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- Section 1: Your views on the draft guidance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

X 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Section 1: Your views on the draft guidance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):

This is comprehensive but perhaps a little convoluted – perhaps could be more effective in a checklist format?

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

- ☐ Yes
- X   No
- ☐ Unsure

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

It is a very tricky distinction to make as these are definitions under different legislative frameworks. Perhaps they should be kept separate. However they are both elements of transparency, which is also confusing. "Could", "should" and "must" are all used in this section – perhaps these could be the headings in this section, rather than the headings 'privacy information' and 'transparency information'.

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 section should also link back to the applicable sections of the main guidance on transparency.

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

X   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):

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│ I don't remember reading much about social care. Often just patient referred to │
│ rather than patient/service user.                     │
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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):

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│ Worth noting that the term 'shall' is also used in the legislation. │
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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

X   Disagree

☐ Strongly disagree

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

Found this section unclear. Don't think there is a clear definition on honesty – however this is a fairly straightforward principle. The examples provided under honesty all seem to be more like openness.

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):
Not very well explained that this section is talking about potential harms of <u>not</u> being transparent. I don't find the term 'transparency harms' very helpful.

When engaging with patients/service users it is likely they will focus mostly on harms from potential data breaches.

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):

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

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

Sets out some good approaches but does seem to be quite wordy where a more 'bullet point' approach may be clearer. Should also mention that electronic methods may not be suitable for many audiences.

After this sentence "When assessing how to provide transparency and privacy material to patients and service users as part of this requirement, you **should** think about the following questions." the next bit should be presented as sub-headings.

The section on complexity is not very helpful. Perhaps this should refer to engaging with patient groups to understand how to do this. Currently the guidance should refers to "considering" this but not how.

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

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

The checklist itself is not in a logical order which might be helpful.

Sections should link back to the applicable bit of the guidance.

Don't understand this point We have allocated responsibility to delivering transparency where it is most effective.

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.

One point which I felt was not clear was about TREs as it doesn't really give any detail about what data is being used here and how – how does this relate to health and social care organisations. It says you must clearly explain these but do all HSC organisations have this responsibility? HSC organisations may not recognise yet their role in TREs (if they have one) so this may just confuse.

It is unclear in the example "a small GP practice updating their privacy notice would not have to consider transparency in the same depth as a hospital trust implementing a new health record system" what is meant by 'consider in the same depth' – possibly would be clearer to describe it as them not having as many applicable matters to consider. Otherwise it seems like you are saying that they don't need to take it very seriously.

Not sure about the example "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." – this is not very clear and think it would be better refer to how they can do it e.g. "The organisation must communicate and be transparent up front about what is planned. If a lack of trust is identified and the organisation is unable to rectify this, then they would not be able to implement it."

Think it would be worth linking to information about the NHS opt-out as this will be relevant for many readers and it is mentioned (although separate from this work).

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?

X 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)

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.

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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)

X   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):

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

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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.

DPOs supporting general practices

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

X   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

X   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?

This guidance may improve confidence in the production of transparency and privacy information, therefore improving the quality of this information and public confidence. Also compliance with the requirement to share transparency and privacy information.

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?

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?