllers to help unleash health and care data in a standard and anonymised form where there is value in secondary analysis by third parties.
- 2.2 Government has done too little to incentivise ‘healthcare data quality by design’ through the exercise of relevant policy and funding levers – thereby impacting its immediate value to public bodies and their service users as well as to third parties – albeit we acknowledge the growing emphasis that the Department of Health and Social Care (DHSC) and, in particular, NHSX is placing on the introduction of open standards to improve interoperability. There are too few instances of funding being made reliant upon comprehensive data returns.
- 2.3 Ultimately, however, the core issue remains that the UK has invested only relatively modest sums in health and care data access and curation to help stimulate research and innovation – for example, via its Digital Innovation Hubs programme. By contrast, other countries have seized the opportunity to put health and care data to work both for their citizens and their economy. For example, China has declared promotion of the use of big data in healthcare a national priority since the State Council of China acknowledged that big data in health and medicine represented a strategic national resource back in 2016. Israel, meanwhile, has said that it will invest circa \$287m in a project to make data about the health of its population available to researchers and innovators.

Leadership and Cross-Government Coordination

- 3.0 We agree with the NAO’s finding that “there has been a lack of leadership across government...[it] needs to develop the capability, leadership and culture to support sustained improvement”.
- 3.1 Cross-government coordination is urgently required if the value of data, insights and tools controlled by and/or generated with publicly funded and accountable health and care organisations is to be optimised to deliver significant benefits for individuals, clinicians, SMEs and the public finances upon which pertinent services, treatments and technologies depend. There is a real risk we run out of time such that its value ‘leaks’ or depreciates beyond a critical tipping point.
- 3.2 We have for some time advocated exploration of the potential to establish a [Sovereign Health Fund](#) with all of the above borne in mind, but it is a big idea and will require political courage as well as leadership if it is to be seriously explored – let alone, realised in practice.

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