

Parliamentary Debate Briefing: this House takes note of the value of NHS and healthcare data and how it could be used to improve the health of our nation.

House of Lords: September 6th, 2018.

About Us

Future Care Capital (FCC) is a charity which uses evidence-based 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.

Ahead of the debate, this briefing builds upon [our report](#) about how the UK might support data-driven research and innovation to transform health and care outcomes, and outlines the areas which FCC believes parliamentarians should reflect upon.

The Challenge

The potential for data to improve the efficiency and effectiveness of health R&D, healthcare delivery and the National Health Service more broadly is substantial, and a number of NHS bodies are currently exploring ways in which to harness its social, economic and environmental value whilst addressing the technical, legal, ethical and cultural barriers to delivering potential benefits.

Whilst there is merit to experimentation at the local level, there is a risk that:

- (a) data sharing agreements entered into by individual Trusts provide access to data in keeping with **priorities that are set by industry** (i.e. in accordance with a commercial imperative) rather than by clinicians and/or the wider public sector;
- (b) **data sharing agreements do not conform to nationally agreed standards** – impacting the value created in different places and, potentially, public trust;
- (c) **individual Trusts benefit from differential control over data of interest to researchers, entrepreneurs and innovators** – impacting the extent to which they are able to harness the financial value of data assets relative to others;
- (d) Trusts that are ‘data/expertise poor’ will have to compensate other ‘data/expertise rich’ Trusts in future for the Intellectual Property they (help) develop – potentially, **exacerbating the ‘postcode lottery’ and, with that, health inequalities** (i.e. the social value that healthcare data should, ideally, create for the NHS as a whole – and, with that, everyone living in the UK); and
- (e) **some Trusts lack the in-house expertise that is needed to enter into commercially savvy deals** relative to the corporate entities approaching them.

Central Government has also tried in recent years to manage and harness the value of healthcare data collected by the NHS and affiliated bodies but, to date, has:

- 1) 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 the NHS as well as to third parties;
- 2) **invested only relatively modest sums in healthcare data access and curation** to stimulate third party access and innovation;

- 3) been **slow to take steps that are designed to improve and/or join-up data collection across healthcare organisations** through an emphasis on standards, open interfaces and interoperability;
- 4) **neglected to act at a national level to prevent ‘healthcare data leakage’** from NHS data controllers – whether through ‘barter deals’ between individual 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-EU countries (in particular, the USA); and
- 5) had **an adverse effect upon public and professional trust** in mishandling large-scale data-driven initiatives - in particular, the care.data 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 has said that it will invest circa 1 billion shekels (\$287m)** in a project to make data about the health of its population available to researchers and private companies. Meanwhile, companies including **Amazon, Alphabet and Microsoft have pledged only this month to “share the common quest to unlock the potential in health care data, to deliver better outcomes at lower costs.”**¹

The Opportunity

The UK Government is investing £37.5m to establish Digital Innovation Hubs and harness healthcare data to tackle some of Britain’s biggest health challenges². Related activities will commence in Autumn 2018, so this cross-party debate affords parliamentarians a timely and important opportunity to explore whether and how best to harness the social, economic and environmental value of healthcare data to transform the health prospects of everyone living in the UK. It should also serve to raise awareness of this issue amongst the general public – whose involvement in next steps, trust and ongoing support is critical.

Digital Innovation Hubs will seek and learn from local examples of research partnerships that are already working in practice, but Government should also:

- 1) engage clinicians, the wider public sector as well as the general public to **establish the priorities for healthcare data sharing** initiatives with third parties and, thereby, maximise the broader social value they have the potential to generate;
- 2) put in place **measures to ensure ‘data quality by design’ and/or fund data clean-up and curation to hasten delivery** of those priorities;
- 3) develop **a framework for healthcare information sharing agreements** involving NHS bodies to ensure they conform to **nationally agreed standards**;
- 4) explore the scope to **place healthcare data assets controlled by NHS bodies on the national balance sheet** integral to the balance sheet review – the findings of which the Chancellor will reflect upon in his Autumn Statement;
- 5) provide Trusts with **access to a dedicated commercial team** in order to optimise the financial value derived from healthcare information sharing agreements they enter into with third parties; and
- 6) require that Trusts working with Digital Innovation Hubs and/or entering into healthcare information sharing agreements with third parties work with the Government to **co-design a mechanism for recycling or redistributing associated revenues** (or part thereof) to ensure everyone living in the UK benefits from data-driven healthcare advancements in an equitable manner.

¹ US tech giants pledge to ease patient and provider access to health data -

<https://www.wsj.com/articles/tech-giants-pledge-to-ease-patient-provider-access-to-health-data-1534192429>

² Digital Innovation Hubs - <https://www.hdruk.ac.uk/news/37-5m-investment-in-digital-innovation-hubs/>

A UK Sovereign Health Fund

The value of health data is appreciating faster than the rate of increase in healthcare costs. However, realising their potential value represents a time-limited opportunity in a globally competitive market, and there is **currently no clearly agreed strategy which sets out how the NHS and UK PLC intends to benefit from providing access to and/or usage of the data the NHS controls.** The UK Government could approach access to and usage of broad-ranging NHS data assets in a commercial manner to deliver impact across the nation through the establishment of a **Sovereign Health Fund.**

When North Sea oil was first discovered, the British approach was to spend it as if it were additional tax revenue. In Norway, they established a Sovereign Wealth Fund into which the license fees from the oil revenues were accumulated. Today, that fund approaches \$1 trillion and it is used for the benefit of the Norwegian people. **The UK Government should explore the scope to recycle financial value from the broad-ranging data assets the NHS controls to generate additional funds for healthcare R&D and/or healthcare provision** to benefit individuals and improve the nation's health long into the future.

A Sovereign Health Fund, wholly owned by the Secretary of State for Health and Social Care and operated akin to other sovereign wealth funds around the world, could be established in order to:

- 1: leverage the UK's unique health data assets;
- 2: establish the UK as the go-to place, internationally, for healthcare R&D;
- 3: contribute to the growing cost of healthcare provision in the UK.

This is something that the new expert panel, chaired by former US President Obama's chief economic advisor, Professor Jason Furnam, could perhaps look at as part of its work to examine competition in the UK's digital economy.

Key questions to ask during the debate:

1. Will the Government agree to develop an action plan to harness the value of NHS controlled healthcare data?
2. How will the Government support efforts to directly engage the public in harnessing the value of their healthcare data to deliver better outcomes for society?
3. What measures will the Government put in place to prevent the 'leakage' of both social and economic value from healthcare data sharing with third parties and, in particular, corporates headquartered in other countries?
4. Does the Government support the principle of harnessing healthcare data on a commercial basis and, if so, what ethical safeguards will it put in place to maintain public trust in sharing NHS controlled data with third parties?
5. Will the Government agree to value the healthcare data it controls and include the valuation in the Chancellor's balance sheet review ahead of the Autumn Statement?
6. Does the Government agree that a UK Sovereign Health Fund is a viable option to recycle the value of healthcare data and IP that flows from its usage?

Further Information

If you have further questions about the debate or would like to meet to discuss any of the issues raised in this briefing, please do not hesitate to contact:

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