

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
<p><b>Please provide any comments you have:</b> The guidance does this pretty well.</p> <p>However, I have some concern with the use of the term "secondary care purposes" in the guidance. Personal data in health and social care may be used for direct care purposes, i.e. for the care of the patient/person, but in respect of planning and research, there is no certainty it will be for a care purpose, secondary or otherwise. It is best in my view to avoid this phrase, which can only cause confusion and set false expectations, and instead go with the phrase "secondary uses" or "both direct care and other non-direct care purposes".</p>
2(a). Do you agree that this guidance provides a clear definition of transparency and privacy information?
Agree
<p><b>Please provide any comments you have:</b></p> <p>Yes, generally clear definition, but as with other ICO guidance, I'm not clear why "personal information" is the term deployed rather than "personal data". Indeed it's inaccurate to quote from Art 5(1) UK GDPR and refer to "personal information" rather than "personal data". Clarification on the rationale for this choice and mis-direct quoting the UK GDPR terminology would be useful.</p> <p>I would also say that the example about the organisation that 'wants to deliver a system to patients using pseudonymised data' is rather vague. Further details on what this system might be (hypothetically) and how it plans to use pseudonymised data would be really helpful.</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
<p><b>Please provide any comments you have:</b></p> <p>In the bullet point rationales for why providing transparency information can help organisations achieve other legitimate objectives, there is a bullet point that states: "gaining acceptance for innovative uses of information that have a public benefit". I would qualify this as *may* have a public benefit. The use of an AI-based technology in health and social care may bring public benefit, but this is often not a guarantee. Transparency would also include honesty about expected benefits.</p>

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></p> <p>I did not see much info on social care. While I'm not an expert in this area, my sense is a bit more explanation and examples can be drawn from this sector.</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

**Please provide any comments you have:**

In the section, "How should we reflect choice?", I was not clear on what is meant by "explaining genuine choices available to patients and service users about how you use their information". What might these choices be, especially in a context where consent is unlikely to be a lawful basis? An example would help. Exercising a data subject right such a right to object would not be a choice per se, as opposed to say, exercising a choice about whether to have data collected in the first place without comprising access to health and social care. For example, it might mean declining (no opt-in or exercising opt out) to not provide data for research or planning purposes.

Also, I wasn't clear with the statement about the Common Law Duty of Confidentiality. It is stated that it "may" apply when processing personal information for planning and research purposes. It seems to me that the duty \*always\* applies in the health and social care context, whether for direct care or other purposes. So, organisations must be mindful not only of their data protection legal obligations, but also their common law obligations -- which includes \*both\* the duty of confidentiality as well as the need to protect against misuse of private information, i.e. protecting against both breach of confidence AND misuse of private 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

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

**Please provide any comments you have:**

The example on the GP survey providing patients with privacy information about local and national data use programmes and information rights was very vague and didn't seem to fully reflect the above points/guidance about providing transparency. More detail in the example would be welcome, as would an additional detailed example in the social care context.

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

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.

[REDACTED]

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?
No
17. Are you answering as: (tick all that apply)
An academic

