

**Consultation response:**

**ICO draft guidance**

***Transparency in health and  
social care***

*Submitted 4 January 2024*

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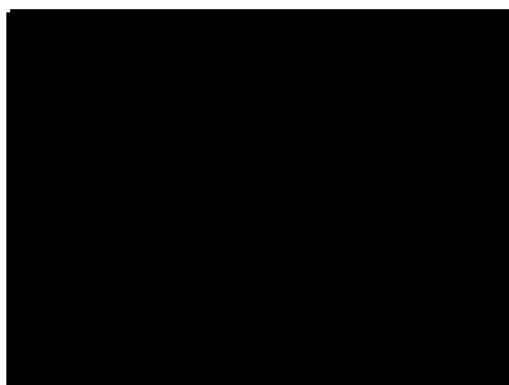
# 1. Introduction

This is the National Data Guardian response to the ICO's consultation on its much-welcomed draft guidance: Transparency in health and social care.

Our response is divided into two parts:

1. Our survey response: answering the quantitative and qualitative questions you posed related to the guidance.
2. A detailed line-by-line review of the guidance itself, in which we make comments in the margin and sometimes suggest changes and alternative wording in the body copy. For this reason, please review this document with track changes 'all mark-up' enabled.

If you have any questions about the contents of this response, please contact:



## 2. Survey response



### Consultation on the draft Transparency in Health and Social Care guidance

**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):

Whilst the importance of being transparent about the uses of health and social care data is generally understood in the healthcare sector, views about how this might be achieved and the resources which should be allocated to achieving this vary, resulting in inconsistency as to what constitutes 'good enough' transparency in practice. This guidance could, therefore, be very helpful in standardising good practice regarding transparency of the use of health and social care data.

However, we feel that a drawback of this guidance, as currently drafted, is that good practice is only set out at a high, general principle level. Our view is that the importance of these principles is largely understood in the health and social care context; what the sector needs is more granular guidance about how these principles might be achieved in practice. To this end, we feel that there could be a greater use of case studies to demonstrate good practice.

The main strengths of this guidance are the *How do we develop transparency materials* and *How do we provide transparency materials* sections. These do provide some specific and

practical advice regarding how to meet data protection privacy and transparency requirements. They begin to clarify expectations and responsibilities relating to the implementation of the transparency principle. Developing these sections further would help organisations to successfully meet those responsibilities. Although the guidance explains how patient involvement can be beneficial, it lacks any practical, process-oriented, or best-practice information on how to achieve it (Please see more about our views on this in response to question 8).

There are a number of issues relating to the scope of the guidance that significantly affect its clarity. These scope issues go to the heart of determining what is appropriate in terms of a particular organisation's transparency responsibilities, so we think these need to be clarified at the start. In particular, the scope of the guidance needs to be clearer in relation to the following issues:

1. The guidance is written for health and social care organisations. However, the use of health and social care information occurs in a much wider range of organisations. What are the responsibilities of those organisations?
2. Does transparency carry an expectation of creating only awareness, or does it entail enabling understanding? We would suggest good practice transparency needs to be sufficiently meaningful to serve the more ethical purpose of the latter.
3. Clearly define that this work relates only to secondary uses of health and social care data (and perhaps some novel third-party-provided electronic patient record systems)

Below, we explain why it is important to be clear on the scope of the guidance in relation to these three issues:

### **1. For which organisations is this guidance intended?**

This guidance is explicitly written *to help health and social care organisations understand our expectations about transparency.*

By only incorporating organisations that provide health and social care and collect personal data in this context, you create a very narrow focus in the context of secondary use of health and social care data: one which risks unfairly placing responsibility for transparency solely on health and social care organisations. You must factor in that many secondary uses of health and social care data occur *outside* of organisations that provide health and social care. This is particularly true in the research context.

Currently, the guidance seems to put the responsibility for complying with the transparency principle solely on the health and social care organisations that collected the personal data, even where the secondary use is by a third-party. This is an inappropriate allocation of responsibility.

Where a health or social care organisation gives a third-party organisation access to information it holds, the health and social care organisation's ongoing responsibility will depend on the nature of that relationship. Where the third-party has been engaged as a data processor for the health and social care organisation's purposes, then placing ongoing responsibility on the health and social care organisation for transparency may be appropriate. However, if the third-party is accessing information for its own purposes, it is not appropriate to place onerous responsibilities on the health and care organisation to meet transparency requirements relating to how the third-party is using the information it provided.

