

## Public consultation on draft Transparency in Health and Social Care guidance

20 December 2023

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This is a summary response from [use MY data](#), produced for the Information Commissioner's Office (ICO) on the contents of the document 'ICO consultation on the draft Transparency in health and social care guidance'.

[use MY data](#) is the only independent UK movement of patients, relatives and carers focused on the use of patient data to save lives and improve outcomes. Our vision is of every patient in the UK willingly giving their data to support medical research and their own care.

Our Mission is to be a Trusted Voice for patients and the public in all discussions and decisions about the use of our data for research and improving healthcare.

This response will be shared with [use MY data](#) Members and published on our website, alongside all of our consultation responses.

### Background to our response

On 13 November, [use MY data](#) received details from the ICO of the public consultation on its draft 'Transparency in Health and Social Care guidance'.

Following a call out by the Secretariat to [use MY data](#) Members, Members submitted their individual responses to the Secretariat, for collation into a single summary response.

As with all [use MY data](#) responses, Members' words reflect a range of views and these views can sometimes be conflicting. The Secretariat views the ability of [use MY data](#) Members to present/represent different patient voices on the use of their patient data, as a strength.

We hope this submission is helpful and would welcome following up further, as needed.

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## Section 1: Your views on the draft guidance

**Question 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?**

Responses from Members: **Agree.**

Comments:

“I consider that this is a good document for people within relevant organisations but it is probably too complex for ‘individuals’ in terms of the general public. There are some very helpful examples. A summary designed for the public might be useful.”

“Yes, the guidance is very clear, but could perhaps be more concise.”

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

Responses from Members: **Agree.**

Comments:

“From this, I assume that transparency is the information about privacy in the particular situation?”

“Yes, the definition of transparency and privacy information is very clear.”

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

Responses from Members: **Yes.**

**Question 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?**

Responses from Members: **Neither Agreed nor Disagreed.**

Comments:

“I don’t know what the existing guidance is.”

“I don’t have sufficient knowledge to answer this.”

At this point, we would like to highlight use MY data’s **Transparency Principles**, which were written by Members.

**Our guiding principles for transparency**

Transparency should underpin everything and is essential if the trust and support of patients and the public is to be maintained and developed. Transparency means operating in such a way that it is easy for others to see what actions are performed. In a nutshell - Say what you do, do what you say.

Our guiding principles for transparency:

- Accessible - easy access to information
- Understandable - the right language for the audience
- Relevant - addresses audience concerns
- Useable - in a form that meets the audience needs
- Assessable - is checkable/provides sufficient detail
- Being as pro-active with ‘bad news’ as with ‘good news’
- Being timely with communication

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

Responses from Members: **About right.**

Comments:

“There does not seem to be much distinction between health and social care which, in my opinion, is as it should be. I do not see any reason why individuals receiving social care should have any less rights to privacy and transparency than the general population receiving health care, unless there is an individual case for this.”

“Yes, proportionate balance.”

**Question 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?**

Responses from Members: **Strongly agree.**

Comments:

"I consider that 'should' is too often used in official documents as a polite form of 'must', and this is confusing and unhelpful."

"This is common sense."

**Question 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?**

Responses from Members: for this question divergent responses were received, which were **Neither agree nor disagree** and **Strongly agree.**

Comments:

"Both of these terms may refer to explanations which do not intend to deceive, although they may not give full information which is understood by the recipient."

"Yes, this has been very well thought out."

**Question 7. Do you agree with the section on harms is useful for organisations when considering the risks of failing to provide sufficient transparency material?**

Responses from Members: for this question divergent responses were received, which were **Disagree** and **Strongly agree.**

Comments:

"The text does not seem to clearly explain the wider categories of harm, which seem to me to be:

- Lack of explanation to public individuals which results in loss of trust and hence allows the use of their data for the public good, i.e. not opting out
- Effective privacy of all individuals' data. The difficulty with this includes the risk of indirect identification, as well as security regarding access to 'standard' identification data."

"In my opinion, an important source of individuals' data is the data collected during research projects. Unlike 'big' data from primary and secondary sources, this usually requires an 'opt in' rather than an 'opt out', even where the legal justification is 'in the public interest' rather than 'consent', so this may be more affected by lack of transparency, and also by public lethargy (i.e. 'cannot be bothered to opt out')."

