

## National Data Guardian Bill: probing amendments for Committee Stage

medConfidential supports the principle of the National Data Guardian Bill, and supports much of the current Bill draft, as far as it goes, but – noting several significant ways in which the Bill falls short of the Government’s own proposals and commitments in the National Data Guardian consultation – below are a number of questions and probing amendments.

Some of these may be addressed in the Ministerial speech about the Bill.

medConfidential is, of course, happy to discuss this further.

medConfidential

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### medConfidential probing amendment 1

Amend sub-clause 1(2) and insert:

*“, and public health ” after “social care”*

#### **Justification:**

This amendment seeks to probe the boundary between the NHS and the public health system.

The work of the public health system often includes heavy use of data collected by and in the NHS – such as the cancer registry. Taking the cancer registry as an example; this register makes use of data collected by the NHS, including uses that affect the direct care of patients. Inclusion in the cancer registry is subject to patient dissent, which could affect their care, and yet it sits inside Public Health England, whose information systems do not recognise this vital distinction – instead of the NHS, whose systems do distinguish.

In short, why is the National Data Guardian excluded from Public Health?

*Likely Government response:* Denial of the existence of the problem.

*medConfidential comment on likely Government response:* Any inadequate response may be critiqued in the other place. Ministers may wish to reflect on current practices, potentials for improvement, and be clearer upon Report. Given the forthcoming McNeil review<sup>1</sup>, that medical data used in public health is excluded from the National Data Guardian’s remit will appear strikingly anomalous.

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<sup>1</sup> Which may be informed by this article: <https://medconfidential.org/2017/public-health-england/>

## medConfidential probing amendment 2

Insert at end of sub-clause 1(5):

*“; and must be provided with appropriate information by any persons which, for any reason, process health and adult social care data in England.”*

### **Justification:**

While the National Data Guardian is a cornerstone of a consensual, safe and transparent data infrastructure for the NHS, as proposed in this Bill draft, the National Data Guardian is – in effect – both blind and deaf. The Guardian has no powers to require that necessary and appropriate information be provided, in order to arrive at a properly informed judgment.

For the National Data Guardian to take a view on an issue, the Guardian first has to know that there is an issue on which to take a view. While some bodies are likely to cooperate in this, the Bill as drafted provides no obligation that they do. And it is precisely those bodies which raise issues of concern that are least likely to cooperate (e.g. TPP, Pharmacy2U).

In practice, sending a copy of every data sharing agreement across the health and adult social care system to the National Data Guardian would likely overwhelm their small office. Were there instead to be a published Register of data sharing agreements to which all NHS and relevant bodies must submit a copy, this would provide the NDG with a single point of reference from which to note new agreements that are outwith the norm.

A Register of data sharing agreements would also increase patient reassurance, as such registers<sup>2</sup> have done elsewhere, since patients would be able to identify the places to which their data may have been copied, and those by whom it may have been accessed.

While NHS Digital's Register of data releases is a necessary step, it does not cover data sharing agreements for secondary uses of data that are not released by NHS Digital, such as those by Public Health England.

In a similar fashion, while NHS Digital makes some releases to organisations for purposes that include commercial re-use, it is only the agreement with those 'information intermediary' organisation that appears in the NHS Digital Register. Those organisations' commercial customers who receive data escape inclusion. In other words, it is the middleman that is registered, rather than the end recipient. It is therefore unclear whether section 1(8) is expected to specifically exclude such activities, which currently include pharmaceutical marketing.

The Government's consultation on the National Data Guardian "proposes that: the remit of the National Data Guardian role should follow the health and care data" – i.e. the Government's own proposal was not just public bodies, and not just those providing services. This amendment seeks to confirm that the current wording in fact achieves what the Government proposed.

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<sup>2</sup> e.g. NHS Digital's Register of data releases, and the CAG Register of approved applications.

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### **medConfidential probing amendment 3**

Insert at end of Schedule, paragraph 17(b):

*“, and the effect of such advice or guidance.”*

#### **Justification:**

While organisations and individuals may draw matters to the attention of the National Data Guardian, and the National Data Guardian may take action, there is nothing in the Bill as currently drafted which ensures that patients will necessarily be able to find out what happened in response.

As the National Data Guardian does not have powers to perform audits directly, and is not currently resourced to do so, will the Memoranda of Understanding with the ICO, NHS Digital, CQC and others empower the Guardian to request that facts are established independently via audit wherever necessary?

*Likely Government response: Yes.*

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### **medConfidential probing amendment 4**

Insert at end of sub-clause 1 (3), a new paragraph:

*(c) the Secretary of State on matters relating to the processing of relevant information by any person, as requested or otherwise.*

#### **Justification:**

As currently drafted, the National Data Guardian does not have the ability to give either advice or guidance to the Secretary of State. This is a serious omission.

The lack of any clear basis for the National Data Guardian to provide advice to Secretary of State would make the new National Data Guardian significantly less independent than otherwise, and provide fewer powers than the existing Confidentiality Advisory Group. Such a discrepancy, were it to remain, would place the Guardian in an inferior position to the Health Research Authority.

The Secretary of State or NHS England may publish information standards, and both may direct NHS Digital to establish information systems and collect information, including patients' confidential information. That there is no statutory requirement for the Secretary of State to have regard for the advice or guidance of the National Data Guardian again calls into question the independence of the Guardian – who is appointed by the Secretary of State but thereafter, as the Bill is currently drafted, may be ignored.