The guidance needs to make clear that whilst health and care organisations have an obligation to be transparent about their processes for making decisions about data access and provide a mechanism for people to see who has had access, the responsibility for being transparent about the ongoing use of the information collected by the health and social care organisation (and the outcomes) lies with the receiving organisation.

We would suggest, therefore, that consideration be given to focusing the responsibilities in this guidance on those *using* health and social care information, as opposed to solely health and social care organisations.

## **2. Terminology: *awareness or understanding?***

The guidance uses the terms awareness and understanding interchangeably (we have highlighted this throughout the document). We think it is important to be clear about whether the aim of the principle of transparency is to create awareness or understanding.

Creating awareness alone is a significantly lower responsibility than creating understanding, and by itself would not, to our reading, fulfil the injunction in the introduction that uses of personal information must be clearly explained.

Furthermore, creating awareness without creating understanding can be problematic because when people are aware of the processing of personal data but have not been given sufficient information to understand it and see why it might be beneficial, safe and trustworthy, this sets the scene for misinformation to creep in.

GDPR is an example of this. Many people had some awareness of the plans to create a central collection of GP data, but they had not been given enough information to understand the need for it, the benefits of it and the safeguards of the collection. Thus, people were susceptible to the misinformation that was circulating on social media at that time. For some people, and in some uncontentious circumstances, creating awareness may be sufficient.

However, it should be incumbent on organisations to provide deeper levels of information, other than simply awareness-raising materials. This will allow the people who do want to

understand how and why data is used, the benefits it brings, and the risks and safeguards protecting it, to access sufficient information to enable that understanding.

### **3. Should the guidance be confined to secondary uses?**

It is not clear whether the guidance is confined to secondary uses, or whether it covers some aspects of direct care.

In the *Who is this guidance for* section the guidance notes that *large amounts of personal information are being developed to support both direct care and secondary care purposes*. In addition, this section states that it is aimed at 'staff 'amongst others'.

We are concerned this casts the guidance too wide and potentially creates unnecessary burdens regarding the transparency of direct care uses of personal data. This may, in turn, place overly burdensome transparency activities on frontline staff.

We know that people who present for care want their information to be shared appropriately for their care, and they don't need detailed transparency information about this. It is the position of the NDG that people who present for care expect their information to be shared for the purposes of their care. We said this in the Information Governance Review:

*Most people who use health and social care services accept and expect that doctors, nurses and other professionals will need to share personal confidential data if they are going to provide optimum care. People get frustrated if they have to answer the same questions repeatedly as they move along a care pathway.*

It is appropriate, meanwhile, for organisations to provide high-level information in their privacy notices about who provides the electronic patient record and how this functions to enable health professionals to provide care.

## **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 guidance sets out a distinction which is clear at a high level. However, it does not then link to the sections of the GDPR and existing guidance that might help the reader make more sense of the distinction between privacy and transparency information.

For example, it could provide a link to Articles 13 and 14 alongside the existing guidance on the *right to be informed* so those creating privacy information can see what is required as a legal minimum. A link to the content of Articles 13 and 14 would also make the distinction between required privacy information and good practice transparency information clearer.

One element of the distinction that is not clear relates to responsibilities about how people are provided with the two types of information. In some ways, this is one of the crucial distinctions between privacy information and transparency information. Often, the legal minimum *right to be informed* information required in Articles 13 and 14 is contained in privacy notices. Whereas the information which should be provided as good practice transparency is expected to be delivered in more public facing, plain English material.

With this distinction in mind, this section could address how the transparency principle in Article 12 of GDPR applies in the context of the privacy information/transparency information distinction. As it applies to the provision of information under Articles 13 and 14, it seems to require more effort to achieve the communication of the privacy information (as defined here) than putting that information in privacy notices.

**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):

Yes, this distinction makes sense. As set out above, this approach highlights that there is a legal distinction between the minimum privacy information that organisations are required



to provide under the right to be informed (in Articles 13 and 14) and the requirement to be transparent about the processing of personal data, which is a wider ethical responsibility that sits at the heart of earning public trust in the use of sensitive personal data.

**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):

This guidance is a welcome addition to existing guidance.

Its focus on transparency information, in addition to privacy information, gives more granular advice on how to meet the distinct responsibilities under the legal *right to be informed* and the ethical need to be transparent about how people's health information is used outside their care.

Alongside making this distinction clear, this guidance adds value by providing practical advice about good practice for involving people in the uses of health and social care information and improving communication with the public about those uses.

