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- Section 1: Your views on the draft guidance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Section 1: Your views on the draft guidance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

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):

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):

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):

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):

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):

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):

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):

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.

We are grateful for the opportunity to comment on your draft transparency guidance. As the regulator of doctors, we provide guidance on the professional standards of all doctors in the UK (and in the future this will apply to physician associates and anaesthesia associates when we begin regulating those groups). This includes our recently updated edition of *Good medical practice* and specific guidance on Confidentiality. Our guidance on confidentiality is

consistent with the two legal frameworks which doctors are expected to uphold: the Data Protection Act 2018 and the common law duty of confidentiality.

Transparency is a key element to maintaining patient confidentiality and trust between doctors and patients. One of the main principles in our confidentiality guidance is to support patients to access their information and help them exercise their legal rights to be informed about how their information will be used (see paragraph 8h). It is therefore helpful that the ICO has developed guidance to support and increase transparency in the sharing of patient information. We have included feedback below in relation to the scope of the guidance, the use of terminology and the scope of the common law duty.

Scope of the guidance

We understand this guidance is aimed at information governance staff, data protection officers, and others within the health and care sector. However, we think it would be helpful to include audiences beyond the health and care sector within the remit of this guidance. We are aware that sharing information between the health and care sector and other sectors has previously posed challenges, for example between the Home Office and NHS Digital. Greater transparency in the use of health data, in all sectors, will help to maintain the trust patients place in medical professionals.

Most patients understand and expect relevant information must be shared to provide them with direct care. But we also recognise that there are key secondary uses of patient information, whether for research purposes to improve health and social care, or for wider purposes like the administration of justice or insurance claims. It would be valuable for the guidance to place greater emphasis on the need to help patients understand how their information will be used, both for direct care purposes, and, importantly, secondary purposes, in order to increase transparency.

Use of terminology

In the guidance you make reference to what practitioners ‘must’ and ‘should’ do. You explain that your expectations of what practitioners ‘must’ do refers to legislative requirements, and that what they 'should' do refers to non-legislative requirements and what you expect them to do to comply with the law. And that those subject to the guidance who choose to take a different approach must be able to demonstrate this approach also complies with the law.

In our guidance we provide a different explanation of the terms ‘you must’ and ‘you should’. ‘You must’ is used for a legal or ethical duty medical professionals are expected to meet (or be able to justify why you didn’t). Whereas ‘you should’ is used for duties or principles that either, may not apply to a medical professional or the situation they are in, or which they may not be able to comply with because of factors outside of their control. These different uses of the terms ‘must’ and ‘should’ may prove confusing for medical professionals who are required to uphold our guidance on professional standards.

The common law duty of confidentiality

The risk from the different use of ”must” and “should” is particularly relevant to the references the draft guidance makes to the common law duty of confidentiality. The draft guidance currently states that those following the guidance should be clear about how they are meeting the common law duty. We are clear that doctors and health practitioners must comply with the law. This includes upholding the common law duty of confidentiality, alongside data protection legislation. Although your draft guidance explains that the term ‘should’ sets out what medical professionals are expected to do to comply with the law, it could be perceived as creating a lesser standard of protection for the common law duty, as opposed to the use of ‘must’ for data protection standards. Any perceived difference in the standards expected between data protection law and the common law could undermine the latter. This in turn could pose challenges for medical professionals as they are expected to uphold both legal frameworks.

In the draft guidance you also only make reference to the common law in relation to the sharing of personal information for secondary uses. In our guidance we are clear that the common law duty applies to the sharing of personal information, for direct care purposes, as well as secondary uses such as the protection of patients and others, planning and research. In our guidance we are also clear that consent is the starting point when considering whether to disclose personal information. Asking for a patient’s consent to disclose information shows respect and is part of good communication between doctors and patients (see paragraph 13 in Confidentiality). If doctors disclose personal information without consent, they must be satisfied there is a legal basis for breaching confidentiality (see paragraphs 15 and 9).

All doctors registered with us are required to follow our guidance. Any inconsistency between ICO and GMC guidance could cause confusion for medical professionals and interfere with appropriate information sharing. We think it is therefore important that the ICO guidance reflects that medical professionals must uphold the common law duty of confidentiality, the common law duty applies to sharing personal information for direct care purposes, as well as secondary uses, and the continued role of consent for information sharing under the common law.

I have focused on some key areas where there is a need for greater consistency with our guidance, however I would reiterate that we support the aim of this draft. Maintaining transparency is vital to appropriate information sharing and we look forward to continuing to work with you as you develop the guidance. I would be very happy to meet and discuss these points.

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)

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?

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):
Professional Regulator

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

General Medical Council

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
- [X] 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
- [X] 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?

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?