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:

It broadly set outs what is required but by definition it is only guidance.

2(a). Do you agree that this guidance provides a clear definition of transparency and privacy information?

Agree

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

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

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?

Neither agree nor disagree

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.

Whilst the principle of transparency and its benefits are clear there is little to acknowledge or address potential associated issues and risks. Such as:

(i) potential security risks by over advertising how data is processed and inadvertently exposingvulnerabilities and weak points.

(ii) lack of consistency in the quality of information communicated and methods used etc which cancause organisational and regional differences for data subjects. Health Boards and Local Authorities could, for example, all communicate a similar message in a number of different ways, with varying quality, using a variety of methods. The result may be increased confusion and frustration for data subjects.
(iii) information overload - there are risks associated with providing too much information. It can

overwhelm and confuse people and cause them to miss the key points.

(iv) resources required to achieve and maintain the correct balance.

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 representing the interests of patients in social care settings (eg care home)

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

500 or more members of staff

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:

cost(s) or burden(s) to your organisation

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

Increased (bilingual) communication costs - all requiring maintenance and support.

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

Unknown