Comment	Paragraph	Comment
1	Introduction	Do we need to explain that the lack of trust created by not being transparent may lead people not to engage with health and care service or to opt out of the use of their data beyond their care because they don't understand those uses. Perhaps in some cases where transparency is poor, people have some knowledge of what is happening but this has not be properly explained so they are then susceptible to believing misinformation about uses of personal data as happened with GPDPR
2	Introduction	SDEs is the terminology usually used.
3	Introduction	It is really confusing to see this term used in ICO guidance. This terminology does not map across to your own guidance on anonymisation. In that guidance you explain de-identification in this way: What about 'de-identified' personal data? While the term 'de-identified' is widely used, its meaning may differ depending on the circumstances. For the purposes of data protection law, it is important to note that Section 171 of the DPA 2018 refers to 'de-identified personal data' in the context of the re-identification offence. Section 171(1) states: Quote 'It an offence for a person knowingly or recklessly to re-identify information that is de-identified personal data without the consent of the controller responsible for de-identifying the personal data'. Section 171(2)(a) then says: 15 Quote 'personal data is "de-identified" if it has been processed in such a manner that it can no longer be attributed, without more, to a specific data subject.' The DPA 2018's explanatory notes clarify that this provision: Quote '…reflects the definition of pseudonymisation in Article 4(5) of the GDPR.' Therefore, for the purposes of the re-identification offence, the DPA 2018 refers to 'de-identified' personal data as personal data that has undergone pseudonymisation as defined in the UK GDPR rather than (for example) anonymous information. Should this then refer to Pseudonymised data so it has meaning within ICO terminology in corresponding guidance?
4	Introduction	Some uses such as the sharing of personal health information for the purposes of your own care will be self evident, expected and strongly desired and will not need to be subject to the tranpspardcy requiremts in this guidance.

5	Who is this guidance for?	There is a real issue in placing responsibility on frontline clinical staff members to provide transparency information about national and regional programmes about uses of CPI for secondary uses. So where projects that require transparency about uses of personal data are led by the NHS,esponsibility for transparency should not fall to frontline staff - Those leading programmes should also be transparent with staff so they can answer questions and play their part in the process. But responsibility should not be transferred to them. We are seeing attempts to transfer this responsibility form central NHS organisations to local clinical teams in some NHS programmes which process personal data. Given this, this list including staff and DPOs should be more granular and explain what the responsibilities might be at each level.
6	Who is this guidance for?	What about those who use health and social care information collected in these organisations but are not themselves a health and social care organisation. Is there an argument for shifting the focus on this transparency guidance on to health and social care information as opposed to health and social care organisations?
7	Who is this guidance for?	I wonder whether the focus here should be health and social care organisations or those using health and social care data? Or whether there should be a definition of health and social care organisations. Where a research organisation wants to use data collected through health and care, that organisation should have significant responsibilities for ensuring the transparency of the processing of the data it will be allowed to access. If this guidance is just for health and social care organisations, maybe it should cover what health and care organisations can expect from third parties who need access to health and care data.
8	Who is this guidance for?	I don't see this as transparency about uses of health and social care data which is what this guidance is about. This is about properly informing people about a service which is a different issue.

9	Who is this guidance for?	I'm concerned that this example creates distinctions between health and social care organisations that should not exist in the context of the provision of direct care. Wherever a person is discharged to a further service information should be shared to support their ongoing care. We need to make sure social care is not put in a difficult position with regard to access to the data it needs to care for people. We said this in the Information Governance Review: The Review Panel concluded that for direct care of an individual, registered and regulated social workers must also be considered part of the care team and covered by implied consent when the social worker has a legitimate relationship to the individual concerned. The review also noted that the transfer of necessary information for direct care was sometimes poor in the cases of transfers between hospitals and care homes So we would not be keen to separate out discharge to social care for direct care purposes as a situation which required more onerous transparency requirements that sharing discharge data with other health care providers such as the GP. As this is direct care, people will reasonably expect their data to be shared for their care and people could be put at risk of harm if onerous transparency requirements are put in place where the ongoing care provider is a social care organisation.
10	Legislative requirements	We use the word must to describe legislative requirements; these are mandatory activities you must carry out to comply with the law.
11	Good practice	I'm not sure if this is me, but I can't see the difference between this and a legal requirement.
12	Good practice	Perhaps changing the phrasing to something like: We use the word should to describe an action or approach we expect you to take to satisfy a legislative requirement. This action or approach is strongly urged, and you should do this unless there is a good reason not to. If you choose to take a different approach, you must be able to demonstrate that this approach also complies with the law.
13	Good practice	We use the word could to suggest actions and options you might like to consider to help you comply effectively with what is required by law. These suggestions are rooted in good practice and intended to be helpful, but there are likely to be various other ways you could also comply.

