

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:

The examples are useful for understanding what organisations should/could be doing. The bold clarifications between must, should and could are useful for understanding what's legislative versus good practice. It's good that abstract recommendations like openness are operationalized into actionable things.

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 make sense, though they could be less separated out from the explanations further up about legislative requirements and good practice. The two things are interlinked, but have been separated out which makes it more confusing, i.e. privacy is legislative, transparency is good practice

2(b). Does the distinction between transparency information and privacy information make sense to you?

Unsure

Please provide any comments you have:

They make sense but each explanation could maybe include more detail. The examples should sit alongside the definition rather than come separately (and in opposite order) below, and perhaps spell it out more: "Not providing privacy information like this would be illegal under this legislation...not providing transparency information is not illegal, but can still impact important things like patient trust, etc. etc. so is worth considering"

4. Do you agree that this guidance is balanced between the separate areas of health and social care?

Too focused on health

Please provide any comments you have:

Most examples are centred around health, e.g. GP surgeries, hospitals etc. It could be good to incorporate examples specifically for social care especially to show any differences in how transparency principles might play out between the two. Especially as social care does tend to be the forgotten element, it would be good to draw this out more, especially if we want those who work in to be on board.

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

Please provide any comments you have:

The distinctions really helpful for easily identifying what is hard and fast legislation and what is advisable. The checklist at the bottom is a useful summary and overview as well. It might be useful to briefly explain why the should's and could's are still really important even if it not a legal requirement, to encourage people to go beyond the bare minimum.

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

Please provide any comments you have:

The element of honesty about being clear on what could go wrong and being honest about contentious issues is really important, particularly for health. In terms of openness, the alternative forms point could be more explicit about why this is important for ensuring that anyone with accessibility needs has equal access to information.

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:

Particularly in terms of contentious things like data breaches, it's important for organisations to recognise that the risks of talking about that is outweighed by the risks of avoiding talking about them. The example is good in terms of general transparency of information, but an additional one that highlights what happens when they don't respond openly and honestly about e.g. data breaches would be helpful too. I.e. it seems like a good idea at the time to brush it under the rug, but in the long term it does a lot more damage not only to people's immediate trust but long term health outcomes.

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?

Neither agree nor disagree

Please provide any comments you have:

A worthwhile point adding might be about ensuring accessibility for the public to actually engage in these activities, e.g. offering different formats (remote, in-person), having translators, etc. Also adding that public engagement needs to be iterative and ongoing, not a one-off activity that's "proved" you did it.

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:

The section does a good job of making the point that while all this stuff is important, the public don't want data protection to become another big thing to worry about, there needs to be high level messaging as a given with more detailed information available for those who are interested. The example at the end falls a bit flat and doesn't further understanding, it could be improved.

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:

Tickbox checklist is a good idea for orgs to refer back to

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)

A representative of a professional, industry or trade association

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

Understanding Patient Data

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

0 to 9 members of staff

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

Policy & Engagement Managers

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 are a policy organisation so are not directly making data protection decisions for patients but having clear guidelines for health and care organisations supports our efforts to make information about patient data more transparent and trustworthy. It is guidance for organisations but it in turn helps the public to feel reassured that those organisations know what they need to do in a standardized way when it comes to privacy and transparency.