



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- Section 1: Your views on the draft guidance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

Y 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Section 1: Your views on the draft guidance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
x Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

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

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

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

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

There are clear definitions but it is too far down the document – please move this section (p5) nearer the start for non-IG people to understand the definitions.

“How does this guidance approach transparency?”

To help provide you with clarity for legal compliance and best practice, we use the following terminology when referring to separate elements of transparency:

- **Privacy information:** *This describes the specific information you **must** provide to people in order to comply with transparency obligations under the right to be informed.*
- **Transparency information:** *This describes the total range of material you **should** provide to comply with the transparency principle. However, this also includes additional information that you **could** provide to people to make your transparency material more effective.”*

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

- x Yes
 No
 Unsure

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

Non information governance staff have recommended that should include definitions of what is meant by the terms 'transparency information' and 'privacy information' in advance of them being referred to in the rest of the doc. [Policy & Comms] – linked to comment above....

The definitions are currently on p5

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):

The guidance is helpful but is for a 'provider' audience.

Might have been helpful if the ICO had mentioned specific things for regulatory organisations such as CQC and Care Inspectorate Scotland and Wales.
[Intelligence] [Scrutiny & Assurance]

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):

please see comments above about regulators...

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
x Agree
 Neither agree nor disagree
 Disagree

Strongly disagree

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

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

x Agree

Neither agree nor disagree

Disagree

Strongly disagree

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

There is an argument that it should be 'integrity' which has a wider scope than 'honesty'?

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):

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
- x Neither agree nor disagree
- Disagree
- Strongly disagree

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

1) *Example p8*

*An organisation wants to deliver a system to **patients** using **pseudonymised** data. However, there is a lack of public trust in the system, which means the organisation cannot use it. If the organisation were transparent about identifying and addressing the public’s concerns, this may increase trust and confidence in the system.*

From our perspective as a regulator or for the care services we regulate it would be helpful to not refer to **patients** as this is a health term – can we refer to people? [scrutiny & assurance]

We need to explain the term **pseudonymised** [scrutiny & assurance & Policy & Comms]

2) *Example page 17*

How do we engage with patients and service users?

This section talks about service users as well as patients in the title and then refers to patients throughout can we amend in the content?

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
- x 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
x Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

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

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) There is an absence of mentions of Scotland and Wales, the ICO covers both areas and many references to England and law that does not apply in Scotland.

e.g.

p10 The **National Data Guardian** has published guidance for the health and social care system in **England**

p12 However, there may be circumstances where you need to consider the separate **Common Law Duty of Confidentiality**

p13 Data opt-outs – The opt-out policies used in the health and social care sector in **England**

2) General comment

The document overall is a bit longwinded - could do with a plain language check/editing to make it more direct and snappier so people can more easily and thoroughly digest it

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)

Patient centric – care service users?

England centric – Scotland and Wales?

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

- Yes
 x 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.

n/a

16. Are you acting on behalf of an organisation?

- x 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
 x Other (please specify):

A regulator – The Care Inspectorate Scotland

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

SOCIAL CARE AND SOCIAL WORK IMPROVEMENT
SCOTLAND
is registered with the Information Commissioner's Office under
registration reference:
Z2582022

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)?

n/a

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

The majority our staff as we all process the data relating to care services and their employees as well as the care service users but operationally we have inspection staff who perform our scrutiny and assurance work (regulatory and strategic) and

Registration Team
Complaints Team
Improvement Team
Intelligence and data team
Information Governance Team
Finance Team

And others....

Please see our privacy notice for more details

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
- x unsure / don't know

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

Guidance from the ICO is helpful to underpin our local policies and procedures and provide 'gravitas' to our framework.

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?

It doesn't feel like it covers our organisation specifically in its current form as we are a regulator, and in Scotland – see previous comments

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?

Example p 10

- 1) People's support for you using their information for secondary care purposes may depend on how much they understand the proposed use. People might not reasonably expect you to use their information for a purpose outside of their immediate care or treatment. If it is not clear what you will actually do with their personal information in practical terms, and the potential impact, then it is likely they will be reluctant to agree to you sharing their information. However, people may appreciate the benefits of sharing personal information for certain purposes, such as planning and research, if you explain it clearly to them. Being transparent about the use of personal information for secondary care purposes can help inform people's expectations and build trust.*

We are not a provider of health and social care and we do sometimes hold records that relate to 'immediate care or treatment'.

However, as the regulator we have access to these in our regulatory work and this is covered by legislation. Some of the wording is not very inclusive to our processing activities.....