



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- Section 1: Your views on the draft guidance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? *

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Section 1: Your views on the draft guidance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 the guidance is clear in setting out the requirements of transparency and compliance with data protection legislation where personal data are being processed. However, there are some sections where further detail/explanation would support clearer understanding of the distinctions to be made between privacy and transparency. It would also be useful to explain that there are

circumstances where organisations are not required to comply with the GDPR transparency principle. A Data Controller may usually be fully obliged to meet the privacy information requirements but when asked to share data for a purpose which is not obliged in the same way (or at all) it is useful that these differences are up front in the guidance.

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):

Clarifying the distinction between the definition of transparency as opposed to privacy information with more contextual examples. This would assist the application of the principle in practice & strengthen understanding e.g., where an organisation makes publicly funded data, publicly available under open licence, there is a need for transparency about its origins, but no requirement for privacy information. The guidance should make it clear that GDPR privacy information requirements do not apply when the provision of such information proves impossible or would involve a disproportionate effort, particularly for processing for archiving purposes in the public interest, scientific/historical/statistical research purposes.

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):

As above response & the way that it is laid out is disjointed. Putting the topics in the same order in the section would make it clearer and support further understanding of the difference between transparency & privacy information. Where an organisation is not processing personal data, but is handling effectively anonymised data the need for privacy information is not required but transparency information should be published. When privacy information requirements do not apply, it might be useful to present transparency information as the obligation that arises instead.

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
x Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

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

This guidance references processing for secondary care purposes, a vital element of targeted health & social care guidance as organisations can be using data opaquely (utilising 3rd parties to support services or mobile care provision) & individuals must be made aware via the necessary transparency information. However, it will usually be the case that patients will not be made aware directly that their information is being processed for scientific research or statistical purposes. Transparency about such purposes is the substitute. It would be useful if this was in the guidance.

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
x Unsure / don't know

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

As RDS are not part of the health and social care sectors it is difficult for us to comment on the equity of the guidance written for these different areas.

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):

It would be helpful to have examples of what best practice looks like in 'should' and 'could' scenarios. What benchmark are the ICO considering when they use these terms as best practice can mean different things in different sectors and look very different from one organisation to the next? There are also instances where 'must' does not apply where health and social care records are being used for the purposes of scientific research, and some privacy information matters are 'could' at most. Clarity around where 'must' does not apply would add more depth to the guidance.

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 are reasonably clear but the use of the word 'honest' could be replaced with 'clear' or 'with integrity' as most organisations aim is to be honest about their processing of personal data not deliberately dishonest. Being clear or acting with integrity places more emphasis on the need for quality and accuracy of the information which an organisation publishes about its processing of personal data, both privacy and transparency information.

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

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

This section is useful in that it provides detail around the different types of harm that should be considered when assessing processing risks. However, linking it directly to the DPIA section by outlining that harms to data subjects from the purpose of the processing, in terms of lack of transparency information, are integral to the risk assessment would give the section more clarity and impact. Individuals need to know that all hazards have been considered & mitigated where possible.

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

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

It would be useful to include at the start of this section more information around the need for organisations to clearly identify their audiences, tailoring information to meet their needs/priorities. Further guidance around the circumstances where organisation’s need to clearly state the purpose of processing the data, the safeguards they are implementing to protect personal data and conversely when it is not necessary for transparency and/or privacy information where data are rendered functionally anonymised and social licence applies rather than the transparency principle.

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):

This section is helpful in providing key elements for organisations to consider when assessing their processing of health and social care personal data. However, clarity around the differences between privacy and transparency information, and including in the 'must' section that a DPIA must be considered around processing data of this nature to identify (and mitigate where possible) any harms associated with the processing would add further clarity to the checklist.

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 checklist is a useful summary of some key elements for organisations to consider when assessing the transparency of their processing of health and social care personal data. However, as in the above response further clarity between transparency and privacy, and how these fit into the 'Must' and 'Should' headings would assist understanding and the completion of the checklist.

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.

Further clarity and definition around the difference between privacy and transparency information, explaining what elements are key for inclusion in each would enhance understanding of the guidance.

Providing more details of where privacy information does not apply but the need for transparency information is still required/recommended would be helpful in reinforcing the difference between the two elements.

Reference to the forthcoming DPDI Bill and the proposed changes to transparency requirements which when introduced will impact this guidance.

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)

Links to further research on public attitudes to use of their personal data in health and social care would lend more weight to the assessment. One of the links to a report on research carried out by YouGov outlines a project carried out with a cohort of 2000 people involved to inform the research outputs. Perhaps inclusion of other research studies to support the need for the guidance in the sector evidencing public opinion and feedback.

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.

Chief Information Officer, Information Governance Manager, Information Governance Officers, Public Engagement Manager, Communications Manager Partners & Strategy, Data Approvals Transformation Lead, Partnership & Strategy Director, Senior Communications & Engagement Officer, Digital Content Editor

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?

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

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

The guidance will not have a direct impact on our organisation as RDS do not process health and social care identifiable personal data. However, we are building a Researcher Access Service where information assets, derived from functionally anonymised health and/or social care related datasets, will be accessible to researchers for the purposes of public good scientific research. Data for scientific research derived from sources of personal data is either personal data or anonymised data. The term “functionally anonymised” (or “effectively anonymised”) does not denote some middle status. RDS’s personal data processing purpose is to create anonymised information assets for scientific research use, and not to create what amounts to just a different version of the personal data.

Going forward RDS will be working with different health and social care data controllers, to assist them with making their data available for public good research, by using our design combining the limited access controls of a Trusted Research Environment, which contribute to achieving anonymisation by limiting the availability of other information which could undermine the de-identification of the data, and by limiting the type of user to scientific researchers. Our approach aligns with the best practice guidance around the anonymisation of personal data published by the Information Commissioner’s Office.

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?