

# ICO call for views on updating the data sharing code of practice



Data sharing can bring important benefits to organisations, citizens and consumers, making our lives easier and helping to deliver efficient services. It is important, however, that organisations who share personal data have high data protection standards, sharing data in ways that are fair, transparent and accountable. We also want controllers 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 2018, we are working on updating our data sharing code of practice, which was published in 2011. The updated code will explain and advise on changes to data protection legislation where these changes are relevant to data sharing. It will address many aspects of the new legislation including transparency, lawful bases for processing, the new accountability principle and the requirement to record processing activities.

The updated data sharing code of practice will continue to provide practical guidance in relation to data sharing and will promote good practice in the sharing of personal data. In the first instance we will address the impact of the changes in data protection legislation on data sharing and will then move on to developing further case studies. Our intention is that, as well as legislative changes, the code will also deal with technical and other developments that have had an impact on data sharing since the publication of the last code in 2011.

Before preparation of the code the Information Commissioner must consult with the Secretary of State. She is also seeking input from trade associations, data subjects and those representing the interests of data subjects. This call for views is the first stage of the consultation process. We will use the responses we receive to inform our work in developing the updated code.

You can email your response to [CentralGovernment@ICO.org.uk](mailto:CentralGovernment@ICO.org.uk)

Or print and post to:

Data Sharing Code Call for Evidence  
Central Government Department  
Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire SK9 5AF

If you would like further information on the call for evidence, please email the Central Government team.

Please send us your views by 10 September 2018.

## **Privacy statement**

For this call for evidence we will publish responses received from organisations but will remove any personal data before publication. We will not publish responses from individuals. For more information about what we do with personal data please see our [privacy notice](#).

## Questions

Q1 We intend to revise the code to address the impact of changes in data protection legislation, where these changes are relevant to data sharing. What changes to the data protection legislation do you think we should focus on when updating the code?

### **1. Lawful Processing**

Consent has been subject to change under the latest legislation and latest guidance suggests alternative lawful basis for processing should be applied where possible. We have noted that this change has led to some confusion about applying alternative conditions, in some cases key data sharing has stopped because of this issue.

### **2. Accountability**

### **3. Anonymisation and Pseudonymisation**

Pseudonymisation was a concept brought about by the new legislation so the security sections of the code do not reference this security measure. Anonymisation is referenced in the 2011 code but it appears to suggest if data is statistical or anonymised the code doesn't apply. Recent guidance (Working Party 29) suggests that to achieve true anonymization is very challenging so the code may need to be updated with this in mind; technology has obviously advanced since 2011.

#### **4. DPIA Requirements**

As a legal requirement, where and when a DPIA needs to be carried out is now vitally important.

#### **5. Legal Obligations of Data Processors**

The 2011 code assumes that Data Processors (DPs) have no legal obligations which has changed under the latest legislation so changes to the code need to reflect that. It would also be helpful to have examples of how the DP and Data Controller (DC) works as well as DC to DC and where the risks and responsibilities lie.

Q2 Apart from recent changes to data protection legislation, are there other developments that are having an impact on your organisation's data sharing practice that you would like us to address in the updated code?

Yes

No

Q3 If yes (please specify)

The most recent guidance that consent as a condition for processing should only be relied upon if no other conditions apply has caused many bodies and organisations to move away from relying on consent. However, whilst it is generally accepted that consent may not be the most appropriate condition, it is often not known what alternative condition is most appropriate.

Without a clear steer as to which condition is most appropriate, organisations are determining themselves the most appropriate condition to apply and there are instances where the same types of organisations have applied different conditions to the same type of data sharing. This can only be confusing for data subjects as the basis for which their personal data is shared may be different depending on which organisation

they use in the same sector, for the same processing. For example in the healthcare industry special category data is shared without consent under Article 9h for medical purposes but issues have been raised about sharing for research requirements and/or national registries/audits where there is no regulatory requirement.

