



## Health and Social Care (National Data Guardian) Bill HL Bill 122 of 2017–19

### Summary

The [Health and Social Care \(National Data Guardian\) Bill](#) is a private member's bill that seeks to establish, and make provision for, the National Data Guardian for health and social care, which is responsible for advising and producing guidance on patient data and confidentiality. The bill, introduced by Peter Bone (Conservative MP for Wellingborough), would place the office of the National Data Guardian for health and social care on a statutory footing. The National Data Guardian came about following three reviews: the [Report on the Review of Patient-Identifiable Information](#), the [Information Governance Review](#) and the [Review of Data Security, Consent and Opt-Outs](#). A commitment to place the office on a statutory footing was included in the 2017 Conservative Party general election manifesto. The bill extends to England and Wales only. It has thus far received cross-party support.

The bill was introduced in the House of Commons on 5 September 2017, had its second reading on 1 December 2017 and completed its stages in the House of Commons on 6 July 2018. The bill was introduced in the House of Lords on 9 July 2018. It is sponsored by Baroness Chisholm of Owlpen (Conservative) and is due to have its second reading on 26 October 2018.

### Background

The National Information Governance Board (NIGB) for health and social care, introduced by the Health and Social Care Act 2008, was created to oversee the processing of patient information relating to the physical or mental health condition of an individual which was obtained during the provision of health services. However, as part of a wider review of non-departmental public bodies, on 14 October 2010, the Government announced its intention to abolish the NIGB with its statutory functions to be transferred to the Care Quality Commission (CQC).<sup>1</sup>

The Health and Social Care Act 2012 formally repealed the statutory basis for the NIGB.<sup>2</sup> In 2012, the then Government commissioned an independent review of information governance across the health and care system in England. This was led by Dame Fiona Caldicott, then chair of the National Information Governance Board, and previous chair of the 1997 [Report on the Review of Patient-Identifiable Information](#) which set out six principles for processing patient information, known as the 'Caldicott Principles'. The [Information Governance Review](#) was published in April 2013, containing seven revised principles and 26 recommendations for Government. In 2013, a new independent panel, the Independent Information Governance Oversight Panel (IIGOP), was set up to oversee the implementation of the recommendations of the *Information Governance Review*.

In 2014 the panel was renamed the National Data Guardian (NDG) for health and social care, with Dame Fiona appointed as the first National Data Guardian. In 2016, the NDG published the [Review of Data Security, Consent and Opt-Outs](#), which set out a number of recommendations, including the introduction of ten new data security standards across the NHS and a national data opt-out programme for patients.<sup>3</sup>

Whilst the CQC undertook responsibility for the NIGB's statutory function of monitoring the information governance practices of health and care providers, the IIGOP commented in its 2014 annual report that the abolition of the NIGB's other functions had "left the system in England without a statutory arbiter, to which organisations could turn for the authoritative resolution of difficult questions".<sup>4</sup> Further, it stated that "although IIGOP has tried to assist organisations over the past year by offering its opinion, when asked, it has not had the NIGB's level of statutory authority or resource".<sup>5</sup>

In 2014, Lord Owen tabled an amendment to the Care Bill (which became the Care Act 2014) which would have put the IIGOP on a statutory footing. The then Health Minister, Earl Howe, stated that:

[T]here may well be merit in establishing the panel in law and giving legal force to its advice on data sharing. I strongly feel, however, that on this important matter, so crucial to people's privacy and confidentiality, to the safe and efficient operation of the health and care system, and to the research agenda, it is vital that we ensure the system of oversight, scrutiny and advice is robust and coherent. I undertake that we will explore with Dame Fiona Caldicott and all interested parties how best to achieve this, which may include using existing legal powers to establish an independent committee able to advise on data-sharing matters. Dame Fiona Caldicott has confirmed that she would explore options on existing legal powers to establish an independent committee and has noted the importance of considering further and clarifying the functions of the panel before doing so.<sup>6</sup>

In 2015, the then Department of Health carried out a consultation on the functions of the NDG. It published a summary of responses in 2016 which acknowledged support for putting the NDG on a statutory footing, and committing to doing so at the earliest opportunity. Jo Churchill (Conservative MP for Bury St Edmunds) sponsored a private member's bill with the support of the Government, the Health and Social Care (National Data Guardian) Bill in the 2016–17 session, to place the NDG on statutory footing, but this had insufficient time to progress due to the general election of 2017.<sup>7</sup> Subsequently the Conservative Party's 2017 general election manifesto set out a commitment to put the NDG on a statutory footing.<sup>8</sup>

