



Consultation on the draft Transparency in Health and Social Care guidance

The Information Commissioner's Office (ICO) is producing guidance on transparency in the health and social care sector.

The draft of this guidance is now published for public consultation.

The draft transparency in health and social care guidance has been developed to help health and social care organisations understand our expectations about transparency.

We are also seeking views on a draft summary impact assessment for this guidance. Your responses will help us understand the code's practical impact on organisations and individuals.

This survey is split into four sections. This covers:

- Section 1: Your views on the draft guidance
- Section 2: Your views on our summary impact assessment
- Section 3: About you and your organisation
- Section 4: Any other comments

The consultation will remain open until 7th January 2024. Please submit responses by 5pm on the 7 January 2024. We may not consider responses received after the deadline.

Please send completed form to PolicyProjects@ico.org.uk or print off this document and post to:

Regulatory Policy Projects Team
Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Privacy statement

For this consultation we may publish the responses received from organisations or a summary of the responses. We will not publish responses from individuals acting in a private capacity. If we do publish any responses, we will remove email addresses and telephone numbers from these responses but apart from this we will publish them in full.

Please be mindful not to share any information in your response which you would not be happy for us to make publicly available.

Should we receive an FOI request for your response we will always seek to consult with you for your views on the disclosure of this information before any decision is made.

For more information about what we do with personal data please see our privacy notice.

Are you happy to proceed? *

Yes - I am happy to proceed.

Section 1: Your views on the draft guidance

Answers to the following questions will be helpful in shaping our guidance. Please use the comments boxes to provide further detailed information as far as possible. Some of the questions may not be relevant to you or your organisation, so please skip these as necessary.

1. Do you agree that this guidance clearly sets out what is required of health and care organisations to comply with the data protection transparency principle?

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

Please provide any comments you have (max. 500 characters):

Overall content is clear and appropriate. However, "How does this guidance approach transparency?" should be moved to the 'Introduction' section.

2(a). Do you agree that this guidance provides a clear definition of transparency and privacy information?

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

Please provide any comments you have (max. 500 characters):

2(b). Does the distinction between transparency information and privacy information make sense to you?

- Yes**
- No
- Unsure

Please provide any comments you have (max. 500 characters):

We would agree, however there was inconsistency throughout the guidance as to when terms were in **bold** or not. This makes identifying this distinction within the guidance difficult at times.

3. Do you agree that this guidance provides useful additional information to the Health & Social Care sector that is not part of our existing guidance on the principle of transparency and the right to be informed?

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

Please provide any comments you have (max. 500 characters):

In the context of using personal information for secondary research purposes, much of the guidance is known requirements or expectations of the Health Research Authority.

4. Do you agree that this guidance is balanced between the separate areas of health and social care?

- Too focused on health**
- ~~Too focused on social care~~
- ~~About right~~
- ~~Not enough information on either~~
- ~~Unsure / don't know~~

Please provide any comments you have (max. 500 characters):

Very few, if any, specific examples or guidance points related to social care.

5. Do you agree that the use of the terms must, should and could in this guidance clearly defines the ICO's expectations in the legislative

requirements section and that the terms are applied consistently throughout the guidance?

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

Please provide any comments you have (max. 500 characters):

Overall, it was clear from the outset and consistently indicated throughout.

However, it is not clear how several of the 'should' good practices are an expectation of the ICO in relation to compliance with data protection legislation rather than wider health and social care-specific requirements or expectations. For example, the patient engagement section would benefit from clearer linkage to the principles or obligations of the DPA2018 or UK GDPR.

6. Do you agree with the definitions we have provided on openness and honesty? Are the examples of how you can demonstrate that you are being open and honest useful and accurate in the context of health and care?

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

Please provide any comments you have (max. 500 characters):

The definitions were clear, but more detailed examples demonstrating good and bad practice would be useful.

7. Do you agree with that the section on harms is useful for organisations when considering the risks of failing to provide sufficient transparency material?

- Strongly agree

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

Please provide any comments you have (max. 500 characters):

This section should be enhanced with considerations of when providing transparency information in a health and social care setting may lead to harm. For example, writing to a patient who has recently died to inform them about a new technology platform which will enhance patient care. This has a high likelihood to cause distress for family members and can be mitigated by undertaking a Demographics Batch Service check prior to mailings.

8. Do you agree that the section on patient engagement provides useful information to help organisations develop transparency information that responds to people’s needs and priorities?

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

Please provide any comments you have (max. 500 characters):

The information reflects existing guidance frequently used in the context of secondary uses of patient data for a research purpose.

9. Do you agree that the section on providing transparency information sets out clearly how organisations should approach the delivery of transparency and privacy information?

- Strongly agree**
- ~~Agree~~
- ~~Neither agree nor disagree~~

- Disagree
- Strongly disagree

Please provide any comments you have (max. 500 characters):

10. Do you agree that the transparency checklist provides a useful summary of the guidance and a mechanism to assess an organisation's transparency level?

