



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- Section 1: Your views on the draft guidance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Section 1: Your views on the draft guidance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

This guidance appears to present a framework which outlines the fundamental requirements of transparency provision for the Health and Social Care sector, at least as far as Data Protection requirements are concerned. While not as detailed as it could reasonably be, the document outlines the basics of what transparency work needs to offer, at least to satisfy legal requirement.

A shortfall exists, however, through not providing more comprehensive detail. It would be beneficial to not only expand upon certain topics in an effort to establish absolute clarity but also to offer the definitive guidance this document could possess.

The guidance should also offer clarification of differing impacts between health and social care provision and providers.

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):

The explanation of the two is lost in there being no clear headers to define the difference between 'transparency' and 'privacy'. It also seems to have taken the onus off of providing the basic level of 'privacy information' by never mentioning the basic requirement that an organisation must have a privacy notice.

For example, under 'What is transparency' there are definitions of both privacy information and transparency information with defined examples offered. Under privacy information the guidance says that privacy information, 'describes the specific information you must provide to people in order to comply with transparency obligations under the right to be informed.' Under 'How do we provide transparency and privacy information', however, the guidance says that, 'Providing privacy information means more than just providing a privacy notice on your website. You should make efforts to inform people where they can find your privacy information and to notify people when you make significant changes.'

It would be to the benefit of those using the guidance should these statements, and the transparency one in tandem, be clearly stated near the start of the document, so setting a clear understanding for readers before delving further into the guidance.

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):

The distinction, as offered by the guidance, makes sense when viewed on a UK wide level, though the guidance is clearly primarily focused on the English Health & Social Care sector. One fundamental area upon which we feel it infringes is that of the Scottish Information Commissioner and their respected jurisdiction of FOISA. A lot of these processes can be found using the transparent FOISA process open to all. Regarding information regarding personal data, we agree transparency is a necessity and is legislated for, but we feel this guidance needs to be clearer when it comes to specific policies the ICO expects organisations to clarify when being transparent.

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):

We agree that in the Data Protection sphere guidance is needed for organisations to ensure they are compliant and that this document supports that need to some extent. The guidance, however, fails to acknowledge the structures and processes already in place in Scotland and it further fails to mention the roles of central positions such as Caldicott Guardians and Senior Information Risk Owners. These roles support understanding of the duty of confidentiality and the latter hold the risks, positive and negative, of all data matters within their organisations.

Throughout the document, confusion is allowed to exist over when and when not DPIAs should be produced. More onus should be put on producing DPIAs to ensure requirements are appropriately assessed for the protection of individuals' information.

More confusion is generated through the document's repeated references to 'secondary care'. The guidance appears to define secondary care as an opposition to 'direct care'. It mentions 'secondary care purposes, such as planning and research'. Within health and social care, and in the understanding of most publics, 'secondary care' invariably refers to care provided directly to citizens through the health service (e.g. hospital care), usually after referral from primary care (e.g. General Practitioner care). The guidance confuses this

understanding considerably and will not be easily understood by most audiences.

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):

The guidance is vague and, as previously noted, lacking detail. This results in it being representative of actions required in most sectors, not just those of health and/or social care. Further, health and social care here are looked at holistically, rather than as the individual and distinct functions they yet still are to a great extent. The two areas of service provision, though coupled in title and increasingly in policy direction, act individually in most areas. Greater detail is required for each individual area of service provision.

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):

There is clarity over the requirement to fulfil 'must' tasks but this is lost when the guidance speaks of 'should' tasks. Placing 'should' under 'Good Practice' immediately gives a feeling of downgraded need, despite the clear expectation of fulfilment where possible and the necessity of explanation should an organisation decide not to carry out a 'should' task. Practitioners are less likely to fulfil 'should' tasks, and so run foul of expectations, as a result of this presentation.

Furthermore, 'should' tasks are exemplified through tasks which should be included in any DPIA required through the processing of any special category data.

The terms may be helpful in defining the expectations of the ICO for a learned person, however a layperson in the area of data protection is likely to become confused.

Impact examples of must, should, and could would benefit readers through their inclusion in aiding better understanding of needs and consequences.

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 proposed definition of 'honesty' is not useful, even when considering the guidance's admission of the breadth of the term. It is too open to interpretation.

When noting, in Bullet Point 3, that 'You **must** only apply exemptions about the right to be informed in the limited circumstances where this is appropriate', links to explanations or definitions of these circumstances should be included.

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):

Between the descriptions of harms to the individual and that of societal harm should be described harms to organisations. Illustrations of harms caused to NHS providers, for example when financial consequences occur, would help bring the importance of transparency to the mind of decision makers in this area.

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):

While useful for large service providers, this section describes an approach simply unrealistic for small scale service providers. Consideration of and description of how small scale providers of both health and of social care can engage with publics before carrying out their transparency work would go a long way to allowing fulfilment of this 'should' task.

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):

There should be more attention paid within this section to the basics of providing a privacy notice. From that provision, organisations can expand into providing more transparency. The guidance should, then, begin at that earlier, more basic, point and work its way into other, following complexities.

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 good starting point. A lot more detail is needed, however, through providing examples in bullet form. That would also provide a useful and quick-reference synopsis of the guidance itself, making it more digestible.

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.

The guidance leads towards an unintentional focus on the Health & Social Care landscape in England, through mentions of the National Data Guardian. In the section on public benefit evaluations, for example, appropriate reference must be made to any guidance and relevant processes within Scottish, Northern Irish and Welsh systems. The guidance is unbalanced in this regard.

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.

The National information Governance Programme of Scottish Government has extensive plans around the improvement of transparency within Scottish Health and Social Care. These examples may be available to you in due course but potentially beyond your timescale.

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)

While interesting, the focus is on NHS England. We do agree with the rationale for intervention and believe that none of the four home nation Health & Social Care services differ in the need and necessity to be open and transparent. The examples available from other nations should, therefore, be used.

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)

We ask you to contact us for further illustration and discussion.

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

The table should make very clear that the NHS referenced in the document is NHS England. As noted above, it would benefit enormously from examples from all four home nations.

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 (e.g. care home)

A trade union

An academic

- Other (please specify):

A representative of the Scottish Government Health and Social Care Digital, Finance and Governance Directorate's Information Governance Team

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

Scottish Government Health and Social Care Digital, Finance and Governance Directorate's Information Governance Team

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.

n/a

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?

The Directorate's own work within Information Governance across health and social care in Scotland will likely need to respond to the finalised guidance in all areas of its advice and future work.

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 has the potential to re-embed within organisations the unfortunate and blinkered belief that transparency in data is only a data protection issue. Conversely, we are trying to grow transparency across all areas of Information Governance in Scottish health and Social Care.

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?

It would be most useful if the guidance were to acknowledge that data protection is only one aspect of beneficial transparency work, however fundamental, and that organisations should seek to ensure transparency across all of their Information Governance practices, so improving outcomes for organisations and service users in myriad other ways. For example, there is no reference within the guidance of the need to build trust in how data is eventually destroyed.

It would also be useful to have an 'easy read' version of the guidance. This is a difficult task given the often technical nature of the matters under discussion but would, in itself and most valuably, improve transparency and public trust.