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 X

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 Research Charity

Cancer Research UK welcomes the opportunity to respond to this consultation on the National Data Guardian. Patient confidentiality is of the utmost concern to researchers, who are aware of the unique value of patient data but also of the precariousness of public trust in the use of this data for research. Despite the delicate balance that must be struck, there is a consensus among the research community that providers of potentially identifiable Health and Social Care (HSC) data have become excessively risk averse. This is in spite of a clear will from patient advocates and representatives to see their data employed safely and responsibly for patient benefit.

Currently 2 in 4 patients survive cancer, Cancer Research UK is aiming to accelerate progress towards 3 out of 4 patients surviving cancer by 2034. In order to achieve this ambitious aim, CRUK funded researchers require timely access to patient data and means...
of securely linking this data to other sources, whether from HSC sources such as CPRD or with other genomic, clinical or cohort data.

Health and social care data can contribute to a range of research and healthcare interventions, from upstream prevention of cancer all the way through to clinical trials exploring new treatments to improve cancer prognosis. For example studies currently seeking access to HSC data range from cohort studies exploring the complex associations between lifestyle factors like diet and cancer incidence, through to surgical trials for improved brain tumour treatment. More broadly, looking forward to an era of precision medicine and optimised, personalised cancer treatment, researchers and clinicians will need to be able to link data from electronic health records with data generated through clinical trials, genetic sequencing and imaging. At a time of growing complexity for information governance, the establishment of a National Data Guardian marks an important step forward.

Current situation regarding data access

Many researchers funded by CRUK are aiming to link data from different sources as discussed above, with HSCIC often being employed as the trusted third party linking Hospital Episode Statistics with primary care or mortality data.

Over the past 18 months, CRUK population researchers have had particular problems navigating the infrastructures and accessing relevant HSCIC data. This has delayed progress on grants and led to a waste of resources which could have been dedicated to research. Several researchers have made CRUK aware of delays linked to renewal of Section 251 approval, which can involve a heavy investment of staff time and requires an Information Governance Toolkit to be in place across the whole institution.

Not only are delays to this data release costly, time-consuming and prohibitive to the undertaking of the research, but they can also jeopardise the public’s trust in the research process. CRUK is aware of a research team which was unable to obtain ONS mortality data at regular (monthly) intervals and therefore inadvertently contacted study participants who had died causing upset to their families.

This current environment for projects which use HSCIC data in turn risks affecting funding decisions. Even though there is recognition that the situation is improving, CRUK Panels and Committee members have questioned funding proposals when the planned research projects are heavily reliant on HSCIC or CPRD data. We hope that the oversight of the NDG can support further progress of work in this area.

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.

Cancer Research UK supports the proposal that the National Data Guardian should be
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concerned with trust in how the data are used across the system rather than regulating specific organisations. This will require a clear definition of what HSC data is; for the purposes of this consultation, we believe that is personal confidential data held about patients/clients of health and social care data.

Academic research institutions are cited in the consultation as the example of bodies outside the NDG remit. Greater clarity would be welcome on when/whether the NDG powers cease to apply once the data has been granted by an organisation within NDG remit (e.g. HSCIC) to an organisation outside the remit undertaking the analysis such as Cancer Research UK or an organisation that we fund.

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?

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.

A ‘one-stop-shop’ for advice ensures harmonisation across all different HSC data custodians has the potential to be very useful to the community. For example, our researchers have reported that some of the procedures for linking data from HSCIC, cancer registries, CPRD and ONS can be very difficult and time-consuming. A National Data Guardian could potentially function as a safety net, supporting more effective and rapid data exchange between data custodians, which would be highly beneficial for research while maintaining confidence in the system.

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.

This would help ensure that legislation on the use and sharing of data is interpreted in a consistent fashion. One considerable concern is what appears to be inconsistent interpretation of the high-level governance framework in day-to-day decision-making by data holding bodies. For example, there should be more clarity around how HSCIC interprets the “benefit to the system” section of the legislation.