## **Provisions of the Bill**

Clause 1 sets out the role of the National Data Guardian (NDG) and would empower the Secretary of State for Health and Social Care to appoint an individual as NDG. The clause specifies that the NDG can publish guidance about the processing of health and adult social care data in England, and that public bodies exercising health or adult social care functions would be required to have regard to any NDG guidance. The NDG must consult appropriate bodies in relation to any guidance it publishes, and such guidance must also be kept under review. Under this clause, the NDG would also be able to give information and advice on the processing of health and care data.

Further provisions about the NDG's role are set out in schedule 1. These include, for example: the NDG can hold the office for up to three years, and can only be re-appointed once; the NDG can be removed from the role by the Secretary of State if they are unable, unwilling or unfit to carry out their role; and the NDG must produce an annual report, including a statement of accounts and any guidance produced during the year, which the Secretary of State is required to lay before Parliament.

Clause 2 provides interpretation of various terms in the bill, including adult social care, and health and adult social care. Clause 3 refers to consequential amendments made by schedule 2, which include amendments to legislation such as: the Parliamentary Commissioner Act 1967 (to confirm that the NDG is subject to oversight by the Parliamentary Ombudsman); the Freedom of Information Act 2000 (to confirm that the NDG is subject to this legislation); and the Equality Act 2010 (to confirm that the NDG is subject to the public sector equality duty). Clause 4 provides that the bill extends to England and Wales only. However, the bill's explanatory notes state that clause 1, which provides for the NDG to publish guidance and give advice, information and assistance, only applies in relation to the processing of health and adult social care data in England.

## House of Commons Stages

### *Second Reading and Money Resolution Debate*

The bill had its second reading on 1 December 2017, but—due to insufficient time—progressed without debate.<sup>9</sup> However, a money resolution debate did take place on 21 May 2018.<sup>10</sup> In relation to finances, the bill's explanatory notes stated that the bill would require expenditure to fund the office of the National Data Guardian for health and social care so that it would undertake its statutory functions.<sup>11</sup> According to the Department of Health and Social Care, the estimated costs will be approximately £700,000 per annum.<sup>12</sup> Further, the explanatory notes stated that the bill may result in some "implementation costs for the bodies and individuals required to have regard to the Data Guardian's published guidance, in that they will need to review and assess the relevance of the guidance".<sup>13</sup> The bill's sponsor, Peter Bone (Conservative MP for Wellingborough), stated:

The role of health and social care national data guardian has already been established, but the bill would put it on a statutory footing. I thought that the need for a money resolution was a little arguable, as the Government were already paying for the same services, but the excellent advice from the Clerks was that we did need one, and the amount of money involved is reasonably substantial.<sup>14</sup>

The Government confirmed its support for the bill. The Parliamentary Under Secretary of State for Health and Social Care, Jackie Doyle-Price, stated:

I pay tribute to my hon. Friend the Member for Wellingborough (Mr Peter Bone) for bringing forward this important bill. I once again confirm the Government's support for and commitment to it and our desire to see it succeed.<sup>15</sup>

The bill was also supported by the Opposition with Shadow Minister for Health, Justin Madders, stating:

There is well-recorded Labour support for the bill. The use of data has the potential to improve every aspect of the NHS by, for instance, transforming the way in which we diagnose

illnesses such as cancer, and improving the patient experience by ensuring that every clinician at every stage has access to the complete picture. However, as we know from experience, the use of data in the NHS can be controversial, with high levels of suspicion among patients.<sup>16</sup>

### **Committee Stage**

The bill progressed through public bill committee on 6 June 2018 without amendment. However, there were a number of issues discussed during the debate. For example, Mr Madders highlighted the use of data in public health, and wanted the Government and the bill's sponsor to comment on whether the bill was intended to cover health in the broader sense.<sup>17</sup> Ms Doyle-Price stated that the bill as drafted covered public health, and that provisions in the bill “will extend to local authority functions with respect to adult social care, but not to children because they are covered by a different legal framework”.<sup>18</sup>

Mr Madders also raised concerns about the bill giving the Secretary of State for Health and Social Care the power to appoint the NDG without qualification or additional oversight:

