



Consultation on the draft Transparency in Health and Social Care guidance

The Information Commissioner's Office (ICO) is producing [guidance on transparency in the health and social care sector](#).

The draft of this guidance is now published for public consultation.

The draft transparency in health and social care guidance has been developed to help health and social care organisations understand our expectations about transparency.

We are also seeking views on a draft summary impact assessment for this guidance. Your responses will help us understand the code's practical impact on organisations and individuals.

This survey is split into four sections. This covers:

- Section 1: Your views on the draft guidance
- Section 2: Your views on our summary impact assessment
- Section 3: About you and your organisation
- Section 4: Any other comments

The consultation will remain open until 7th January 2024. Please submit responses by 5pm on the 7 January 2024. We may not consider responses received after the deadline.

Please send completed form to PolicyProjects@ico.org.uk or print off this document and post to:

Regulatory Policy Projects Team
Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Privacy statement

For this consultation we may publish the responses received from organisations or a summary of the responses. We will not publish responses from individuals acting in a private capacity. If we do publish any responses, we will remove email addresses and telephone numbers from these responses but apart from this we will publish them in full.

Please be mindful not to share any information in your response which you would not be happy for us to make publicly available.

Should we receive an FOI request for your response we will always seek to consult with you for your views on the disclosure of this information before any decision is made.

For more information about what we do with personal data please see our [privacy notice](#).

Are you happy to proceed? *

x I am happy to proceed.

Section 1: Your views on the draft guidance

Answers to the following questions will be helpful in shaping [our guidance](#). Please use the comments boxes to provide further detailed information as far as possible. Some of the questions may not be relevant to you or your organisation, so please skip these as necessary.

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
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide any comments you have (max. 500 characters):

The document is very useful guidance helping to define the difference between transparency and privacy and to clarify what the expectations are around this. It is useful to highlight the importance of transparency ie public Trust and confidence and what can do wrong when this is not in place –there are real life

examples of where projects have failed due to a lack of communication, consultation etc – noted in the impact assessment.

From a service user point of view it is important to promote the idea that privacy is something that an individual does have control over and the guidance does give organisations a greater range of areas to consider.

However the focus of the guidance is on health care, within social care there is a greater challenges to balance the requirement to carry statutory functions and the need for transparency. The guidance does not highlight this in enough detail and some of the challenges that might occur.

From a DPO point of view the guidance does provide a very useful reference point to back up some of the arguments that have been made in the past in relation to particular initiatives – a overall simplified practical checklist list would be really useful for staff to complete – this could form part of a DPIA and give DPOs more leverage in terms of ensuring that projects are complying with the legislation and to build a culture of transparency as the outset of projects.

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

- Strongly agree
 Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

Please provide any comments you have (max. 500 characters):

The definition is very helpful and guidance should extend to any staff who are developing services within Health and Social Care

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

- Yes
 No
 Unsure

Please provide any comments you have (max. 500 characters):

Although the difficulty may arise when there is other legislation in play Children's Order (NI) 1995, Mental Capacity Act (NI) 2016 etc

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?

- Strongly agree
 Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

Please provide any comments you have (max. 500 characters):

The guidance extends the idea of transparency and gives a much better indication of what is expected.

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

- Too focused on health
 Too focused on social care
 About right
 Not enough information on either
 Unsure / don't know

Please provide any comments you have (max. 500 characters):

Much too focused on Health - some of the bigger challenges will lie in the social care sector where the sharing of information will involve more parties and will be subject to other legislation and guidance. Examples and scenarios appear to be health related although it is noted that ICO are looking for examples etc as scenarios. Terminology in the guidance - uses "patient" most of the time P13 "you should consider using patient and public groups" - excludes social care? Voluntary and community groups?

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?

- Strongly agree
- x Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide any comments you have (max. 500 characters):

The use of the terminology provides a scale of the requirements ie what has to be done, what is expected and alternatives to be considered.

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?

