



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- Section 1: Your views on the draft guidance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Section 1: Your views on the draft guidance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

The RCGP welcomes this guidance as it is a valuable instrument to have a better sense of where GPs' duty of transparency and privacy lies. However, we are concerned that the distinction between direct care and secondary purposes is not clear throughout the guidance. It is important that the guidance is clear which purpose is being referred to at all times.

Additionally, we consider that for better comprehension, the language could be simplified, the terminology should be consistent, and the role of new technologies should be clarified without overstating their importance.

It is important to highlight that GPs as data controllers face a series of duties and liabilities. For the average GP, the issues covered in the guideline are very complex ones. This guidance is potentially difficult to understand and navigate for most GPs, so to make it valuable for GPs, we would suggest making the guidance simpler.

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):

We consider the definition of transparency to be clear. Nonetheless, we would like to stress the need to treat transparency as equally critical regardless of an organisation's size.

It is also important to ensure that efforts to support transparency do not prevent and slow standard processes such as referrals from general practice to secondary care. As above, clarity on how the guidance applies to different purposes would help in this regard.

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):

This distinction is clear, however we would suggest more information is needed on how this applies within general practice.

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):

Within healthcare, and general practice in particular, there may be different expectations of confidentiality as compared to social care, with different information shared. More tailoring of the guidance to recognise the importance of confidentiality in general practice would be beneficial.

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):

The guidance is clear when using the terms 'MUST', 'SHOULD', and 'COULD' to provide advice, which shows an understanding of the concept of proportionality

for small practices versus large health boards or hospital trusts, for instance.

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):

We consider this section of the guidance positive as it reminds data controllers about the Common Law Duty of Confidentiality which extends legislation beyond GDPR requirements. Additionally, we welcome that transparency of data flow for research purposes has been included.

Most GPs are aware of the requirement of developing Data Protection Impact Assessments (DPIAs) to allow data flows, and it is positive this has been explicitly mentioned. The Health Research Authority recently came out with a statement about research and the lack of need for a DPIA in most cases. A caveat was added after our members' feedback. In that sense, we welcome this guidance emphasises the requirement for DPIAs. However, the RCGP considers that there should be a greater emphasis on the importance of this assessments.

We would welcome central guidance to study teams to provide appropriate DPIA templates to allow practices to fulfil this requirement.

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):

The RCGP strongly believes that patient engagement is a key component of the duty of transparency of information. In that sense, we believe that there should be an emphasis on the significance of building public trust and agreements through informed engagement, alongside the need to work with other organisations to improve transparency.

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):

The College considers the checklist to be a simple and useful tool.

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 RCGP recommends broadening the scope of the guidance to explicitly include a variety of health and care professionals. Additional examples considering organisations of different sizes and focusing on general practice would help address differences in approaches between different organisations.

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.

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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)

-distinction needs to be made about the type of data

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.

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?

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?

As set out above, our main feedback on the guidance is the need for it to be easier to understand and navigate for busy GPs who may not be expert in data protection issues. It is critical that there is clarity over how transparency duties apply to different data use cases as the sharing of pseudonymised patient data for research is a very different proposition to day to day patient care and e.g. referrals to secondary care.