There seems to be a discrepancy that leaves the Data Guardian in an inferior position to either the existing Confidentiality Advisory Group or the Health Research Authority. I would be grateful to know if that was the intention of the legislation. The power to appoint the Data Guardian rests entirely with the Secretary of State, seemingly without any qualification. Is it envisaged that the Health Committee might get an opportunity to comment on such appointments? Recent appointments in the health sector have proven controversial, so it would be appropriate for the Select Committee to comment.<sup>19</sup>

On this point, Mr Bone explained that “the appointment will be down to the Secretary of State, but I absolutely expect it to go to the Health and Social Care Committee—I think that is understood”.<sup>20</sup> Ms Doyle-Price did not comment on this point.

Chris Bryant (Labour MP for Rhondda) highlighted MPs' retention of sensitive, personal health and care data for their constituents and requested to know whether the NDG would be able to produce advice specifically for MPs in relation to their processing of this information:

People often come to us with complaints about their local health board—in my case, in Wales—or about their general practitioner or the provision of care in a care home, through the local authority or some private sector deliverer. We often have highly confidential information stored, almost as if we were a GP or a doctor; certainly, to that degree of information. For that matter, that is also sometimes information that has been provided by other authorities such as the police. [...]

I hope that the Data Guardian will be able to provide advice to Members of Parliament as well. I know that is not in the bill and is not its primary purpose, but it would be a mistake if the guardian were to operate in a way that did not take any cognisance of the relationship that Members of Parliament have with local health boards, and with the health service and care provision in general.<sup>21</sup>

Ms Doyle-Price also highlighted the importance of advice being provided to health and social care organisations in relation to their contact with MPs:

[...] it could be helpful to us if the National Data Guardian gave instructions to those bodies about their obligation to be open and transparent. I am sure that the hon. Gentleman, and other hon. Members, have often found that the spirit of openness that we expect when we challenge something is not always respected. In that culture of openness, and with respect for privacy and safety, we support the bill.<sup>22</sup>

### ***Report Stage and Third Reading***

The Bill had its report stage and third reading on 6 July 2018, both of which passed without amendment or debate.

### **Further Information**

- House of Commons Library, [Health and Social Care \(National Data Guardian\) Bill 2017–19](#), 8 June 2018
- House of Commons Library, [Patient Health Records and Confidentiality](#), 25 May 2018

- <sup>1</sup> [Written Question on 'National Information Governance Board'](#), HL *Hansard*, 1 December 2010, WA467.
- <sup>2</sup> Section 157(1) of the Health and Social Care Act 2008 was repealed by the Health and Social Care Act 2012.
- <sup>3</sup> House of Commons Library, [Health and Social Care \(National Data Guardian\) Bill 2017–19](#), 8 June 2018, pp 4–7.
- <sup>4</sup> Independent Information Governance Oversight Panel, [Report to the Secretary of State for Health: The First Year](#), December 2014, p 7.
- <sup>5</sup> *ibid.*
- <sup>6</sup> [HL Hansard, 7 May 2014, col 1528](#).
- <sup>7</sup> UK Parliament website, [Health and Social Care \(National Data Guardian\) Bill 2016–17](#), accessed 12 October 2018.
- <sup>8</sup> House of Commons Library, [Health and Social Care \(National Data Guardian\) Bill 2017–19](#), 8 June 2018, p 6.
- <sup>9</sup> [HC Hansard, 1 December 2017, col 658](#).
- <sup>10</sup> [HC Hansard, 21 May 2018, cols 674–9](#).
- <sup>11</sup> [Explanatory Notes to the Health and Social Care \(National Data Guardian\) Bill 2017–19](#), p 6.
- <sup>12</sup> *ibid.*
- <sup>13</sup> *ibid.*
- <sup>14</sup> [HC Hansard, 21 May 2018, col 675](#).
- <sup>15</sup> *ibid.*, col 674.
- <sup>16</sup> *ibid.*, cols 674–5.
- <sup>17</sup> [HC Hansard, 6 June 2018, cols 5–7](#).
- <sup>18</sup> *ibid.*, col 9.
- <sup>19</sup> *ibid.*, cols 5–7.
- <sup>20</sup> *ibid.*, cols 9–10.
- <sup>21</sup> *ibid.*, col 8.
- <sup>22</sup> *ibid.*, col 9.

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