

ICO consultation on the draft updated data sharing code of practice

Data sharing brings important benefits to organisations and individuals, making our lives easier and helping to deliver efficient services.

It is important, however, that organisations which share personal data have high data protection standards, sharing data in ways that are fair, transparent and accountable. We also want organisations to be confident when dealing with data sharing matters, so individuals can be confident their data has been shared securely and responsibly.

As required by the Data Protection Act 2018, we are working on updating our **data sharing code of practice**, which was published in 2011. We are now seeking your views on the [draft updated code](#).

The draft updated code explains and advises on changes to data protection legislation where these changes are relevant to data sharing. It addresses many aspects of the new legislation including transparency, lawful bases for processing, the new accountability principle and the requirement to record processing activities.

The draft updated code continues to provide practical guidance in relation to data sharing and promotes good practice in the sharing of personal data. It also seeks to allay common concerns around data sharing.

As well as legislative changes, the code deals with technical and other developments that have had an impact on data sharing since the publication of the last code in 2011.

Before drafting the code, the Information Commissioner launched a call for views in August 2018. You can view a summary of the responses and some of the individual responses [here](#).

If you wish to make any comments not covered by the questions in the survey, or you have any general queries about the consultation, please email us at datasharingcode@ico.org.uk.

Please send us your responses by **Monday 9 September 2019**.

Privacy Statement

For this consultation, we will publish all responses except for those where the respondent indicates that they are an individual acting in a private capacity (e.g. a member of the public). All responses from organisations

and individuals responding in a professional capacity will be published. We will remove email addresses and telephone numbers from these responses; but apart from this, we will publish them in full.

For more information about what we do with personal data please see our [privacy notice](#).

Questions

Note: when commenting, please bear in mind that, on the whole, the code does not duplicate the content of existing guidance on particular data protection issues, but instead encourages the reader to refer to the most up to date guidance on the ICO website.

Q1 Does the updated code adequately explain and advise on the new aspects of data protection legislation which are relevant to data sharing?

Yes

No

Q2 If not, please specify where improvements could be made.

We appreciate that this code of practice is made expressly to provide GDPR compliant guidance for organisations wishing to share data.

The draft code does explain and advise on the new aspects of data protection legislation which are relevant to data sharing in a way which offers practical guidance as well as useful case studies rather than a regurgitation of the legislation.

However, we are concerned that the common law duty of confidence which forms a large part of the discussion for many health and social care organisations in the balancing of their duty to protect and share data may be lost within the code and this GDPR legislative landscape.

The duty of confidence is currently mentioned within the draft code at p.61:

'a duty of confidence might be stated explicitly, or it might be implied, either by the content of the information or because it was collected in circumstances where confidentiality is expected, eg medical or banking information. If you are a big organisation planning to carry out complex, larger scale processing, you should consider obtaining legal advice on your data sharing plans'

Given the volume of data being shared derived from health and social care settings, we feel that the current mention of the duty of confidence is hidden away and may escape the attention of many readers. Bearing in mind this data is inherently likely to be more sensitive it demands much more emphasis.

Whilst we are aware that detailed guidance on the common law is likely outside the scope of this code of practice, we do have a real concern that organisations could seek to rely only on this draft code in efforts to discharge their legal and ethical duties in sharing data and potentially be in breach of the common law.

This lack of clear referencing to the common law in relation to health and social care creates the potential for significant confusion particularly as health appears in several of the draft code case studies, including one right at the beginning of the document.

To that end and bearing in mind the substantial nature of the draft code of practice, we would encourage and invite a separate document which deals specifically with data sharing good practice which seeks to resolve the complexities of sharing (health and social care) data in line with the GDPR and the common law duty of confidence.

We note that section 121 of the DPA 2018 states that the commissioner must prepare a code of practice which contains –

- (a) practical guidance in relation to the sharing of personal data in accordance with the requirements of the data protection legislation, and
- (b) such other guidance as the commissioner considers appropriate to promote good practice in the sharing of personal data"

and feel that this suggested separate piece of guidance would fall under (b) above.

(Cross reference response to question 10 below.)

Q3 Does the draft code cover the right issues about data sharing?

Yes

No

Q4 If no, what other issues would you like to be covered in it?

Clear detailed guidance around pseudonymisation, anonymisation and linkage of datasets.

Clarification around Data Trusts (p85) and whether they are intended for use across all data sectors, the NDG is not aware of them having yet been piloted or trialled/tested within health and social care settings.

Q5 Does the draft code contain the right level of detail?

Yes

No

Q6 If no, in what areas should there be more detail within the draft code?

Whilst we appreciate that the intended audiences for the code are organisations (larger organisations presumably having the benefit of IG Leads or DPOs) and that it would be difficult/impossible to draft a one size fits all document; we do note that this is a substantial (both in length and detail) 105 page document, excluding all of the ICO website linked guidance and external references which does take some getting through.

We hope this does not deter smaller organisations and/or those without specialist/dedicated IG staff from using it.

