

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?
Strongly agree
2(a). Do you agree that this guidance provides a clear definition of transparency and privacy information?
Strongly agree
<p><b>Please provide any comments you have:</b>  On the page "What is transparency?" the relevant section should read "Transparency also applies to the requirement to let people know how you will use their information (their right to be informed)". There is an extra full stop in the draft.</p>
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?
Too focused on health
<p><b>Please provide any comments you have:</b>  There is at least one place where patients are mentioned but the term 'service user' is omitted. This should be carefully checked.</p>
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?
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?
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
<p><b>Please provide any comments you have:</b>  Further examples might be useful for health and social care providers, particularly in relation to social care.</p>
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?

Agree

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.

This section of the intro feels like it contains quite a lot of jargon that providers will not necessarily recognise: "Within health and social care, new technologies that use large amounts of personal information are being developed to support both direct care and secondary care purposes, such as planning and research. An example of this is the use of Trusted Research Environments (TREs). TREs are secure environments that provide remote access to health information in de-identified states that protect people's privacy." Definitions and explanations, or at least links to a glossary, are needed. "Deidentified states" to take one example, doesn't have an immediately obvious meaning to the average lay reader.

The intro refers to a DPO as if all data controllers have one. I presume this guidance could apply where there isn't a requirement for a DPO, so that should be clearer.

In the section on 'How do we develop transparency information?', the relevant passage should read "there are sometimes limited opportunities for people using health and care systems..."

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

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

None.

16. Are you acting on behalf of an organisation?

Yes

17. Are you answering as: (tick all that apply)

A representative of a professional, industry or trade association

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

The Homecare Association

19. How would you describe your organisation's size?

10 to 249 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.

Policy team.

22. To what extent (if at all) do data protection issues affect strategic or business decisions within your organisation?

Data protection is a relatively minor feature in 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?

As a representative membership body, we need to be able to advise members on the implications of the guidance, or at the very least direct them to it. It is important that we understand its implications and as such it benefits us as it enhances our ability to support members.

25. Can you provide an estimate of the costs or benefits your organisation is likely to incur and briefly how you have calculated these?

As above, the benefit is intangible. We are a small organisation and we are not directly affected ourselves by the guidance. It is only of relevance to us in respect of supporting our members.

26. Please provide any further comments or suggestions you may have about how the guidance might impact your organisation?

We think it will be helpful in relevant circumstances for our members, who are all homecare providers.

Do you have any other comments you would like to make?

No.