While it may be that the Secretary of State chooses to have regard to the advice of the National Data Guardian, that this is an option not a requirement recreates exactly the same position in which NHS England, NHS Digital and primary care providers found themselves at the start of care.data – and once more, care providers will be caught between contradictory legal requirements, as well as ethical duties.

*Likely Government response:* Secretary of State doesn't wish to listen to advice from the National Data Guardian.

*medConfidential comment on likely Government response:* It was, amongst other matters, the repeated collapse of the care.data programme that prompted the creation of the National Data Guardian in the first place. A Bill which recreates the conditions for another care.data fiasco would be both unwise and unsafe. Patients have been misled and had their wishes ignored; a repeat of that process could be devastating to public confidence and patient trust.

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## medConfidential probing amendment 5

Insert at end of sub-clause 1 (6):

*(a) All data controllers responsible for data within the remit of the National Data Guardian, and their data processors, must have a statutory duty to have regard of advice from the National Data Guardian, and must publish their response to that advice.*

### **Justification:**

In question 5 of the Government's consultation on the National Data Guardian, the Government proposed that: "organisations holding health and care data which could be used to identify individuals should be required to publish all materials demonstrating how they have responded to advice from the National Data Guardian."

In its response to the consultation, Government said, "**Responses were supportive of the proposal that the NDG should be given formal advice giving powers.** Consequently, the responses to this proposal tended to be supportive of mandating a need for those bodies receiving advice to be required to act upon it. **This was regarded as being crucial to demonstrating that the NDG had real authority, and would act as an independent voice of the patient and service user in relation to health and care data.**"

Also: "**5.4. The role of the National Data Guardian will include formal advice giving powers; organisations in receipt of this advice will be required to show how they have responded.**"

Without this duty, it is widely acknowledged that the National Data Guardian's authority and independence is undermined – and that without a requirement on organisations so advised

to provide evidence of their response, the National Data Guardian's annual report will fall short of what is necessary for public confidence.

*Likely Government response:* The Information Governance Alliance (IGA) advises.

*medConfidential response to the likely Government response:* The IGA is a housetrained policy venue of the Department of Health, and is neither independent nor effective. As a venue for discussion and sharing of practice, it is necessary – but as a watchdog or guardian, it is entirely subservient to the policy whim of the week.

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## **medConfidential probing amendment 6**

Leave out 2 (3) (b) in its entirety.

### **Justification:**

Why is it that some of those most vulnerable in society are being denied the oversight of a Data Guardian for their health and social care data just because it is being processed and stored by another public body? s2(3)(b) specifically rules children as being outwith the remit of NDG. While the National Data Guardian may not have a direct remit over children – largely a consequence of other bodies' territorial disputes – the Guardian should not be excluded from writing to any body that processes health or social care data with concerns.

This brings up a related point, which is the lack of mention of Memoranda of Understanding with other relevant bodies and regulators, such as the Information Commissioner, the Care Quality Commission, etc. This Bill does not provide the National Data Guardian with any teeth or sanctions of its own, so it is essential that these Understandings are put onto some sort of statutory basis, as per the National Data Guardian consultation:

“5.7. The National Data Guardian will agree and publish Memoranda of Understanding with key regulators and stakeholders, which will include clarification of their respective roles in relation to information and data and a referral mechanism by which the NDG can refer any concerns or issues for consideration and action by the relevant body.”

“5.8. The National Data Guardian will not have the power to issue or enforce sanctions of its own, for example in terms of financial penalties, but will instead work with relevant regulators to ensure that the sanction making powers of those organisations are utilised in the most effective way.”

Lacking a clear statutory basis for sanction, the Bill as currently drafted says the National Data Guardian will have no sanctions powers at all.

By way of example, in recent weeks the [press](#) covered the inability of the Surveillance Camera Commissioner to have NHS bodies follow his Code of Practice. When used by hospitals and GPs, all such cameras will record information, at least some of which is also

covered by the National Data Guardian. Does the Government now expect there will be a Memorandum of Understanding between the National Data Guardian and the Surveillance Camera Commissioner, and that an acceptable Understanding can also be found with the various bodies of the Department for Education?

*Likely Government reply:* Whitehall politics is hard.

*medConfidential comment on likely Government response:* It remains to be seen whether exempting the health information of one group, amongst the most vulnerable in society, from protections afforded to some others will be deemed acceptable to the medical experts in the other place. The Government consultation and response were clear on this point, the Bill as currently drafted represents a different position. (If the Department cannot resolve the impasse with the Surveillance Camera Commissioner, what hope will it have in its dealings with other Departments?)

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### **medConfidential probing amendment 7**

Amend 1 (1) and append at end:

*(a) This person shall have successfully served as a Caldicott Guardian of a large NHS organisation.*

There are no constraints upon whom the Secretary of State may appoint in the Bill as currently drafted. This amendments probes the restrictions, or absences thereof, on the appointment process. Given recent public debate about appointments, we look forward to reassurances from the Minister.

Any individual clinician, even of great experience, can only have a deep understanding of some part of the remit of Health and Social Care – people’s experiences are so wide and varied. This particular problem is currently addressed by the existence of the National Data Guardian Panel, which advises the National Data Guardian.

While the advice the National Data Guardian wishes to receive is substantially up to the Guardian, what assurances can the Government give about the continuance of the Panel?

We saw, at the creation of NHS England, that some oversight panels ended up being collapsed into a single member, an approach that evades meaningful oversight. What is the Government’s proposed approach to ensure that the Guardian is able to hear diverse views from across the NHS and care system?

*Likely Government response:* To say into Hansard what it has said privately, which is the text of this amendment.

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