14	What is transparency?	Might it be an idea here to ask 'What is the principle of transparency' and then quote Articles 13 and 14 in full, which provide an excellent summary.
15	What is transparency?	Is there a difference between being aware of and understanding. We often talk about creating understanding rather than the lower bar of creating awareness. Awareness without understanding can often be problematic as it sets the scene for misinformation to creep in where people are aware of processing of personal data but have not been given sufficient information to understand it end therefore see why it might be beneficial, safe and trustworthy. GPDPR was a good reflection of this. Many people were aware this collection of GP data was planned and so it was on their radar but they had not been given enough information to understand the need for, the benefits of and the safeguards of the collection. Thus people were susceptible to the misinformation that was circulating on social media at that time.
16	Example	Further to the comment above, I'd say it's more appropriate/accurate to say that a lack of understanding of the system has created a lack of public trust in it. That is the root cause. Typically (as with GPDPR), trust is lost because of a failure to communicate, and information vacuums lead to speculation and misinformation which, in turn, generates that suspicion and lack of public trust. I would suggest the following wording: An organisation wants to deliver a system to patients using pseudonymised data. However, people don't support it because they don't understand it and fear it will make their data less safe. If the organisation were transparent about its aims and the steps it's taking to keep data safe, this may increase public trust and confidence in the system.
17	How does this guidance approach transparency?	Should there be a link to articles 13 and 14 GDPR in this section as this provides very specific information relevant to this guidance.
18	Transparency information	Possibly better to say something more specific/clear like: A hospital creates a policy document that describes the processes it follows and the assessments it makes when determining whether it will share patient data with third-party organisations for medical research.
19	Privacy information	I suggest reordering this and lifting the privacy example above the transparency example to align it with the definitions of privacy and transparency info (which cover privacy information first). It gives a helpful hierarchy.

		Privacy being the 'must', everything else being the 'you really should'!
20	Privacy information	This is too passive, it needs to be made clearer who is sharing the info, along the lines of: A hospital trust publishes on its website a list of third-party organisations it shares patient information with to support the provision of care services.
21	Privacy information	Always helpful to give an example of what these activities might be.
22	Privacy information	Organogram won't be a familiar term to some. I suggest replacing it with the 'old' language: 'organisation chart'.
23	Why is transparency in health and social care so important?	I think something like this is needed here to bridge the point between the two sentences.
24	Why is transparency in health and social care so important?	Is this referring to direct care practitioners, or researchers etc? I'd say something like 'those who need to see it to provide them with care' to be specific about this, if talking about direct care. Keep it broad so it encompasses people beyond clinical practitioners who might need to see that person's information to provide them with care (e.g. person making referrals or doing other essential admin and who may not be a clinician).
25	Why is transparency in health and social care so important?	Just linking to my above point that understanding rather than awareness is the aim of transparency. I think this needs to be more consistent through the document.
26	Why is transparency in health and social care so important?	Does this part need to address the fact that it is not only health and social care organisations that might have responsibilities in relation to transparency where health and care information can be accessed by organisations outside the heath and social care system. The health and care system may need to be transparent about how it makes decisions about whether data can be accessed, but the responsibility for explaining how the date will be used, what for and by who should be the responsibility of the organisation seeking to access the data
27	Why is transparency in health and social care so important?	Could we ask them to reference Caldicott Principle 8 here? I feel the guidance should acknowledge how entwined and relevant CPs are in relation to the topic they're discussing, especially this point about reasonable expectations and no surprises, which is our bread and butter. The health and care sector doesn't only consider transparency within a data

