



Department
of Health

*From the Lord O'Shaughnessy
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Baroness Thornton
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21 NOV 2018

Dear Glenys

Re: Health and Social Care (National Data Guardian) Bill

Thank you for your valuable input on Friday 26th of October at the Second Reading of the Health and Social Care (National Data Guardian) Bill and for your support in the progress of this important Bill.

During the reading you raised a concern on behalf of National Aids Trust, that the bill's definition of "health and adult social care data" could be interpreted to exclude non-clinical, demographic data that relates to an individual - for example, home address and family details - from the scope of the National Data Guardian's (NDG) guidance.

I wanted to write to you directly and address this point, and to expand upon the statement I made during the debate to offer further reassurance and clarification.

Where issues surrounding demographic data have the potential to impact upon, or form part of the processing of health and adult social care data, this would fall within the NDG's statutory remit and they would be able to publish formal statutory guidance on the topic. There would be a corresponding legal duty to have regard to this guidance on the part of public bodies within the health and adult social care sector (and private organisations who contract with them to deliver health or adult social care services). We consider that the Bill is drafted widely enough to allow for this.

Stand-alone demographic data is excluded from the scope of “health and adult social care data” as defined in the Bill. If the NDG was able to issue statutory guidance on purely demographic data which doesn’t impact on the processing of health and adult social care data, then they would have scope over personal data. This would give the NDG an “ICO style” remit which we don’t feel is appropriate or desirable. The ICO is the designated body in the UK responsible for upholding rights in respect of personal data, and it is important that the NDG does not cut across that function.

The role of the NDG is, first and foremost, about good practice and supporting organisations and individuals who process health and adult social care data. The Bill is drafted widely to allow the NDG to issue guidance “about the processing of health and adult social care data”.

This should be interpreted broadly, and would allow for the NDG to produce guidance on issues that impact on the processing to health and adult social care data. This would include, for example, good practice in terms of security standards for storing health and adult social care data. This is an example of where guidance is not strictly focused on the health and social care data itself, but about the processes and issues which could impact upon it. Almost anything which should be taken into account when processing health and adult social care data, or which broadly has the potential to impact, affect or influence that processing would fall within scope of the definition.

There are many examples of issues which have previously been considered by the NDG, which are “about” the processing of health and social care data, without being focused on the data itself. These include:

- Engaging directly with the public on their expectations in relation to data sharing – such as the NDG’s citizen jury work
- Advising on how patients and the public are best engaged in conversations about patient data – such as the advice given to the National Data Opt-out programme
- Engaging with relevant organisations about how the health and care workforce can be better supported to use digital technology and share data in the interests of patients, such as discussions with NHS Digital Academy, medical royal colleges, and UK Faculty of Informatics



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- Engaging with stakeholders about barriers to more joined up sharing of data which are not necessarily about the data, for example where systems or a culture of anxiety about sharing is preventative – this includes discussions with CQC on their work on system reviews

Under the Bill we still consider that the NDG would be able to issue statutory guidance in these areas, and it is our intent that they should.

I hope you will be reassured by this and I welcome the opportunity to discuss any matters with you further.

I have copied this letter to the other Peers who took part in the debate, and I will deposit a copy in the Library.

JAMES O'SHAUGHNESSY

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