If the code could address in more detail how to apply different conditions to data sharing, with examples and the kinds of processing that may be covered under different conditions, this might give some consistent guidance for organisations to apply. Currently the 2011 code does mention that consent may not always be the most appropriate condition but this is only covered in one sentence. Some of the more common alternative conditions are explained, but more detail around electing the most suitable condition and emphasising the importance of getting a clear basis for your data sharing (including any contractual requirements) would be helpful. Ideally this would also be linked into the accountability and transparency requirements as well as the common law duty of confidentiality. An added complication is where in certain circumstance data subjects have the right to opt out regardless of whether consent is required.

Q4 Does the 2011 data sharing code of practice strike the right balance between recognising the benefits of sharing personal data and the need to protect it? Please give details.

Yes

No

Q5 If yes in what ways does it achieve this?

Q6 If no, in what ways does it fail to strike the right balance?

Section 4 –Data sharing and the law covers considerations that may prevent data sharing but there isn't any reference to positive considerations here. They may also be compelling reasons to be sharing personal data that outweigh any risks or constraints.

The factors affecting data sharing are often referred to as 'issues' or 'restrictions' and in some instances this is accurate but sometimes they are just considerations or factors to take into account. Reference to 'issues' or 'restrictions' may elicit the idea that data sharing is something to be prevented or is negative. If personal data is shared properly and within compliance of the DPA it can be incredibly positive and I am not sure in the examples, case studies or the paragraphs of the code, this is necessarily made clear. In the healthcare sector data sharing can improve patient safety and even improve healthcare and advancements in healthcare more generally. We have suggested in our answers to questions below how we think this balance can be evened out.

Q7 What types of data sharing (eg systematic, routine sharing or exceptional, ad hoc requests) are covered in too much detail in the 2011 code?

### **1. Public Authorities Governance**

Pages 11-12 covers the powers of public authorities in quite a lot of detail. This could be quite confusing to private sector organisations as it appears quite restrictive.

### **2. Human Rights**

Page 13 covers Human Rights. Whilst we agree that there is a link between data sharing and human rights, we are not sure if it needs to go into that level of detail. We believe it would be more beneficial to go into further detail on the issues associated with sharing data between private and public organisations or those third sector organisations carrying out a public function (please see further detail in response to Q8).

Q8 What types of data sharing (eg systematic, routine sharing or exceptional, ad hoc requests) are not covered in enough detail in the 2011 code?

## **1. Sharing with Subsidiaries**

For organisations who have subsidiaries or group companies, it refers to data sharing internally but explicit reference to separate companies within the same group isn't covered.

## **2. Sharing with Public Authorities**

On page 12 public sector organisations are covered then private sector organisations are covered. There is a very brief reference to potential issues with data sharing between private and public sector but it doesn't go into any detail. The code goes on to briefly mention there being potential issues for third sector organisations carrying out public functions, but again no further detail. It would be useful to have examples and further detail about the sorts of issues that organisations may need to consider.

Q9 Is the 2011 code relevant to the types of data sharing your organisation is involved in? If not, which additional areas should we cover?

## **1. Risks to NOT sharing personal data**

Sometimes there is actually a risk to not sharing personal data, not only in the healthcare sector but across other industries as well; social services and the police are more obvious examples.

The updated code could focus more on not only positive considerations and factors, but also the risks and issues that organisations may need to consider if personal data isn't shared. We have experienced third party clinicians or organisations who have used the GDPR as a barrier to not share personal data with us that we have needed. Thankfully none of the information has been needed in an emergency situation but we are concerned that this could easily occur.

Q10 Please provide details of any case studies or data sharing scenarios that you would like to see included in the updated code?