		protection legislation context; they also draw in considerations about what is required under CLDoC and CPs.
28	Why is transparency in health and social care so important?	I do we need to think about setting out a clearer scope for this guidance. Does it set out the transparency requirements beyond the context of direct care? Above there are some examples of the application of these principle to setting up systems to share information for the purposes of direct care. Whilst it might be appropriate for these principles to apply to setting up systems for direct care, the level transparency requirements as set out in this document should not apply generally in the context of direct care. There is a general agreement that those who present for care will understand how information needs to be shared where they are accessing care. Thus, we do not generally require significant transparency materials and engagement to explain this principle to patients.
29	Why is transparency in health and social care so important?	In some instances the person won't have the choice to agree or disagree. For example, if its anon/pseudo then the opt-out won't apply. Isn't the point more one of them understanding, accepting and supporting the sharing of information rather than agreeing to it? Might '...then it is unlikely they will support it' be better wording?
30	Why is transparency in health and social care so important?	Denotes understanding rather than awareness
31	Why is transparency in health and social care so important?	Do you mean 'secondary' purposes here? Should not be onerous transparency requirements for secondary care. Again need to clearly set out the scope at the start.
32	Why is transparency in health and social care so important?	I am guessing this is just a typo.
33	Why is transparency in health and social care so important?	As above

34	Why is transparency in health and social care so important?	Can we avoid this terminology wit regard to NHS data? It has a very damaging undertone. The CIDC has done a lot of work in its values haring framework to use the terminology of fair partnerships which recognise propionate value recognition for the role of NHS data.
35	What do we need to do before we consider transparency?	These points align with the Caldicott principles(CPs). It is worth recognising earlier in this guidance that the principle of confidentiality also applies to health and social care data. And there are transparency responsibilities under this corresponding legal framework. The CPs recognise the need for transparency particularly CP 8. It would be good to make that link in this guidance. Also this section aligns directly with CP2 and CP3; might it be helpful for the reader to have this mentioned here? To show people that this advice is in alignment with the CPs? Only talking about transparency under DP legislation creates an artificial barrier that isn't there for healthcare professionals, who also must consider them in light of CPs and common law.
36	What do we need to do before we consider transparency?	Denotes understanding rather than awareness
37	Openness	Is it specified elsewhere what information should be provided? I'm thinking if someone who isn't a DPO or data privacy expert reads this guidance, they might have this question.
38	Openness	Link to Articles 13 and 14 GDPR.
39	Openness	Again, might you need to explain/link through to what one is? Presuming that not everyone reading this may know.
40	Openness	By this, do you mean: 'However, committing to the principle of transparency usually requires you to do more than simply provide information in a privacy notice.'? If so, I suggest rephrasing to make it a little clearer.
41	Openness	Tis relate to the point about whose responsibility it is to provide information that enables people to understand how their data is used. Health and social care organisations might be able to produce data release registers with high level information about the purposes of the release and the way the decision about release was made but the real responsibility for transparency regarding that use should be on the organisation that the information is released to.

42	Openness	I'm quite surprised by this as an example of good practice as a standalone as I wonder if it would meet the Article 12 transparency principle: The controller shall take appropriate measures to provide any information referred to in Articles 13 and 14 and any communication under Articles 15 to 22 and 34 relating to processing to the data subject in a concise, transparent, intelligible and easily accessible form, using clear and plain language, in particular for any information addressed specifically to a child. A DPIA might be appropriate as a layered approach for those who want very detailed technical information but it should be alongside other information that is designed to explain the use of the information to members of the public.
43	Openness	The NDG Public benefit guidance makes clear that organisations should be doing this when they are giving access to confidential patient information on the basis that this will be of public benefit.
44	Openness	This is a much fuller explanation of layered approaches to providing transparency information. Are both the separate bullet lists needed in this section or could the first one on examples be subsumed into the second list.
45	Openness	I was going to make this point, too. Strongly advise having just 1 list of 'could' examples.
46	Honesty	Will you link this up to information about the duty of candour elsewhere?
47	Honesty	At the moment, it's not clear whether what you mean is actual 'issues' or just thorny topics. For example, might this convey it more clearly? Be forthcoming and clear about contentious subjects and activities - for example, commercial access to health information - providing appropriate privacy and transparency information to help people understand them.
48	Honesty	And transparency?
49	Honesty	Also, is 'as much information as you can' the right sentiment? I think it's more around appropriate amount and format and channel.
50	Honesty	I wasn't sure if this could be portrayed as a must in line with the privacy requirements in article 13 and 14.
51	How should we reflect choice?	Is the right to object absolute? Should it instead say something like 'It is important that people are made aware of these rights, any circumstances in which they do not apply, and can exercise them easily wherever they do.'
52	How should we reflect choice?	Rather than it being 'only fair' to do this in a timely and clear manner, I would say that Articles 13 2. and 142. and 3. require this this is this a 'must'?