As explained above, the most useful parts of the guidance are the *How do we develop transparency materials* and *How do we provide transparency materials* sections, as these provide specific and practical advice on how to meet data protection privacy and transparency requirements.

Although organisations understand these principles and the need to comply with them at a high level, they are often unclear about how much resource should be allocated to this kind of activity and what 'good looks like' in terms of what they should be seeking to achieve. Given this, clear advice about practical requirements and examples of good practice will help

organisation to understand their responsibilities. As we expand on in response to question 8, we think the practical advice given in this guidance would be more developed.

**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):

This question is framed in a way which is problematic in the context of how health and social care works or needs to work in future. Given we do not think this is an appropriate question for a health and social care system that should provide seamless care to patients, we have not provided a 'tick box' response to the qualitative question in this section.

As far as information about patients is concerned, healthcare and social care organisations should not be expected to function with separate rules and standards. Patient care suffers when social care is not seen as part of the health and care system. Inappropriate barriers are put in place that prevent access to information and negatively impact care. Whilst there might be digital differences between these areas, this does not seem to be the focus of the distinction in this guidance.

In the *Who is this guidance for* section, there is a potentially damaging distinction made between health and social care. Included in *Examples of activities where this detailed guidance may be useful is: setting up a new system that shares hospital discharge data with social care providers*. Making this distinction between the transparency requirements when patients are discharged to social care (as opposed to discharged to health care) could create barriers to sharing discharge information with the social care services caring for people after their discharge. We have heard direct evidence from social care providers about how this puts patients at risk. We do not think there should be different transparency requirements relating to systems sharing discharge data with organisations that are providing ongoing healthcare and those providing ongoing social care.

To ensure that inappropriate distinctions like this are not made in this guidance, it is important to make sure that social care organisations contribute to this consultation.

**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):

We have made some suggestions regarding slightly clearer wording for these distinctions (you will find these in the margins of our line-by-line review of the guidance in part 3 of this document). Once the terms have been defined more clearly, we are content that they have been used consistently throughout the guidance.

**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):

We **agree** that the definitions you have provided are accurate. However, we want to make the following points.

We think it would be very helpful to provide additional, clarifying information about what providing '*easily accessible and understandable formats*' entails. This is a fundamental point. Communications to the public will fail if they do not recognise and reflect the fact that the average UK reading age is just nine years old. This is essential knowledge that should guide anyone writing for a general audience with varying levels of literacy and comprehension. The NHS website is an example of best practice, demonstrating the best level at which to pitch language so that nearly everyone can understand it.

Without accessible information, there is no transparency. Therefore, providing some degree of instruction about how to achieve it is essential. Providing the following practical, good practice information in a highlighted box (phrased however you see fit) could be a way of incorporating some useful information to improve people's communications materials.

All materials, not just the 'easy read' version, need to:

- use plain English
- speak simply
- use as few words as possible to convey the message
- use short sentences, as people can struggle with multiple clauses
- avoid jargon and acronyms (but using 'the NHS' is okay)
- where there is a simpler way of explaining a complex concept, do so
- only use the 'active' voice, so it's always clear who's doing what
- use bullets for lists
- use subheadings to help people scan and make sense of the copy

There will be lots of established places/resources online the guidance will be able to link to for further information about these things. This one is particularly helpful:  
<https://www.plainenglish.co.uk/how-to-write-in-plain-english.html>

**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):

We think that the section on harms needs to be reconsidered.

Throughout this section, there is unnecessary reaching and misplaced emphasis on the types of harm that can occur when organisations are not transparent about the secondary uses of health and care information.

There is very little chance of bodily harm where organisations are not transparent about their processing of health and social care information for secondary purposes. Indeed, the example used in this section suggests that bodily harm is a risk that relates to failure to provide information about a direct care service (as opposed to failure to provide transparency information about secondary uses of health and care data).

It is also arguable that the potential for psychological harm is overemphasised here. That is not to say that people will not feel rightly annoyed and mistrustful if they feel that organisations are not being transparent about secondary uses of health and care data. However, the focus on individual corporeal and psychological harm here moves the focus away from the significant risks (in terms of likelihood and impact) of real harm where organisations are not transparent: namely, the harms that occur through mistrust, which lead to a number of outcomes that are damaging to patients and society more widely.

Firstly, mistrust in organisations, because they are not transparent about the uses of health and care data, can lead to increases in national data opt-outs and type one opt-outs.