- X Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide any comments you have (max. 500 characters):

Openness and honesty are part of HSC NI values so these would be familiar terms to staff and well understood.
Although applying the points defined with in the documentation may be new to staff and will required changes to IG training internally

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?

- x Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide any comments you have (max. 500 characters):

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?

- Strongly agree
- X Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide any comments you have (max. 500 characters):

Where complaints or incidents have occurred relating to information or data sharing etc , it is also useful to review these to try and understand where work around transparency might have reduced these occurring. There are opportunities for shared learning across HSC organisations.

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?

- Strongly agree
- X Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please provide any comments you have (max. 500 characters):

would be good to have examples of this and how the impact was measured.

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?

- X Strongly agree
 Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

Please provide any comments you have (max. 500 characters):

the checklist is a useful tool to be included in a DPIA - it would probably need to be more practical for use by HSC staff and written in such a way that would be easier to understand and complete.

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.

No mention of audits or national registries eg Cancer Registry – much data sharing is carried out in these projects would be good to reference these.

Who is the guidance for p 4 - much wider audience than detailed - should include staff who are involved in new health & care initiatives.

P13 mention of opt out policies perhaps should mention situation in other jurisdictions eg Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 - opt out doesn't exist at the moment.

P13 Example used – Just to note that in Northern Ireland, there is a statutory obligation on public authorities to promote equality of opportunity between: people of different religious belief, political opinion, racial group, age, marital status or sexual orientation. men and women generally. people with a disability and people without. This means that any new or developing service will need to be quality screened for impact against these categories.

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.

There are good examples of patient involvement in the new Encompass project within the H&SC in NI – Belfast ICO will be aware of these and contacts

Section 2: Your views on our summary impact assessment

The following questions are about our impact assessment. Some of the questions may not be relevant to you or your organisation so please skip these as necessary, or as indicated in the descriptions.

We are seeking views on our [impact assessment summary table](#), which was provided as supporting evidence for the consultation. This sets out a high-level overview of the types of impacts that we have considered.

We will consider the proportionality of further assessment of the impacts as we move towards final publication of the guidance.

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?

- Strongly agree
X Agree
 Neither agree nor disagree
 Disagree
 Strongly disagree

If you answered disagree, strongly disagree or unsure/don't know, please provide further examples of affected groups or impacts we may have missed or require further consideration. (max. 500 characters)

14. Can you provide us with any further evidence for us to consider in our impact assessment?

- Yes
X No

If you answered Yes, please could you provide the impact evidence or a link to it in the box below, or contact details where we can reach you to discuss further. (max. 500 characters)

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

16. Are you acting on behalf of an organisation?

Yes

No

Section 3: About you and your organisation

To further assist our consultation process, it would be useful to know some details about you. Your information will be processed in accordance with our [privacy notice](#).

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

An organisation or person processing health data (**and social care data**)

A representative of a professional, industry or trade association

An organisation representing the interests of patients in health settings (eg GP practice, hospital trust)

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

A trade union

An academic

Other (please specify):

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

Belfast Health & Social Care Trust

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

- 0 to 9 members of staff
- 10 to 249 members of staff
- 250 to 499 members of staff
- X 500 or more 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)?

350,000

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

SIRO, PDG, Directors

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
- X Data protection is a major feature but only in specific circumstances
- Data protection is a relatively minor feature in decision making
- Data protection does not feature in decision making
- Unsure / don't know

23. Do you think the guidance set out in this document presents additional:

- cost(s) or burden(s) to your organisation
- benefit(s) to your organisation
- X both
- neither
- unsure / don't know

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

There is much to consider within the guidance and in such a large organisation there are always service changes and developments, upgrades and system implementations that could impact on transparency and privacy. Need for education for staff, considerations within DPIAs, IG staff to evaluate proposals in this area etc.

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

Difficult to estimate would need to consider so many different areas.

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

Section 4: Any other comments

This section is for any other comments on our guidance or impact assessment that have not been covered elsewhere.

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