

To: Policy Projects team | The Information Commissioner's Office

19 December 2023

Dear ICO Policy Projects team,

Please accept my thanks for sharing your draft guidance on 'Transparency in health and social care'. This is a collated response from teams in the Department of Health and Social Care (DHSC) and NHS England's Joint Digital Policy Unit.

We have considered the guidance document from both a data policy and information governance perspective; our overarching feedback is below. We have also provided more detailed line by line feedback which we have included in an [Appendix](#).

Overall, we found the guidance to be helpful, clearly written, and relevant to the stated topic, aligning with our policy aim of simplifying messaging to the health and care system. It represents a good step forward in providing specific tailored advice for health and care, and simply explaining the consequences of organisations falling short of their transparency obligations.

Scope of the guidance

As it stands, it is unclear whether the guidance applies uniquely to people in health and care organisations, or whether the audience is broader. It would therefore be helpful if the guidance could clarify whether the scope includes or excludes other organisations who process health and care information and who also have requirements to be transparent about this e.g.:

- universities who are processing health data for research;
- suppliers who are processing data to support the health and care system;
- the fire service working with the NHS to provide safe and well checks - for over 65s;
- police who process health and care information to support their investigations;
or
- schools who process health information about their pupils e.g. the school nurse.

Related to this point, the section on working together is helpful. However, given the complexity of how health and care organisations work together, including with organisations from other sectors, it would be helpful to provide further detail or examples. For example, small organisations such as a care home would be overly burdened if the responsibility for preparing transparency materials always rested with

them. An example could be provided of an Integrated Care System (ICS) wide project with the Integrated Care Board (ICB) agreeing to provide consistent transparency materials which the organisations in the ICS could all link to on their respective websites. You could also provide the example of the Health Research Authority's [Transparency information for NHS sites](#) which NHS organisations can link to rather than each developing their own transparency information. This significantly helps with burden and ensures a consistent communication for the public.

Appropriate level of sharing in transparency notices

Whilst providing insignificant information is a problem, sharing too much information can also be a problem. Where the guidance states "This is a prime opportunity for you to provide as much information as possible", there is a risk of health and care organisations interpreting this too literally. Patients and service users will not benefit from transparency materials becoming overly complex with tangential information that they do not need. We feel the guidance should acknowledge that there is a pragmatic approach to transparency which gives patients and service users the information they need, while keeping everything concise and practical.

Inclusion of social care

Additionally, we feel that a few simple changes would make the guidance more inclusive for social care organisations. We have included some specific social-care oriented amendments in the [Appendix](#) which we would strongly recommend, but generally, the examples throughout the guidance are currently predominantly weighted towards health organisations. It would be worth going back over them with an eye to covering situations that might be more common in social care. Of course, we understand it won't be possible in every instance.

Clarifying terminology – "personal information" versus "information"

We would also suggest a small addition at the beginning of the guidance to clarify the meaning of "personal information" with a link to other ICO guidance. This document sometimes uses the specific term "personal information", and at other times opts for the less specific term "information". When it comes to transparency obligations, we are always going to mean "personal information". It might be setting this out in a brief paragraph right at the beginning for the avoidance of doubt.

Related topics

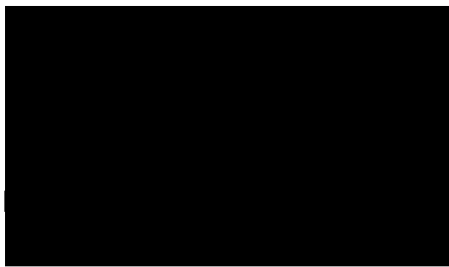
Finally, there are some ways in which the guidance could be expanded to cover other related topics which fall under the "transparency" umbrella. One such topic is Artificial Intelligence, which isn't mentioned in this document, but could be referenced via a short statement and a link to [guidance the ICO has already produced](#) which

includes a section entitled 'How do we ensure transparency in AI?'. This would be helpful given the challenges of ensuring transparency when using AI to process data.

Another topic would be transparency for young people. Young people are unlikely to access information in the same way as adults (for example, having a larger inclination towards social media), so would need specific consideration. In addition, a small number of young people will be competent to make decisions about their healthcare before the age of 13, however they cannot legally access social media until they reach the age of 13.

We hope this feedback is helpful, and we thank you again for sharing the guidance with us for consultation.