This has an impact on the health and care system's ability to appropriately plan healthcare services for the public and may make medical research less robust and relevant to the population it seeks to study and ultimately benefit. This can lead to harm that is felt by particular groups of society who opt out more than others because planning decisions are made and research is conducted without representative data for these groups.

We have also seen that society can be harmed when beneficial health and care data related programmes are derailed because of a lack of public trust in them caused by insufficient transparency. We saw this in the public backlash to the GDPR programme. This was a largely beneficial programme, seeking to provide a superior way of working to the current

situation, but it was thwarted because a lack of transparency allowed misinformation to proliferate, which generated significant public mistrust.

Secondly, harm might be caused to individuals and society as a whole if people come to mistrust the ability of health and social care organisations to safeguard their information and only use it appropriately. This mistrust risks people refraining from using services or being less frank with health and care professionals when they do, to the detriment of their own and potentially others' health.

Ensuring that organisations have good practice transparency embedded in their programmes and processes will enable the public to perceive these organisations as trustworthy. Preserving this trust so that people are confident to use health and care services and provide professionals with the full and accurate information they need to care for them properly is important to protect public and individual health.

Making sure that these important harms are avoided should be the focus of the harms section in this guidance, the utility of which is currently diluted by portraying harms that we do not think are caused by a lack of transparency around secondary uses of health and care information.

**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):

We **disagree**.

We think the 'How do we engage with patient and service users?' section could be greatly improved by providing more practical information to help people successfully deliver their transparency and privacy projects.

- Although the guidance explains how patient involvement can be beneficial, it lacks any practical, process-oriented, or best-practice information on how to achieve it.

For example, it says:

*"The process usually consists of working with groups that are representative of the different communities an organisation serves."*

This feels self-evident. The difficult and daunting part that people will struggle with is understanding how to assemble these groups to ensure proper representation; we feel that this is where granular guidance and examples/case studies would be helpful.

- Also, we believe that this section should be renamed:

**'How can we involve patients and service users?'**

Public involvement and public engagement are two related but distinct activities and we think that what this section of the guidance describes is involvement: research or co-design involving the public in the production of transparency materials to improve their effectiveness. In other words, 'involvement' activity is a tool for designing effective, patient-centric transparency materials for use in subsequent communications and engagement activities.

- Also, when discussing this, it would be sensible to use the terminology typically used by the NHS when describing this activity: **patient and public involvement (PPI)**. This terminology change also needs to be applied to the checklist at the end, which talks about patient engagement (when we think you mean involvement).

**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):

We **disagree** that this sets out clearly enough what organisations need to do.

We think this section needs significant work. The same point we made in our response to question 8 also applies here: this section would benefit from practical guidance and examples to help readers understand the steps they need to take to successfully deliver their transparency and privacy information.

- This part of the guidance contains high-level suggestions and advice that we think are obvious and self-evident and therefore of limited help. We think that people who refer to this guidance will be looking for lower-level and more specific information: a more practical, actionable, and process-oriented approach that provides information on how to implement the recommendations/suggestions. It would also be useful to include real-life scenarios and examples to help illustrate these points.

For example, under *'What are the most effective ways of communicating with your audience,'* you don't list any effective ways of communicating with the audience. You only say that people need to decide what the most effective methods are. We would assert that the reader already appreciates they need to do this – and what they are hoping for from the guidance is a lower level of practical detail about how they could go about this. We suggest it may be helpful to carry out more user research, and perhaps draft some personas, to gain insight into what those turning to your guidance need/expect from it. This, in turn, will reveal the type and amount of information required. For example, some people may be approaching this guidance in order to complete the following task: 'I don't know who my audiences are, and I need help working this out. What should I do? What techniques are available to me? How do others do this?'

- Under *'how do we provide transparency and privacy information,'* you say that providing transparency materials is a *'prime opportunity for you to provide as much information as possible'*. This is the wrong approach: 'As much information as possible' could lead to information overload and the dilution/obscuring of key messages. People don't need as much information as possible. People need the appropriate amount of information, in the right format, distributed through the right channels, at the right time. It is important this this approach is consistent throughout.
- More information (including a case study if possible) would provide a helpful steer in relation to your recommendation that organisations should make efforts to inform/notify people when privacy notices/info change. Informing service users of a privacy notice change (over and above just publishing information on the website) could leave people



at a loss about the best channels/methods of doing this, so the action they take doesn't feel excessive in relation to a topic most people would not expect/care to receive direct communications about. Can you suggest what others have done/usually do?