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

Please provide any comments you have (max. 500 characters):

The 'must' section is very high level and does not reflect the range of requirements highlighted throughout the guidance. This means that an organisation which has answered 'Yes' to the checklist has a false impression of compliance. For example, the first check groups multiple actions – lawful basis and risks - into a single criterion.

In addition, "We have allocated responsibility to delivering transparency where it is most effective" is not clear in what the aim is or how it should be done.

11. Have you identified any aspects of the guidance that you feel are inaccurate or any areas we have missed or not covered sufficiently?

If so, please provide further details.

- 1) The "People **must** be given sufficient time to have meaningful engagement or input on how you are using their personal information." requirement should indicate which part of the legislation it relates to as it is not obvious.
 - 2) The guidance is very relevant to organisations involved in the secondary uses of health and social care data for research. This should be stated in the introduction otherwise such interested parties may not read on.

12. We have provided placeholders for case studies and examples in the guidance to further illustrate certain issues relating to: Public trust in use or sharing of health and social care information; Harms associated with transparency and the impacts on patients and service users; Providing easily understandable information to patients and service users on complex forms of data processing; and Organisations working together to develop a 'joined-up' approach to the delivery of transparency information. Do you have any examples of good practice relating to these topics? Would you like to provide these to the ICO to be summarised and included in the guidance?

If so, please provide your name and email address below and we may contact you to discuss further.

Section 2: Your views on our summary impact assessment

The following questions are about our impact assessment. Some of the questions may not be relevant to you or your organisation so please skip these as necessary, or as indicated in the descriptions.

We are seeking views on our [impact assessment summary table](#), which was provided as supporting evidence for the consultation. This sets out a high-level overview of the types of impacts that we have considered.

We will consider the proportionality of further assessment of the impacts as we move towards final publication of the guidance.

13. To what extent do you agree that the impact assessment summary table adequately scopes the main affected groups and associated impacts of the guidance?

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

If you answered disagree, strongly disagree or unsure/don't know, please provide further examples of affected groups or impacts we may have missed or require further consideration. (max. 500 characters)

We would recommend a clarification as to what is meant by "Health and Social Care Sectors"

14. Can you provide us with any further evidence for us to consider in our impact assessment?

- Yes
- No**

If you answered Yes, please could you provide the impact evidence or a link to it in the box below, or contact details where we can reach you to discuss further. (max. 500 characters)

15. Please provide any further comments or suggestions you may have about the impact assessment summary table.

16. Are you acting on behalf of an organisation?

Yes

No

Section 3: About you and your organisation

To further assist our consultation process, it would be useful to know some details about you. Your information will be processed in accordance with our privacy notice.

17. Are you answering as: (tick all that apply)

- An organisation or person processing health data**
- ~~A representative of a professional, industry or trade association~~
- ~~An organisation representing the interests of patients in health settings (eg GP practice, hospital trust)~~
- ~~An organisation representing the interests of patients in social care settings (eg care home)~~
- ~~A trade union~~
- ~~An academic~~
- ~~Other (please specify):~~

18. Please specify the name of your organisation (optional):

19. How would you describe your organisation's size?

- ~~0 to 9 members of staff~~
- 10 to 249 members of staff**
- ~~250 to 499 members of staff~~
- ~~500 or more members of staff~~

20. If you work in a health or social care providing organisation, how many patients or care users is your organisation responsible for (approximately)?

21. Who in your organisation needs to read the guidance? Please provide job titles or roles, rather than names.

22. To what extent (if at all) do data protection issues affect strategic or business decisions within your organisation?

- ~~Data protection is a major feature in most of our decision making~~
- Data protection is a major feature but only in specific circumstances**
- ~~Data protection is a relatively minor feature in decision making~~
- ~~Data protection does not feature in decision making~~
- ~~Unsure / don't know~~

23. Do you think the guidance set out in this document presents additional:

- cost(s) or burden(s) to your organisation**
- ~~benefit(s) to your organisation~~
- ~~both~~
- ~~neither~~
- ~~unsure / don't know~~

24. Could you please describe the types of additional costs or benefits your organisation might incur?

N/A

25. Can you provide an estimate of the costs or benefits your organisation is likely to incur and briefly how you have calculated these?

N/A

26. Please provide any further comments or suggestions you may have about how the guidance might impact your organisation?

Section 4: Any other comments

This section is for any other comments on our guidance or impact assessment that have not been covered elsewhere.

Do you have any other comments you would like to make?

- 1) Any future guidance for health and social care sectors should consider holding public consultations outside of the busy winter periods to ensure appropriate engagement by the sector itself.
- 2) There should be additional guidance added or signposted as to how and what factors to consider when deciding on the proportionality of transparency measures.
- 3) The 'Introduction' should be explicit that transparency considerations around the common law duty of confidentiality are out of scope of the guidance.