


Are you happy to proceed?
I am happy to proceed.
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?
Agree
2(a). Do you agree that this guidance provides a clear definition of transparency and privacy information?
Strongly agree
2(b). Does the distinction between transparency information and privacy information make sense to you?
Yes
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?
Agree
4. Do you agree that this guidance is balanced between the separate areas of health and social care?
About right
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
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?
Disagree
Please provide any comments you have: The opposite of 'honesty' is dishonesty, I'm not convinced that non-compliance would be dishonest in this context.

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 disagree
Please provide any comments you have: The term is highly subjective and presumes harm is inevitable, we suggest a neutral word be selected an the context of risk be explored in more detail.
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?
Agree

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?
Agree
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?
Neither agree nor disagree
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.
An idea approach would be based on ongoing dialogue, rather than one-off exercises; it would be good to include this in the guidance.
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.

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
14. Can you provide us with any further evidence for us to consider in our impact assessment?
No
16. Are you acting on behalf of an organisation?
Yes

17. Are you answering as: (tick all that apply)
An organisation or person processing health data <input type="checkbox"/>
An organisation representing the interests of patients in health settings (eg GP practice, hospital trust) <input type="checkbox"/>
18. Please specify the name of your organisation (optional):
Moorfields Eye Hospital
19. How would you describe your organisation's size?
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)?
269835 seen in 2023
21. Who in your organisation needs to read the guidance? Please provide job titles or roles, rather than names.
Various
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
23. Do you think the guidance set out in this document presents additional:
benefit(s) to your organisation
24. Could you please describe the types of additional costs or benefits your organisation might incur?
We have already consulted on our approach, but in the era of interoperable data sharing we need others to do the same and consistently.
25. Can you provide an estimate of the costs or benefits your organisation is likely to incur and briefly how you have calculated these?
no