"Transparency rarely details 'your health data' and is usually implied by 'access to your medical records'. For research studies, this could be made transparent by providing a 'case report form (CRF)' which details the particular data fields accessed."

“However, another potential route for loss of privacy is if patient/participant data is then linked to other data sourced.”

“Yes, useful in a very grounded way.”

**Question 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?**

Responses from Members: for this question divergent responses were received, which were **Disagree** and **Strongly agree**.

Comments:

“Public engagement groups can only be a small sample of the population and they are likely to be the ‘interested public’ and so are unlikely to be representative. This may minimise their representation of the public and also may have limited effect on the number of opt-outs.”

“They may not represent or influence the people who do opt out. More research into the detailed reasons for opting out could be useful.”

“Strongly agree.”

“Yes, transparency is a significant public concern across the board.”

**Question 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?**

Responses from Members: for this question responses were supportive, being either **Agree** and **Strongly agree**.

Comments:

“I agree that this is clearly described, but I am not convinced that it is likely to be effective in changing public attitudes.”

“The patient engagement described seems to relate more to research situations than to the general choice to opt out.”

“Communicating with the audience is only likely to be effective if the audience read (or listen) to the communication. There is no description of how this conversation will be initiated. It also seems to assume that health care professionals will have the time and the inclination to do this.”

“Yes, this is a very good section.”

**Question 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?**

Responses from Members: for this question divergent responses were received, which were **Neither agree nor disagree** and **Strongly agree**.

Comments:

“I have no way of determining how useful or effective it would be.”

“Yes, it is a very efficient summary.”

**Question 11. Have you identified any aspects of the guidance that you feel are inaccurate or any areas we have missed or not covered sufficiently?**

Comments:

“How to approach patients who have already decided that they want to opt out, or who have decided that they do not want to participate in research.”

**Question 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?**

Comments:

“Perhaps discuss these issues with research nurses, who may share experience of starting the discussion about data privacy issues, particularly with reluctant patients/participants.”

## 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.

**Question 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?**

Responses from Members: for this question divergent responses were received, which were **Neither agree nor disagree** and **Strongly agree**.

Comments:

“Potential research participants are a category of affected groups.”

“Yes, the degree and extent of coverage is very good.”

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

Comments:

“No, but I am interested to see any evidence on the success rate of persuasion on various participant or patient groups.”

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

Comments:

None provided.

## Section 4: Any other comments

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

Additional comments from Members are recorded below.

“I thought this was a necessary document but by no means a sufficient or helpful document.”

“My perception was that it was written as a ‘make sure our backside is covered’ document by the ICO so that they can demonstrate that they have told health and social care organisations the rules and if something goes wrong, they can claim ‘it’s not our fault gov. We told them the rules, but the health and social care organisation failed to take notice of the rules’. If that really is its purpose, then it meets the needs even if it is a bit impenetrable.”

“However, for it to be helpful in practice it probably needs NHSE [NHS England] to write a lengthier document building on it, which helps with how to implement the rules describing good practice/lessons learnt etc.”

“My overall reaction - not worth spending a lot of time on it. Hence my brief response.”

“The definitions all are clean and understandable with good illustrations.”

“I found the document rather long-winded and am not sure it is really necessary because, nowadays, everyone is fully aware of the need for transparency, privacy etc so I don’t really see why they have spent time stressing what all good practitioners already know.”

“So, if they just want to make sure everyone knows what they would already know, then they have done that, but it seems to be retreading old ground, and so was it really worth spending time on it?”



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focused on the use of patient data to save lives and improve outcomes**

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## **Our Vision**

Every patient in the UK willingly giving their data to support medical research and their own care.

## **Our Mission**

To be a Trusted Voice for patients and the public in all discussions and decisions about the use of our data for research and improving healthcare.

## **Our Aims**

- To promote the responsible and accountable use of our data to improve health and health research, and to help to remove barriers to preventing this.
- To highlight the benefits of using patient data for our individual health and for our communities.
- To help ensure patient data is used to create and support an NHS that is better for all.
- To advocate robust and transparent safeguarding of data, which is clearly communicated to patients and the public.
- To provide balance as a trusted voice in patient data, highlighting aspirations and concerns about the use of patient data.
- To act as a critical friend and sounding board to organisations who want to collect, store and use patient data to benefit society.
- To build knowledge and expertise for patients, family and carers to help them play a more active and informed role in discussions and decisions about patient data.

**"use MY data to help others and help me"**

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