We would encourage and support an (additional) shorter document which sets out only the new aspects for those organisations who are already familiar with the previous 2011 data sharing code of practice or

a summary of changes section within the document referencing the relevant detailed elements.

Q7 Has the draft code sufficiently addressed new areas or developments in data protection that are having an impact on your organisation's data sharing practices?

Yes

No

Q8 If no, please specify what areas are not being addressed, or not being addressed in enough detail

(Cross reference response to Question 2 above.)

Q9 Does the draft code provide enough clarity on good practice in data sharing?

Yes

No

Q10 If no, please indicate the section(s) of the draft code which could be improved, and what can be done to make the section(s) clearer.

Whilst the draft code already includes some reference to human rights, it would be helpful for the ICO to provide additional guidance on the rights, outside of those granted by data protection legislation, that organisations need to consider when ensuring their data processing takes account of the 'rights and freedoms' of data subjects.

We would welcome the ICO taking into account in particular best practice and advice within the health and social care sector as many organisations will be using industry guidance currently and it is important they receive consistent messages.

In particular we would welcome guidance which helps reconcile the application of GDPR with the application of the common law duty of confidence.

The Local Health and Care Record Exemplar (LHCRE) Programme IG Framework which is due to be published September 2019 whilst initially mandatory only for LHCRE areas, is regarded by NHSE/I as best practice for all health and care organisations as it brings together GDPR and common law duties. To this end some clarification around how the draft code fits with or mention of the LHCRE IG Framework would be useful.

Q11 Does the draft code strike the right balance between recognising the benefits of sharing data and the need to protect it?

Yes

No

Q12 If no, in what way does the draft code fail to strike this balance?

Whilst generally speaking GDPR and therefore the draft code is in strong alignment with the Caldicott principles. We do have one comment.

The NDG highlighted by way of the introduction of Caldicott Principle 7 that "the duty to share information can be as important as the duty to protect patient confidentiality".

The NDG and the Caldicott principles are most relevant to health and social care data although they are of wider use. There should not be a

misreading of this principle to the extent that it becomes commonly accepted that the duty to share is always as important.

We noted that several of the respondents to your call for views relied on this principle as support for an 'obligation' to share data and quoted from the NDG's 2013 report.

It remains the central aim of the NDGs work to be the advocate and champion of individuals rights in respect of (safeguarding) their data and ensure that data sharing is conducted fairly and transparently whilst recognising that the reasonable expectations of individuals should be considered.

We are aware that the DPA 2018 and GDPR have led to a focus on the minutiae of process and technical legal compliance without always looking at what is in the best interests of the individual / data subject.

To that end we feel that some of the phraseology in the code , particularly the phrasing of two of the 'misconceptions' in the common concerns about data sharing p.13 ('We Can Only Share Data With Peoples Consent' and 'We Cant Share Data In An Emergency') are not appropriately balanced to protect individual rights and may appear biased for data sharing:

e.g. 'usually share', 'some cases', 'might need to ask for their consent'

Furthermore, some of the case studies (particularly those centred around health care) seem pitched at the benefits of sharing and give little sense of the risks.

Whilst we indeed noted within our review 'Information: To share Or Not To Share? The Information Governance Review 2013 (Caldicott2) that 'when it comes to sharing information, a culture of anxiety permeates the health and social care sector', we are concerned that under these 'misconceptions' the attempt to resolve this, has been to simply state that information can be shared and easily and that consent is not always required rather than setting out a simple balanced user friendly tool to follow to quickly conclude whether data should be shared or not.

We support that the draft code should emphasise the benefits of appropriate data sharing as well as the risks which need to be mitigated when data is shared and as such there needs to be counter balanced messages throughout the document about the importance of safeguarding data as well as sharing.

We believe this to be particularly important in maintaining the public's trust around balanced and appropriate data sharing.

Q13 Does the draft code cover case studies or data sharing scenarios relevant to your organisation?

Yes

No

Q14 Please provide any further comments or suggestions you may have about the draft code.

(Cross reference response to Question 2 above.)

We support medconfidential's comment within their response to your call for views suggesting a discussion between the ICO and the NDG about the definitions and limits of sharing and re-use of clinical data and the duty of confidentiality within the NHS and by NHS clinicians. We would welcome an opportunity to collaborate with the ICO on a joint 'mythbuster' style document to achieve this.

The NDG would welcome some horizon scanning / future proofing of the code to include case studies which deal with data sharing and data protection when data is passed through a digital device or app.

We would welcome reference being made to the NDG being put on a statutory basis within the data ethics section (p87) as a key element in maintaining public trust in data sharing.

Q15 To what extent do you agree that the draft code is clear and easy to understand?

Strongly agree

- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Q16 Are you answering as:

- An individual acting in a private capacity (e.g. someone providing their views as a member of the public of the public)
- An individual acting in a professional capacity
- On behalf of an organisation
- Other

Please specify the name of your organisation:

The National Data Guardian (NDG)

Thank you for taking the time to share your views and experience.