Yours faithfully,



Joint DHSC/NHSE Digital Policy Unit

Appendix – detailed feedback

Guidance section	Text passage	Comments
Introduction (PDF p.4)	A lack of transparency can negatively impact levels of trust and lead to poorer outcomes for patients, service users and the public.	It would be useful to provide an example here to explain exactly how the lack of transparency leads to poorer outcomes. For example, increases in opt-outs leading to a poorer quality pool of data for approved researchers and planners to work with.
Introduction (PDF p.4)	“An example of this is the use of Trusted Research Environments (TREs). TREs are secure environments that provide remote access to health information in de-identified states that protect people’s privacy.”	We would suggest amending this to refer to “Secure Data Environments (SDEs)” as it is the more appropriate term in this context.
Introduction / Who is this guidance for? (PDF p.5)	“It is important to involve your DPO in your transparency process.”	Not all health and care organisations have a DPO, for example small care homes. The text could be revised to: “your DPO (or the person with responsibility for data protection in your organisation)” to be more inclusive of smaller health and care organisations.
What is transparency? / What is transparency? (PDF p.8)	“However, there is a lack of public trust in the system, which means the organisation cannot use it.”	The forcefulness of the phrase “cannot use it” suggests there may be some legislative reason why projects must be discontinued if there is a lack of public trust, which isn’t the case. We would suggest reframing the example here to make it more about positive engagement: “However, there is a lack of public trust in the system, which means the organisation needs to be transparent and work with the public to address their concerns before they can use it. ”
What is transparency? / Why is transparency in health and social care so important? (PDF p.9)	“If it is not clear what you will actually do with their personal information in practical terms, and the potential impact, then it is likely they will be reluctant to	This claim makes sense intuitively. However, is there any public engagement or qualitative engagement piece which has been conducted which shows that the public are more likely to share their information after receiving practical information about the proposed secondary use? If so, it would be worth referencing.

	agree to you sharing their information”	
What is transparency? / Why is transparency in health and social care so important? (PDF p.10)	“setting the agenda for public discussions to inform expectations (eg Do we sell information? What is the impact of third-party commercial organisations accessing information in this way?)”	This has the unintended consequence of making it seem like it’s a possibility that health and care organisations would sell people’s information. It would be better to replace these sentences with different examples, e.g. “... what safeguards do we have in place to ensure your information is not used for other purposes? ”
What is transparency? / Why is transparency in health and social care so important? (PDF p.10)	“ Further reading ”	We feel the recent <u>publication on transparency</u> from Understanding Patient Data should be added to the further reading list as a useful resource for explaining data use in more general terms to the public.
How do we develop transparency information? / How can we demonstrate that we are open and honest? (PDF p.12)	transparency material (including relevant updates) prompted by requests you may already be receiving from people	It would be useful to give some examples of what exactly ‘transparency material’ means in the context of this list. We realise ‘transparency information’ is defined on the way into this section, but it is hard to identify what separates transparency material from other items in the list such as “additional information”, “clarity on design decisions”, “alternative forms of transparency information”, “accountability information” etc.
How do we develop transparency information? / How can we demonstrate that we are open and honest? (PDF p.12)	“(ie which research studies used the data...”	Another bullet point could be added to this list referencing patient portals: <ul style="list-style-type: none"> • patient portals which allow patients to access their own data This could be integrated into the bullet above (i.e. “improved information access tools...”) if they’re talking about the same thing.
How do we develop transparency information? / How can we demonstrate that we are open and honest? (PDF p.12)	“However, there may be circumstances where you need to consider the separate Common Law Duty of Confidentiality and its associated concepts of ‘implied’ and ‘explicit’ consent.”	The Common Law Duty of Confidentiality applies to all uses of identifiable health and care information, not just a narrow selection of circumstances. We would suggest revising the sentence to: “However, for all uses of identifiable health and care information, you need to consider the separate Common Law Duty of Confidentiality... ”

		It may also be worth briefly acknowledging exemptions to the Common Law Duty of Confidentiality where consent is not sought from the data subject, e.g. when there is a statutory basis or legal duty to disclose, e.g. by court order.
How do we develop transparency information? / How should we reflect choice? (PDF p.13)	“Further reading”	If appropriate, the Health & Care IG Panel’s guidance on ‘ <u>Consent and confidential patient information</u> ’ could be added to the list of references here. We worked on this guidance with the ICO as one of our key stakeholders.
How do we develop transparency information? / How do we identify transparency harms (PDF p.13)	“Psychological harms - when people do not understand the intended use of their health and social care information, this can result in fear, anxiety and embarrassment”	“Fear”, “anxiety” and “embarrassment” seem overstated for the problem being described, particularly as no concrete example is given of a lack of transparency situation that might lead someone to be genuinely fearful. It may be better to stick to something more widely acknowledged in health and care such as: “Mistrust - when people do not understand the intended use of their health and social care information, this can result in anxiety and a loss of trust.”
How do we develop transparency information? / How do we identify transparency harms (PDF p.13)	“Loss of control of personal information - if descriptions of how you use information are overly complex, or difficult to locate, it can deter people from accessing and reviewing them. As a result, people lose control of their information. This lack of certainty can lead to emotional distress”	“Loss of control of personal information” is not an effect of what is being described. The effect of information being overly complex or difficult to navigate would be: “Confusion - if descriptions of how you use information are overly complex, or difficult to locate, it can cause confusion and deter people from reviewing how their information is used. As a result, people lose control of their information. Additionally, “emotional distress” seems overblown to describe the effect of bad transparency information.
How do we develop transparency information? / How do we identify transparency harms (PDF p.13)	“Chilling effects - a lack of transparency around how you use personal information could lead to people stopping using services or reducing their use.”	All of the items in this list could be seen as ‘chilling effects’. We would recommend the third bullet point be changed to “withdrawal from services” as it is more specific.
How do we develop transparency	“if people choose not to share their personal information, this could	Because it only says “choose not to share personal information”, this passage could be interpreted to mean people choosing not to

