

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?
Please provide any comments you have: While the guidance seems clear for people who are familiar with the subject matter, it may be more difficult for people who do not have this knowledge and understanding. The guidance needs to be accessible to all stakeholders with varying degrees of knowledge around the subject matter and resources. While larger organisations may have dedicated data protection teams, small independent health and social care providers are unlikely to have such resources and therefore will not have Data Protection professionals to consult with. ICO may wish to consider how the guidance can be made more accessible and easier to read.
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 are explained simply.
2(b). Does the distinction between transparency information and privacy information make sense to you?
Yes
Please provide any comments you have: The definitions are explained simply.
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
Please provide any comments you have: The examples given are useful to help people understand, however they are mainly health related examples referring to Hospital's/GP's processing of patients' data. It would be useful to include some examples relating to social care also for the benefit of care providers.
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?
Neither agree nor disagree
Please provide any comments you have: The values of openness and honesty are intrinsically linked and are difficult to define as separated entities. Some of the examples given could have sat in either area. It was therefore not clear why they have been separated, so this may cause confusion.
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

Please provide any comments you have:

Agree, however in social care we tend to use the term 'people who use services' as opposed to 'service users'. Perhaps the title of this section could be 'How to engage with people who use health and social care services'. The ICO may wish to use this throughout the guidance.

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?

Neither agree nor disagree

Please provide any comments you have:

Whilst the guidance sets this out clearly in terms of how organisations should provide transparency and privacy information to people from whom they have collected their personal data directly, it does not cover how organisations should approach the delivery of transparency and privacy information to people whose personal data has been collected indirectly.

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?

Strongly agree

Please provide any comments you have:

The checklist is very useful.

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.

As per question 9, it would be helpful if the guidance could also cover the requirements, considerations and expectations around providing privacy and transparency information to people whose personal data has been collected indirectly rather than directly.

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)

Other (please specify):

An organisation processing social care and health data, and as a regulator of social care who has also considered the use of the guidance by the providers of social care services.

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

Care Inspectorate Wales

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

250 to 499 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.

Information Asset Owner, Information Asset Manager, Members of the Information Team, Senior Management Team

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:

both

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

Benefits in giving us a clearer position on what we need to consider.
Additional resource & cost involved in reviewing that our privacy and transparency information and arrangements are suitable for all audiences.

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

Review how we communicate and engage people about how we use their personal data in respect of all our processes and provide more awareness for our staff around this subject area.

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

Terminology in the guidance tends to be aimed more at health and patients.

Consider how well the guidance may be understood by small independent health and care providers who are not data professionals. Providing more accessible versions i.e. Easy read guidance.

Consider including privacy and transparency arrangements for processing of personal data that is collected indirectly.

