

Parliamentary Debate Briefing: this House takes note of the case for protecting the National Health Service in future trade deals entered into by the United Kingdom.

House of Lords: July 4th, 2019

About Us

Future Care Capital is an independent charity which undertakes research to advance ideas that will help shape future health and social care policy to deliver improved 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 briefing outlines a number of areas which, we believe, parliamentarians might usefully reflect upon ahead of the debate.

Context

It has been widely reported that a no-deal Brexit or, indeed, Brexit of any kind is liable to impact healthcare trials and other projects pursuing medical innovations, in particular, where they are reliant upon cross-border cooperation in respect of data sharing. One of the areas about which far less has been said, to date, is the potential for future data sharing arrangements with non-European Economic Area (EEA) countries to impact ongoing efforts to build and maintain public trust in the use of patient data controlled and/or generated by the NHS in order to develop new treatments and technologies.

In recent years, we have undertaken extensive research, policy development and advocacy activities as well as producing several publications which explore whether and how the UK might better harness the clinical, social, economic and commercial value of healthcare data whilst championing the rights of individuals – including: [Intelligent Sharing](#) (2017) and [Taking Next Steps to Harness the Value of Health and Care Data](#) (2019).

The need to safeguard patient data is, of course, taken very seriously by the Department for Health and Social Care (DHSC) and the UK has already enacted laws enshrining the General Data Protection Regulation (GDPR) into national legislation. However, Brexit is not only about our future relationship with EU Member States – it is also about the freedom to enter trade agreements in our own right. With that in mind, we recommended that the Government develop a dedicated ‘privacy shield’ for UK health and care data, applicable to any future trade negotiations outside Europe, as highlighted in our Intelligent Sharing report and would wish to emphasise here that such a shield is needed more now than ever.

The Challenge

Recent talk of the NHS being ‘on the table’ in future trade deals has largely been concerned with maintaining public sector control of strategy development, national ‘corporate services’, commissioning and provider contracts. Others, still, have concentrated upon market access for products and services and, in particular, the potential for drug pricing to be impacted by new arrangements. These are all valid concerns and important issues. Meanwhile, the future of healthcare products and services is liable to be data-driven to a very significant extent, and we believe too little has been said about the implications of proposed data sharing arrangements post-Brexit – with the notable exceptions of recent articles published by [Phil Booth](#) (MedConfidential), [Caroline Molloy](#) (Open Democracy) and [Philip Aldrick](#) (Economics Editor at The Times).

A recent [survey](#) commissioned by Sensyne Health and undertaken by YouGov found that the UK public strongly supports the analysis of anonymised NHS patient data for medical research but is less supportive of this being conducted by multi-national technology companies. In particular, just one in ten respondents (11%) said that

they were happy for NHS data to be analysed by businesses that do not pay tax in the UK, whilst 69% raised concerns about this information being analysed in other countries with different laws governing data security and confidentiality. Dame Fiona Caldicott, the National Data Guardian for Health and Social Care (NDG) has only this week echoed [our own call](#) for a public debate to shape the future of commercial relationships between the NHS, universities and private companies – citing the results of a [recent poll](#) which found that there is a need for further dialogue and education before public trust and buy-in to the Government’s plans to maximise the value of healthcare data can be relied upon.

The DHSC, helpfully, continues to publish iterations of its [Code of Conduct for Data-driven Health and Care Technology](#) and is widely expected to update Principle 10 with guiding commercial principles in due course. However, the Code remains voluntary in nature and it is, as yet, unclear whether those guiding principles first referred to in the latest Life Sciences Sector Deal (December 2018) will read-across to public sentiment about the use of healthcare data about them for the purposes of innovation in the context of future trade deals.

At the same time, the Government has indicated that it will not pursue a policy of data localisation nor stand in the way of the ‘free flow of data’, and the Secretary of State for the Department of Digital, Culture, Media and Sport (DCMS) is afforded considerable powers concerned with the transfer of data based on adequacy regulations in sections 17A and B of [Statutory Instrument 2019 No. 419: the Data Protection, Privacy and Electronic Communications \(EU Exit\) Regulations 2019](#).

We are concerned that any exercise of such powers which pre-empts a comprehensive public engagement effort, an explicit and meaningful commitment to radical transparency, as well as the development of dynamic consent mechanisms could result in mass opt-outs on the part of the general public and do damage to the life science and technology sectors in the UK.

The Opportunity

The Secretary of State (DCMS) can, by virtue of Section 17A of the Regulations cited above, specify any of the following which s/he considers ensures an adequate level of protection for personal data:

- (a) a third country;
- (b) a territory, or one or more sectors within a third country;
- (c) an international organisation; or
- (d) a description of such a country, territory, sector or organisation.

There is, then, the opportunity to rule out or ‘take off the table’ the health and care sectors globally until such time as those measures outlined above (i.e. public engagement, radical transparency and dynamic consent) are put in place and a dedicated health and care data privacy shield co-produced under (d) to garner maximum support from the general public as well as optimum benefits for UK entrepreneurs and businesses.

Key Issues and Questions for consideration

- 1) Under what circumstances might the Government deem a third country adequate from the point of view from data protection even if the EU does not in relation to Section 17A (a)?
- 2) What assurances can the Minister offer the UK public regarding taxation and digital competition in relation to Section 17A (b) as they pertain to the future of treatments and technologies in health and care?
- 3) Will the Government consider co-producing a dedicated health and care privacy shield which reads-across to public sentiment in anticipation of entering into future trade deals post-Brexit to allay concerns that health data controlled by the NHS is very much ‘on the table’ as the legislation currently stands?

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: Annemarie Naylor MBE, Director of Policy and Strategy - Future Care Capital at annemarie.naylor@futurecarecapital.org.uk.