

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
Please provide any comments you have: We welcome this specific guidance and view it as a useful tool
2(a). Do you agree that this guidance provides a clear definition of transparency and privacy information?
Agree
Please provide any comments you have: The definitions of transparency and privacy were very well explained. We are content that communicating privacy information to service users and staff has been embedded although there is more work to be done in terms of achieving the same with transparency.
2(b). Does the distinction between transparency information and privacy information make sense to you?
Yes
Please provide any comments you have: As Information Governance staff it makes sense to us.
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?
Disagree
Please provide any comments you have: We found the suggestion of publishing DPIAs interesting however in practice it may bring about unwarranted scrutiny and add additional burden in the form of queries regarding risks and might cause public concern or harm (i.e. psychological harm, loss of control of personal information harm) There may be occasions where publishing a DPIA would not be appropriate and organisations may need further guidance on meeting the public interest when publishing.
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
Please provide any comments you have: We found this very useful and the terminology could be applied when drafting IG guidance and providing advice.
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?
Agree
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?

Agree

Please provide any comments you have:

We felt this was useful and provided clear examples.

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

Please provide any comments you have:

We agree this is very useful information. The challenge lies in implementing this across our large and diverse organisation.

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

Please provide any comments you have:

We currently have many tools to help with issuing privacy information but achieving the same with issuing transparency information will take time.

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?

Agree

Please provide any comments you have:

We welcome the transparency checklist. We think it would be a useful tool in addition to completing DPIAs.

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.

No, the guidance is comprehensive.

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?

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

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)

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

Northern Health and Social Care Trust

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)?

479,000

21. Who in your organisation needs to read the guidance? Please provide job titles or roles, rather than names.

Data Protection Officer, IG staff, SIRO and PDG

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 but only in specific circumstances

23. Do you think the guidance set out in this document presents additional:

both

24. Could you please describe the types of additional costs or benefits your organisation might incur?

There may be additional staff costs in implementing the guidance on being more transparent, most of which would fall to the IG teams in terms of interpreting and implementing the guidance across the width of the organisation

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, it would be difficult to estimate