The NDG’s office should have a mechanism for organisations attempting to access datasets to raise concerns that data are not being shared. This will allow cases where criteria for data sharing has been misinterpreted to be shared with the NDG. Overall the NDG could help support changing the conversation around data release away
from assessing the risks of releasing data to make data holding institutions consider the risks for patients and the public health of not releasing data.

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 support the focus on transparency that the National Data Guardian role brings to the Health and Social Care data environment. However publication of these materials should be proportionate and not labour intensive.

For organisations where dealing with these data is only a minor part of their role this requirement may be burdensome and not particularly effective for transparency; for example responses will be widely distributed across different bodies and therefore hard to find. A better mechanism might be to require a response to NDG which would then be published on the NDG website / in an annual report. This would allow for commentary by NDG and give a single place to see advice and action taken.

Many organisations holding HSC data like HSCIC/PHE ODR already have significant pressures on their resources and are understaffed so any measures to make these measures proportionate will ensure that transparency is practical to the system.

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.

A requirement stating that all advice is published has a potential to be excessive, if a relatively high level of detail is required. Themed summaries of the advice provided would be more feasible and more useful to the public and other organisations.

All advice provided by the NDG is unlikely to be particularly informative or easy to extract information from, however storing advice online in a searchable format on an ongoing basis may be of more use.

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.

Academics will be mainly using this data for research and grant awarding/infrastructure funding bodies such as Cancer Research UK would therefore want to have a productive working relationship with the NDG.

Major funding bodies could be given a list of researchers/institutions which have not complied with legislation, so they can take this information into account when considering how to award grants. Also key academic journals could sign up to not publishing research which isn’t compliant with NDG standards.

The NDG has the potential to provide research institutions with guarantees that their data proposals will be approved within a set timeframe, for example setting out targets for timeframes within which the appropriate data custodians should respond to applications and avoid clock stoppages while the assessment is taking place.

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.

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

It will be important to consider how the National DG could ensure harmonisation between the data release procedures for HES and cancer registry data across the devolved nations. A new ALB is probably the best option as all other orgs have some interest in either collecting data or seeing it used in particular ways.

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.

Patient and public engagement in this work is important and an independent NDG can play an important role in both reflecting the views of the public and helping to build trust in the system.

This will complement activities being coordinated by Wellcome Trust and Macmillan to improve understanding of public attitudes towards their data being reused. The “public” should include a strong focus on patients; and such a consultation would provide a good opportunity to get a more profound and nuanced understanding of the concerns patients genuinely have around data being shared, for research and otherwise.
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.

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 NDG should engage with all relevant regulators to ensure there is a better understanding of responsibilities towards HSC data across government and in society. Trust in government’s ability to safely store and protect data is fragile. One part of the system mishandling data or communications with the public about data could result in a loss of trust in general toward health and social care data.

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

   CRUK is supportive of research which can reduce health inequalities¹. This research can only take place through timely access to and linkage of a variety of demographic data, cancer registry data and Hospital Episode Statistics, among others. For example research relying this kind of data has already shown us that two cancers of unmet need, lung and oesophageal cancer, are more likely to be diagnosed in the most deprived groups² ³, and that more deprived people are more likely to have poorer survival outcomes⁴. Going forward, we will need to capitalise on various different sources to explore cancer prevention, early detection and treatment strategies among certain sub-groups of the population with co-morbidities, such as those with major mental disorders. A more efficient infrastructure to support the flow of HSC data to researchers will help nuance and build our knowledge base and thus help reduce inequalities in cancer prevention, diagnosis, treatment and survival.

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?

¹ http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@pol/documents/generalcontent/crukmig_1000ast-3347.pdf
² http://www.ncin.org.uk/publications/data_briefings/lung_cancer_incidence_and_survival_in_england
⁴ http://www.cancerresearchuk.org/health-professional/cancer-statistics/survival/socio-economic-group#heading-Zero