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- Section 1: Your views on the draft guidance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? *

✓ 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Section 1: Your views on the draft guidance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):

A companion guidance piece aimed at the data subject (patient, service user) would also be very beneficial as it would set out clearly from the ICO what they should/might expect from those using or asking for their data, and how they can assure themselves that their data is being used legally/appropriately and in a trustworthy way.

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):

Where readers are signposted to 'further reading' for example "National Data Guardian guidance - What do we mean by public benefit?" it would be useful to also include key information from the reading, in this example the definition:

"Public benefit means that there should be some 'net good' accruing to the public; it has both a benefit aspect and a public aspect. The benefit aspect requires the achievement of good, not outweighed by any associated risk. Good is interpreted in a broad and flexible manner and can be direct, indirect, immediate or long-term. Benefit needs to be identifiable, even if it cannot be immediately quantified or measured. The public aspect requires demonstrable benefit to accrue to the public, or a section of the public."

There is a balance needed between being clear but succinct in this guidance and expecting the reader to navigate backwards and forwards between other sources.

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):

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):

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):

We find this 'about right' in that neither health nor social care are covered, or given attention to, in a way that is to the detriment of the other. However, overall, the guidance does not read with any great degree of specificity to one or the other or both.

Given that this is a very specific focus on health or social care there is little focus on the cognitive or information processing needs of the data subject (patient, service user). Health and social care are both areas where users of the services will have wide differences in their individual ways of understanding what is being explained to them, and what they are being asked to consent to.

There is no mention or consideration of when/where an individual may not be competent to consent, or where a guardian should be consenting for them.

There is mention within engagement activities, but this is different from the consideration of whether an individual can consent for themselves or for another.

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

✔ Agree

☐ Neither agree nor disagree

☐ Disagree

☐ Strongly disagree

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

"Transparency information: This describes the total range of material you should provide to comply with the transparency principle. However, this also includes additional information that you could provide to people to make your transparency material more effective."

The wording could be made clearer by removing the use of "however" and simply starting the 2nd sentence "This also …"

"However" implies 'but' 'in spite of' 'despite' 'although'. This does not give the same sense as the definitions used, where 'could' is complementary/additional to 'should' and 'must'.

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?

☐ Strongly agree

✔ Agree

☐ Neither agree nor disagree

☐ Disagree

☐ Strongly disagree

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

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?

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

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

 The section is very useful and lays out the foundation of why improving transparency and trust is so important.

However, more could be done in the guidance to consider bias and the implications for creating trust. For example, when and where the health or social care organisation should be open about their considerations of bias arising, mitigating bias, and challenging bias in the context of analysis and interpretation of the data that is being provided. In particular, but not limited to, bias introduced within the AI or software systems being used and the due diligence that organisations should/could do in selecting AI or software systems.

Mistrust can be built/exist where data is used by AI/software to profile and predict and where, in turn, this is perceived as having significant negative outcomes for individuals in a profiled group. This can be particularly true where health data or health data analysis outcomes are share with commercial organisations (for example insurers).

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

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

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
- [✓] Agree
- [ ] Neither agree nor disagree
- [ ] Disagree
- [ ] Strongly disagree

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

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
- [✓] Agree
- [ ] Neither agree nor disagree
- [ ] Disagree
- [ ] Strongly disagree

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

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.

This has already been covered in previous comments above.

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.

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

✔ 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

✗ 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
- ✔ 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):

Chartered Institute of Library and Information Professionals (CILIP)

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
- ☐ 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)?

Not applicable

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

1. CILIP members working in health and social care settings
usually in the following roles supporting staff, patients and the wider public:
Librarians
Library and Knowledge Service managers
Information Scientists and Information Managers
Informaticians
Knowledge Managers
KM facilitators and advisors
(note that there is a wide variety in actual job titles used in these roles)

2. CILIP staff supporting professional development and research, directly or indirectly, to members working in health and social care settings

3. CILIP members advancing the fields of literacies
(information literacy, digital literacy, health literacy etc) and developing best practice

4. CILIP members working in the public sector/public library service supporting
patients and carers in their information literacy, digital literacy, health literacy needs

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

☐ 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

☐ both

☐ neither

☐ unsure / don't know

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

CILIP's definition of information literacy "Information literacy is the ability to think critically and make balanced judgements about any information we find and use. It empowers us as citizens to reach and express informed views and to engage fully with society." already has application and usage in the health and social care context, where it is also known as health literacy and includes informed choices and informed dialogue, see
https://infolit.org.uk/ILdefinitionCILIP2018.pdf

Additionally, our members work within an ethical framework that includes the specific principles of

- The confidentiality of information provided by clients or users and the right of all individuals to privacy
- The development of information skills and information literacy

see https://www.cilip.org.uk/page/ethics

The benefit that will be derived from this guidance is the clarity and amplification this gives to the need for health literacy, transparency, data rights, data protection and informed decision making in the specific area of patient/service user data.

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

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?

We would like to include a response directly from our Health Libraries Special Interest Group (HLG):

"Health Libraries Group (HLG) support the ICO proposal to improve transparency in health and social care information.

The CILIP Health Libraries Group consists of librarians and information professionals from across the health sector, including the NHS, the voluntary sector and commercial organisations. HLG members therefore work both with staff in health and social care and with members of the public. We see improvement in transparency and data skills as a data literacy issue for both staff and members of the public. Much of what the ICO proposes in the consultation document reflects issues around the wider use of information in

health and social care regarding health and digital literacy and lack of both understanding and access to information. Issues around trust of both the information and lack of knowledge of health systems compounds this. Greater transparency using tools like patient engagement can help bridge some of these gaps and address problems of digital literacy, including the specific data literacy issue, if people understand how their data are being shared. The ICO clearly underlines this with its comments on the potential harms of having low levels of transparency in terms of damage to public health and reduced health outcomes.

HLG also recognises that these guidelines have implications for workload in implementation of greater transparency in a system that is already overloaded, but hope the guidance will help reassure that the benefits are worthwhile."