

Dear (MP)

Re: The Data (Use and Access) Bill 2024

I am writing as one of your constituents and as a member of Keep Our NHS Public.

I am deeply concerned that the Data (Use and Access) Bill, which has already had its second reading in the House of Lords, contains a range of provisions that will reduce data protections for personal health data, and increase access and use of NHS-held data by government and the private sector. These provisions are concerned with the Government's plans to increase economic growth without adequate regulation and protection of the public interest. The Bill also weakens the role of Parliament in its role of holding the Government to account: a large number of its proposals contain little detail but instead provide largely unfettered powers for the Secretary of State.

For example:

i) New powers will enable the Secretary of State to introduce, redefine or change conditions for the use of 'special categories of data' (sensitive information about a person's health or genetic make up, for example) in response to the demands of new technologies. These powers will allow increased (and potentially commercial) access to what is currently confidential information, and could create significant risks to an individual's fundamental rights and freedoms.

ii) The Bill aims to make it easier to share data, so that information collected for one reason, such as healthcare, may be shared with public authorities and private companies who may use it for other purposes, such as immigration control or predictive policing. At the same time, transparency about the reuse of data will be reduced: those reusing data will be exempted from the current requirement to inform data subjects about their data's reuse if the effort involved is thought to be 'disproportionate'.

iii) The Bill will amend the definition of 'scientific research' to facilitate the processing of data for research, whether this is publicly or privately funded or a commercial or non-commercial activity. A range of well designed, cross-sectional studies show that most people are happy to share their health data with NHS researchers when research is wholly in the public interest, but are extremely wary about sharing their data with profit-driven companies.

This Bill undermines Parliamentary process by providing the Secretary of State with significant powers to introduce or amend regulations. As the Lord's Constitution Committee¹ stated in its consideration of the Bill, "[d]ata protection is a matter of great importance in maintaining a relationship of trust between the state and the individual", and that the power to use personal data should not become so broad as to unduly limit the rights of the individual. If enacted, the DUA Bill is likely to lead to a significant loss of trust in the way our personal health data is used, prompting many people to 'opt out' of data sharing. As the current blanket 'opt out' stands, this would unfortunately mean also having to 'opt out' of research and development that is wholly in the public interest.

I attach a briefing paper from Keep Our NHS Public that provides more information and I urge you, as my MP to raise questions in the House about

- the reduced protections for personal health data that the Bill will introduce
- the Bill's proposals for sharing personal health data with non-NHS public bodies and private companies without explicit consent, and
- the undemocratic nature of the Bill and the significant powers it gives to the Secretary of State.

I would also ask you to vote against this Bill if it comes before Parliament for final reading without amendments to address these concerns.

Yours etc

[Name and address]

¹ <https://publications.parliament.uk/pa/ld5901/ldselect/ldconst/40/4003.htm>