53	How should we reflect choice?	We have reverted to a focus on care here which is not appropriate within the context of this document
54	How should we reflect choice?	Whilst a much earlier recognition of the common law duty of confidentiality would be welcome in this document, I' m not sure about it's relevance n this context. The meeting of the transparency principle and the information requirements of a valid consent are not the same thing. With regard to CLDC the need for transparency has its most important function outside the context of explicit consent. Mostly it would apply where a legal basis such a section 251 were being relied on to support a secondary use of information.
55	How do we identify transparency harms?	Do they actually lose control of their information, or is that loss of control just perceived? Or is the fact that they don't know what is happening what constitutes the 'loss of control'?
56	How do we identify transparency harms?	I've never seen it called this before in this context. Would it be better to refer to the fact that where organisations are not transparent about how they use health and care data this affects people's trust in how those organisations protect and use their information is diminished which may lead to a reluctance to engage with those organisations. Or it could make people less frank when they are providing information for health and care professionals to base their care on. This harm was recognised by the public in the NDG's public benefit guidance public dialogue: NDG_public_benefit_guidance_v1.0_-_14.12.22.pdf (publishing.service.gov.uk) p12.
57	How do we identify transparency harms?	When you say 'choose not to share their personal information', are you talking about opting out and them actively selecting not to allow their information to be used for secondary purposes (research and planning)? Or are you talking about them not sharing information about their own health with those caring for them, for direct care, leading to a lack of health and care information about that person to support their own care (which, in turn, would also have a knock-on effect of producing patient data that is less accurate as it is built on half or partial truths)? I think this could be rewritten to make it clearer.
58	How do we identify transparency harms?	Or those with rare medical conditions?

59	How do we identify transparency harms?	Is there a societal harm that is more clearly linked to lack of transparency as opposed to general lack of trust in how an organisation protects and uses data (and also speaks to the distinction between awareness and understanding). For example where people are aware of a use of health and care information but do not understand that use, its benefits and the protections of the data, because these have not been appropriately explained, the ability misinformation to cause societal harm is intensified. In the circumstances of lack of clear correct material people may be susceptible to believing misinformation. This was seen in the response to GPDPR with clear societal harm, as a centralised collection of GP data, along the lines proposed in GPDPR, could have significant benefits and it is likely to provide significantly greater protection for patient information than the current situation. Misinformation which developed in the context of a lack of information from the programme thwarted a resource of significant public value and left confidential patient information in a less well protected state.
60	Example	This is not a good example in the context of this work about the transparency of secondary uses of personal data collected through health and care. This is a public health campaign. It is not clear that it is collecting health data so what do they need to be transparent about in the context of secondar use of data? This is about giving clear information to the public about services rather than about how their information is processed when they use those services. This does not sit will with this guidance on being transparent about secondary uses of health and care data. Throughout this section, there seems to be some unnecessary reaching and misplaced emphasis on the types of harm that can occur when organisations are not transparent about the uses of health and care. I would argue there is very little chance of bodily harm and 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. But the real harms caused are societal ones through increase in opt out and them impact this has on research and planning and particularly groups with high opt outs and on beneficial programmes that are thwarted through public backlash.
61	Example	This is not a good term to use here. It suggests a legal threshold. I would check this with your legal team. It is very difficult to show causation from not having information to catching a contagious illness.

62	When do we do a DPIA?	What is the 'this' pertaining to here? That the risk will materialise? This needs to be clearer as it's ambiguous and open to interpretation.
63	When do we do a DPIA?	Why does this information present a risk to people's rights and freedoms? Do you mean breaches resulting from the processing of this information? Or the misuse of the information? This needs to be better explained.
64	How do we engage with patients and service users?	I feel that sub-headers would make this section easier to read/make sense of. For example: How engagement will help you help you How you might do it
65	How do we engage with patients and service users?	Could you link to/align with what the NHS says on patient and public engagement? NHS England » Engaging Patients and Carers
66	How do we engage with patients and service users?	This feels a bit clunky. You could perhaps rephrase it to something like: Good engagement requires that you consider both the message and the medium in tandem. This is because the channels and tactics you use to provide your transparency information are just as important as the information you wish to convey.
67	How do we engage with patients and service users?	Consider bulleting.
68	How do we engage with patients and service users?	You have already mentioned the importance of using representative groups above, so I suggest editing it out here so as not to repeat.
69	How do we engage with patients and service users?	This feels like repetition, too, also touching on what's written above regarding the importance of consulting with patients whilst creating transparency materials. Could the two sentences be merged or placed together?
70	How do we engage with patients and service users?	I feel that the 'what it can help you to do' should come above the 'how to do it' in the sequencing here.
71	How do we provide transparency and privacy information?	There e is more about the operation of the transparency principle in Article 12 that is relevant here.
72	How do we provide transparency	I wonder whether this sends out the wrong message without more. Just providing as much information as possible can be quite opaque and often not the best way to clearly

