



Consultation response form

National Data Guardian for Health and Social Care

About you

You do not have to tell us this information if you do not want to.

Please fill in and/or tick the appropriate response.

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Freedom of Information

Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes. The relevant legislation in this context is the Freedom of Information Act 2000 (FOIA) and the Data Protection Act 1998 (DPA).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality

disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties. However, the information you send us may need to be passed on to colleagues within the UK Health Departments and/or published in a summary of responses to this consultation.

I do not wish my response to be published in a summary of responses

Are you responding (please select one):

- As a member of the public
- As a health or social care professional
- On behalf of an organisation

If you are responding as an individual, what is your gender?

If you are responding as an individual, what is your age?

If you are responding as an individual, what is your ethnic group?

Choose one option that best describes your ethnic group or background

- White
- Mixed/Multiple ethnic groups
- Asian/Asian British
- Black/African/Caribbean/Black British
- Chinese
- Arab
- Other ethnic group

If you are responding as a member of the public, please supply the following details:

Are you

- A patient or service user with a long-term condition or disability
- A carer or family member
- An interested member of the public
- A retired health or social care professional

Other (please give details)

If you are responding as a health or social care professional, please supply the following details:

Area of work

NHS

Social Care

Private Health

Voluntary

Regulatory Body

Professional Body

Education

Union

Local Authority

Trade Body

Other (please give details)

If you are responding on behalf of an organisation, please supply details:

Medical Royal College

Consultation Questions

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.

Greater clarity of the role and interface with regulators, professional and existing advisory bodies is required as this role may potentially complicate the existing landscape and may be too broad as currently proposed.

Succession planning will be essential if the impact made by the current individual in post continues to be felt once the term of office concludes.

While offering support for this role, in many ways it is disappointing that this role is felt to be necessary and more effort should be placed on ensuring "everyone has a part to play", as suggested in the Foreword.

2) The Government is seeking your views on: what are the key factors and issues that need to be considered when determining whether children's social care should be part of the National Data Guardian remit and where the National Data Guardian could make a positive contribution to care services for children and young people?

The National Data Guardian should not be involved with individual childcare cases, as there is unlikely to be capacity to do this. The National Data Guardian should act in a facilitatory role, providing national advice and guidance to ensure effective information exchange between the relevant health and social care organisations and encouraging standardisation and harmonisation of processes across different geographies.

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.

The National Data Guardian role should complement existing advisory structures and should focus on providing national advice and guidance rather than offering advice to individual organisations.

Although the National Data Guardian's role is limited to health and care organisations in England, clarity will be required on how this role impacts on, or is replicated in, the devolved administrations so that patients and healthcare professionals who transfer between countries are not confused.

4) The Government proposes that: any regulators with a responsibility for overseeing organisations which routinely hold, use and share health and care data, should consult the National Data Guardian on the criteria they use to assess an organisation's use of data.

The criteria used to assess an organisation's use of data will not necessarily be consistent across all organisations, depending on the intended use and the mechanism of processing

data.

There are already existing regulators and agencies who provide advice. There is a need for greater coordination and standardisation across different regulators and a need to streamline documentation to avoid the significant amount of time and effort spent creating and maintaining different data sharing agreements across health and care services in England. The National Data Guardian's facilitation of greater standardisation and consistency of approach across the country would be welcome.

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.

This appears to replicate the work that organisations have to undertake when responding to enforcement actions by the ICO.

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.

Publication of an annual report highlighting poor practice is unlikely to result in significant improvement. It would be helpful to focus on what has been achieved in terms of education, training and raising awareness, and what impact this has had on outcomes.

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.

RCPE agrees with this proposal.

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.

There are existing policies within employing organisations to manage these situations and escalation to professional regulatory bodies should be the responsibility of the employer, as at present.

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.

The National Data Guardian should influence national guidance to non-regulated

professionals and 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.

The issue of sanctions and fines should continue to be restricted to the ICO, who may wish to seek advice from the National Data Guardian.

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

As the role of the National Data Guardian is to provide an independent view, it is important that they are hosted in a location that reflects this position.

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.

The annual report should focus on outcomes and achievements, including patient and public engagement. The National Data Guardian may wish to consider the need for patient and public representation within their core team.

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.

RCPE agrees with this proposal.

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.

The National Data Guardian should influence and develop national guidance to organisations outside the health and care system.

15) Do you have any comments or views on the potential impact that these proposals have on equality between different groups and health inequalities?

It is important to ensure there is meaningful engagement with representatives from different patient groups in order to avoid inequalities.

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?

The current proposal will have a significant impact on administrative burden to organisations. Some of the recommendations included in the proposal will result in the need for an expanded team to support the National Data Guardian otherwise capacity to fulfil all the requirements will not be achievable. It is questionable whether this is the correct approach or whether investment should be directed towards development of comprehensive fair process notices, which will ensure greater consistency of approach across the country and will ease the administrative burden for staff.

The National Data Guardian should be complementary to existing regulatory and advisory bodies rather than taking on similar functions.