<p>information? / How do we identify transparency harms (PDF p.13)</p>	<p>lead to a general lack of availability of health and care information”</p>	<p>share information generally, i.e. not telling your doctor your name when going for an appointment. Or it could be more narrow, i.e. opting out of sharing your health information for research. Or it could mean both. Whichever meaning is intended, it should be made clearer, perhaps through the use of examples.</p>
<p>How do we develop transparency information? / How do we identify transparency harms (PDF p.13)</p>	<p>“Also, if people in a particular demographic group choose not to share, this could result in medical findings through research or service planning not being appropriate to that part of society.”</p>	<p>Here it seems like the meaning is secondary purposes rather than any broader meaning. Suggest revising to: “if people in a particular demographic group choose not to share their information for research and planning, this could result in...”</p>
<p>How do we develop transparency information? / How do we provide transparency and privacy information (PDF p.13 - 16)</p>		<p>We have produced a suite of <u>Universal IG templates</u> which were approved by the ICO. These included a template DPIA and Privacy Notice. It would be useful if these could be linked in this guidance as they are directly relevant to the topic and would be helpful for health and care organisations.</p>
<p>How do we develop transparency information? / How do we identify transparency harms (PDF p.14)</p>	<p>“Example A person does not own or have access to a mobile phone [...] They also experience psychological harm in the form of emotional distress from knowing that everyone else is getting the messages, but they are being excluded.”</p>	<p>The example needs to be more specific. Because it is not specific, the jump from the description of an individual not being informed about a public health campaign via text, to them damaging their health and becoming emotionally distressed seems like a very far-fetched scenario. It could perhaps be justified in a circumstance where a viral illness was spreading around an individual’s local area that they were susceptible to, but that picture would need to be more explicitly drawn in the example. We think it would be better to enhance the example or replace it with a different one.</p>
<p>How do we develop transparency information? / What are the most effective ways of communicating with your audience? (PDF p.17)</p>	<p>“What are the most effective ways of communicating with your audience?”</p>	<p>Minor point, but all the other subtitles are framed in terms of “we” – “How do we engage with patients and service users?”, “How do we provide transparency and privacy information?”. This appears to be the only one using second person (“your”).</p>

<p>How do we develop transparency information? / What are the most effective ways of communicating with your audience? (PDF p.17)</p>	<p>You may also decide to use different communication methods depending on your audience.</p>	<p>A few examples of communication methods are mentioned throughout the text e.g. “a letter”, “advert at a bus stop”, but this section of the guidance would be more useful as a resource if it contained a fuller list of specific examples which organisations could choose from. A starter for ten:</p> <ul style="list-style-type: none"> • Posters • Letters • Emails • Texts • Social media campaign • DPIA published (best practice rather than requirement)
<p>How do we provide transparency and privacy information / How should we work together? (PDF p.18)</p>	<p>“Example A GP surgery decides to provide their patients with privacy information about local and national data use programmes and information rights.”</p>	<p>It looks like some text is missing from the one sentence example. As it stands, people can’t learn much from it. We would suggest it be expanded to make it more specific, referencing the concrete ways in which the GP practice could make its privacy information available to different audiences.</p>
<p>How do we assess if we are being transparent? > Transparency checklist (PDF p.20)</p>	<p>“We have involved our DPO in the development of our transparency material.”</p>	<p>Same comment as above with regards to small care homes not having a DPO.</p>

- **Distinction between ‘secondary care’ and ‘secondary uses of data’:** In the context of health services, secondary care is specialist care, often provided within a hospital. Secondary uses of health data are uses of data beyond delivering direct care (such as planning and research purposes). The two terms mean very different things. On page 4 of the guidance (and several instances later on), you refer to ‘secondary care’ when the context suggest you mean ‘secondary uses of data’.
- **Comments relating to specific wording in the draft guidance:** I have set out in the table below some specific feedback regarding particular parts of the guidance:

Page	Wording in draft guidance	Comments
5	<p><i>Although a range of people may be involved in considering and delivering transparency information, it is a data protection issue.</i></p>	<p>This seems like too broad a statement as transparency is not only a data protection issue. It is also potentially a communications and PR issue, an ethics issue, and may also cover other regulatory and legal requirements beyond just data protection.</p>

5	<p><i>A small GP practice updating their privacy notice would not have to consider transparency in the same depth as a hospital trust implementing a new health record system.</i></p>	<p>This example is missing key information about why the GP practice is updating their privacy notice – without that context, it reads as though privacy notices are inherently more important for larger organisations.</p>
8	<p><i>A hospital creates a policy document describing how they make decisions when sharing personal information with research organisations. This is transparency information. It is about sharing personal information, but is not specified as part of the right to be informed.</i></p>	<p>The policy would only be transparency information if published – many policies are not published so we suggest explicitly stating that it is made available to the public.</p>