

# Response from the Nuffield Council on Bioethics to the Department of Health Consultation on the roles and functions of the National Data Guardian for Health and Care



*December 2015*

## Introduction

This response draws on the conclusions of the Nuffield Council on Bioethics' report *The collection, linking and use of data in biomedical research and health care: ethical issues*, which was published in February 2015. This report looks at the ethical issues raised by the use of data in the context of biomedical research and health care and sets out key ethical principles for the design and governance of data initiatives. The full report is available at <http://nuffieldbioethics.org/project/biological-health-data/>.

In responding to this consultation we have answered the questions and commented on the proposals to which the approach and recommendations set out in the Council's report are most relevant.

### KEY POINTS

- The Council welcomes, in the establishment in law of the role of the National Data Guardian, the recognition that an opportunity for missing or underrepresented voices in the governance of data is needed. Though the National Data Guardian (NDG) cannot be expected to represent 'the voice of the public' they should have sufficient powers and resources to broaden participation and provide the opportunity for a wider range of interests to be represented.
- The powers of the NDG should include the initiation of criminal proceedings for the deliberate misuse of data. The Government should legislate to create an offence of deliberate misuse of data whether or not it results in demonstrable harm to individuals.
- The NDG should help to ensure that the frameworks and procedures of data governance are in accordance with publicly statable set of moral reasonable expectations, which take account of the underlying norms of privacy and disclosure at stake, the appropriate level of freedom for individuals to make choices about data use that concerns them and the duties of professionals to safeguard privacy while promoting the public interest.

## Our response

### **1) The Government proposes that: the remit of the National Data Guardian for Health and Social Care role should follow the health and care data.**

One of the fundamental findings of our report is the divergence between data protection and privacy perspectives when data are repurposed (for example, when health data are used to support research, or service or policy development), especially where they are linked with data from other sources. Data are only contingently 'health' data, in the same way that whether they are 'personal' data or not may depend greatly on the context in which they are used. Nevertheless, we think that it is desirable that the remit of the NDG should extend to uses of data outside health and care settings, given that the use outside health and care settings of data collected within those settings is often of greatest concern to people.

The Council recommends that the Information Governance Oversight Panel (which will be superseded by the NDG role) should supervise the maintenance of comprehensive maps of data flows for UK health systems (and the HRA should carry out a similar function for research systems). (*Recommendation 2, paragraph 2.50*).

### **3) The Government proposes that: the National Data Guardian should be able to provide advice to all organisations that hold health and care data which could be used to identify individuals.**

We strongly support the proposal that the NDG should be able to provide advice to a range of organisations and note that this ability will only be effective if the NDG's office is sufficiently resourced to do so. Nevertheless we believe that the scope of 'data which could be used to identify individuals' potentially misses a number of uses of data that have important consequences for privacy. The Council wishes to draw attention to the findings in our report that, firstly, practically all individual-level data can be 'health' data in some possible contexts and, secondly, that potential privacy impacts are not coextensive with the use of personal data, nor with the possibility of re-identification.

### **5) The Government proposes 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.**

We have already expressed our concerns about the limitations of 'health and care data' and the indeterminacy of 'data which could be used to identify individuals'. Nevertheless, we agree with the proposal as a means of increasing transparency. We note that this should extend this to organisations outside the health and social care sectors.

### **6) The Government proposes that: the National Data Guardian should be required to publish an annual report which should include a report of all the**

**advice provided in the relevant year and an overview of how the relevant organisations responded to it.**

We agree with, and welcome this proposal.

**7) The Government proposes that: the referral role of the National Data Guardian with the CQC and ICO should be set out in a Memorandum of Understanding.**

**8) The Government proposes that: the National Data Guardian should have power to refer actions by an individual to the appropriate regulator for the profession concerned.**

**9) Please also provide any other comments on how the National Data Guardian might advise and challenge professionals working outside the regulated professions or organisations.**

**10) Please also provide any other comments on how the National Data Guardian and regulators can maximise the appropriate use of existing sanctions and fines.**

Proposals 7 and 8 and the invitations to comment at 9 and 10 rely on the premise that “the National Data Guardian should be able to rely on existing regulators’ powers to apply sanctions and fines”. We agree that close working with other organisations and the avoidance of duplication is highly desirable and can be assisted by appropriate memoranda of understanding. However, we argue in our report that existing sanctions for misuse of data are insufficient, and recommend that the government should act to introduce an offence with criminal penalties for the deliberate misuse of data, whether or not it results in demonstrable harm to individuals (*Recommendation 5, paragraph 2.50*). In view of this, we think that a function of the NDG should be to refer abuses of data to the Crown Prosecution Service.

We acknowledge that this is outside the scope of the present consultation on the role and functions of the NDG, but would welcome the opportunity to make further representations on this matter.

**11) The Government is seeking views on the most suitable long-term location for the National Data Guardian.**

We do not have a particular view on this, but would stress the importance of the NDG being formally independent from its hosting location, and separately resourced.

**12) The Government proposes that: the National Data Guardian’s annual report should include a section demonstrating how the National Data Guardian has sought and gathered the views of the public and how those views will inform work in the future.**

We agree with and support this proposal. The principle of participation (along with the principle of accounting for decisions) is a core concept in the Council’s report. The views of the public and participants should be at the centre of any data collection and sharing initiatives.

**13) The Government proposes that: The National Data Guardian, CAG and the HSCIC should agree and publish a Memorandum of Understanding that sets out the National Data Guardian remit in relation to the additional safeguards that are being put in place as described at paragraph 4.2.**

We agree that these matters should be agreed and stated publicly. The relationships set out in any Memorandum of Understanding should be mutually supporting (or reinforcing) rather than mutually limiting.

**14) The Government proposes that: The National Data Guardian should engage with the relevant regulators of organisations outside the health and care system to ensure that they understand their obligations and responsibilities in relation to the health and care data to which they have access.**

We agree, but suggest that this alone will not be sufficient to address public concerns about possible misuses of health data. One step that we believe would give this force is to legislate for the introduction of a criminal offence of the deliberate misuse of data (see above).

**16) Do you have any comments or views on the potential impact that these proposals have on the potential for additional administrative and financial burdens?**

In our view the burden is entirely justifiable, when weighed up against the potential benefits. The Council's report discusses cases in which failures of trust in public institutions have compromised the delivery of potential public goods, having a negative impact on care, service development and research.