## **1. Applying Exemptions**

On page 54 there is a case study involving two health authorities however, a more common example we see is that public health trusts will approach a private healthcare provider for information under the crime and taxation exemption and it will be a request for a one off sharing of personal data i.e. the Local Counter Fraud

Specialist for a NHS trust would approach a private hospital requesting the dates and times someone worked at the hospital as they suspected their employee was working whilst claiming sick pay. The LCFS would quote the crime and taxation exemption and the hospital would consider whether data could be shared under this exemption. It would be useful to have a case study that covered an organisation exploring an exemption such as this, even if it wasn't in the healthcare sector.

## **2. Considering lawful basis for processing**

All private healthcare providers are required to share information with PHIN (Private Healthcare Information Network) and there are other bodies e.g. the National Joint Registry where data sharing is encouraged to improve healthcare. Submission of information to these bodies is not always mandatory for private patient's data so we are required to explore alternative conditions for processing. It would be useful to see a case study exploring and applying different conditions for processing. As mentioned in previous answers the factors to take into account and how to apply and justify different conditions is causing some issues across the industry. Currently there is no consistent approach across the industry and therefore data is being withheld for lack of certainty.

Q11 Is there anything the 2011 code does not cover that you think it should? Please provide details.

- Examples of data sharing being positive
- Risks of not sharing personal data
- More examples throughout the code generally
- Data sharing between subsidiaries and group companies
- Where DPIA and LIAs should be considered by organisations
- The potential issues of data sharing between the private and public sector
- More information on accountability and transparency
- Guidance on applying the appropriate lawful basis for processing – including research and statistics.
- Examples of how the lawful basis links to transparency and accountability as well as confidentiality

Q12 In what other ways do you think the 2011 code could be improved?

### **1. Less detail for 'generic' sections**

Page 32 covers individual's rights. As there are separate codes on individual's rights and this is also covered in the section of the code on Data Sharing Agreements, this might be covered in too much detail.

Page 36 covers ICO powers and penalties. Page 38 covers notification. These sections are not specific to data sharing or this code so this information could be found by linking out to a document or code covering this information or a pared down reference included in the code.

Page 39 covers FOI which isn't applicable to all organisations. The important point with regards to data sharing and FOI is, if a private section organisation is sharing personal data with a public authority FOI may apply to that personal data. We are not sure if it needs any more information than that included as there are separate codes and guidance on FOIA more generally.

### **2. 'Governance' incorporated into the code**

Governance is covered in a separate section on page 26. We believe the code could be improved if most of those requirements and considerations were weaved into the code e.g. DPIA and the requirement to have a DPIA should be included in sections that are talking about considering individual's rights, such as section 5 'deciding to share personal data'. Within this section it would be a logical place to refer to DPIAs and that being something organisations need to consider.

### **3. More Examples**

There are case studies at the end of the code and some examples weaved into the code but to give the code a more practical connect for organisations more examples would be useful. One example is at the bottom of page 18 the section is considering how to communication with individuals about data sharing and the signposting of privacy notices. The factors or variables that might require active communication of the privacy notice are included but a practical example would be really useful. Equally at the bottom of page 12 organisations are advised to review their articles or similar to make sure no restrictions would prevent data sharing. Examples of what those might look like or common restrictions would be really helpful for



that point. In the same section the code considers issues that third sector bodies that are carrying out public sector functions. Examples of what sorts of issues they may face would be helpful here and also examples of issues that may present themselves when sharing personal data with a public body. A similar approach to the WP29 schedule of examples would be beneficial.

#### **4. Clearer Guidance on Emergency Data Sharing**

Clearer guidance on whether the relevant sections apply to emergency data sharing or not (it isn't always clear).

About you:

Q13 Are you answering these questions as?

- A public sector worker
- A private sector worker
- A third or voluntary sector worker
- A member of the public
- A representative of a trade association
- A data subject
- An ICO employee
- Other

Q14 If other please specify:

Q15 Please provide more information about the type of organisation you work for, ie a bank, a housing association, a school.

Private Healthcare Provider  
Fitness & Wellbeing Provider

Q16 We may want to contact you about some of the points you have raised. If you are happy for us to do this please provide your email address:

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