**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):

We **agree** that the transparency checklist is a useful summary and a good tool for keeping communications projects focused.

- However, currently, this section includes two lists: 1) the bulleted points of questions and 2) the list of 'musts' and 'shoulds' in the highlighted box. Might it be an idea to rephrase the bullets and merge the two, helpfully categorising the five bulleted points as either 'musts' or 'shoulds'? This may help to improve focus and keep all tasks/considerations grouped together.

- You say: "*We have employed public engagement processes to develop and refine our transparency material.*"

This could be better phrased as:

"We have involved the public in the development of our transparency material."

- The checklist says, '*We have considered...*' against numerous tasks.

We would suggest that consideration is perhaps not a detailed or involved enough word to describe the type of action required. What does consideration entail? A more descriptive, relevant verb would be helpful. For example, instead of 'we have considered the most effective means to communicate our transparency information to people...'

You could say: 'We have researched the most effective means...'

With communications planning, all decisions should be based on evidence and best practice; this involves research and analysis, which then reveals the most appropriate course of action. 'Consideration' requires a lot less commitment or effort; it could amount to nothing more than the momentary reflection of one person with little to no communications expertise making decisions motivated by their own views (rather than supported by evidence and analysis).

**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.**

All feedback has been incorporated into earlier responses and our line-by-line review of the draft guidance document.

**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)

We **agree** with the ICO's problem definition in the impact assessment.

We think the focus on societal harm in that assessment is appropriate. We think this focus on societal harm should be drawn throughout the impact assessment because we feel that it is here where this guidance could have a significant impact if it is able to improve transparency where health and social care information is used for secondary purposes.

It is important not to overemphasise the focus on bodily and psychological harms. This is because the guidance does not provide evidence of lack of transparency as a cause of such harm. Therefore, it is not easy to determine if the guidance can effectively address a harm that it has not evidenced.

The cost-benefit analysis section of the impact assessment needs significant work to be an accurate reflection of the resources required (in terms of time, cost and effort) by the health and social care sector to meet the guidance's transparency principle requirements. However,

it is important to recognise this and highlight it in this piece. One of the problems with GDPR was the lack of resources allocated to transparency throughout the project.

If this guidance seeks to create practical guidance about involving patients and engaging them to enhance transparency this should be recognised in the health and social care sector of the impact statement, so that organisations can see they will need to allocate resources to comply with this guidance.

There are some costs associated with this guidance as currently written that we think should not be placed on the health and social care system. These are not currently detailed in the impact assessment (we think they are unintended). The first is that the guidance could, in parts, be interpreted as applying to transparency about direct care uses of health and care information (as we set out in our response to question 1). This could have a negative impact on frontline health and care staff, who may feel less confident to share information for care where they think the transparency principles set out in this piece are not followed. This will, in turn, have a negative impact on patients if extra obstacles are created to sharing information for care. We think the guidance needs to be amended so that it is clear that it does not apply to uses of health and care information for the direct care of individual patients.

As also set out in response to question 1, we think that it needs to be clear that where a health and care organisation allows access to health and care information by a third-party for a use which is for public benefit, it is the accessing organisation that is responsible for providing transparency information about the use of the information. There will be an unfair and overly onerous impact on health and social care organisations if they bear the responsibility for explaining how third parties who have access to health and social care information will use that information. Currently, the 'costs to wider society' box is empty, but we think these concerns would incur costs in that wider society (as well as the health and social care section) if the guidance is not amended to address what we think are unintended consequences.

The NDG public benefit guidance (link below in response to question 14) distinguishes between the responsibilities for the sharing health and social care organisation and the accessing/recipient third-party in the guidance link below. The case studies in that guidance may also be helpful.

**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)

What do we mean by public benefit? Evaluating public benefit when health and adult social care data is used for purposes beyond individual care - GOV.UK (www.gov.uk)

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

No further comments.

**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):**

We are responding as the National Data Guardian for health and social care in England. The National Data Guardian role was established by Government to provide advice and guidance on the safe and appropriate use of confidential health and social care data information.

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

Office of the National Data Guardian.

**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. National Data Guardian
2. Senior privacy specialist
3. Communications and engagement manager
4. Privacy specialist
5. Project manager
6. Head of office

**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?**

Does not present additional costs to the Office of the NDG but this guidance will have both benefits and costs to organisations that use health and social care information. This should be recognised head on so that these additional costs can be factored into business plans.

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

Not applicable.

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

Not applicable.

**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?**

Not in addition to those already stated in the line-by-line review of guidance below.