		communicate with the public. The provisions of Article 12 are relevant here.
73	How do we provide transparency and privacy information?	I have the same comment to make. As much information as possible is not the best sentiment. What people need is the right information at the right level, so that they can navigate a path through it without becoming confused or overwhelmed. For example, data release information. It is not enough to just provide a swathe of documents that are used internally for an external audience and consider it 'job done'. This information would be quite impenetrable and frustrating to read, and therefore not transparent - therefore a public-facing version would need to be created to provide the type and amount of information appropriate for a general public audience.
74	How do we provide transparency and privacy information?	What would these 'efforts' look like? Could an example be given as to how, when and where they might signpost to the privacy information? I appreciate that this is difficult, and I don't know what the answer is. But if this is definitive guidance about transparency, I think people will be expecting that practical level of advice. Are there examples of how some organisations are doing this well?
75	How do we provide transparency and privacy information?	Same as per my last comment: how might this be done? I have seen other companies sending emails, but this usually isn't a possibility for healthcare. An example would be helpful if you have one to bring the advice to life and ground it in practice.
76	What are the most effective ways of communicating with your audience?	I think it's the vehicle for transmitting this paper-based communication that most organisations will struggle with. No point in producing a leaflet, for example, if they don't know the most effective way to share it. Is there best practice within healthcare? To me, the options seem quite limited, for example, direct letters to homes (which seems disproportionate just for a change in privacy information) and flyers to hand out at the point of care (which will only reach a handful of people and only when they are sick and visiting a care setting). Again, I appreciate that giving this level of specificity is difficult but I think it's this that people will be struggling with, and if you have practical suggestions I think they'd be welcomed.
77	What are the most effective ways of communicating with your audience?	Perhaps say something about personas to better understand/segment the audience and understand how they access information.

78	What are the most effective ways of communicating with your audience?	I think the problem lie more in ensuring that staff with public facing roles under stand the particular use of personal information so that they can play their part in enabling the organisation to be transparent with people about how information is used. Staff often have not bee educated about those data uses so they are not in a position to be able to speak to patients about them.
79	How direct do communication methods need to be?	After reading this section, I don't think readers will feel any clearer. The points are too high-level and it feels like it's often just stating the obvious. Some examples might bring it to life.
80	How direct do communication methods need to be?	This recognises the distinction between understanding and awareness. However, it does not make clear that transparency is about more than creating awareness. As suggested above raising awareness without creating understanding could be problematic in transparency terms as it allows for the harms associated with misinformation to occur.
81	How direct do communication methods need to be?	Which circumstances might necessitate direct forms of communication? It would be good to point to examples of where these methods have been used to good effect before.
82	How direct do communication methods need to be?	Argue this should be 'appropriate' rather than effective. I think direct comms would always be the most effective method, but whether it's necessary or not is another matter.
83	How direct do communication methods need to be?	Again, an example would really bring this to life. What might be so impacting that it would demand a letter to people's homes or a push text message or whatever?
84	How should we present our privacy and transparency information?	Perhaps change to 'structure and sequence'
85	How should we present our privacy and transparency information?	You might need to explain what is meant by layers of information. Comms staff will know, but others might struggle with the concept without an example of what multi-layered comms might look like/entail. I think a fleshed-out example would be very helpful.
86	How do we deal with complexity and prevent 'information overload'?	Perhaps 'activities' might work better?

87	How do we deal with complexity and prevent 'information overload'?	This feels vague and would benefit from a clear example to take it out of the conceptual.
88	How should we work together?	Who is 'we'?
89	Example	Without more this example is not very meaningful. Also it ignores the current tension regarding placing responsibility for communicating about central uses of NHS data onto overstretched frontline staff. Frontline staff should have a role in speaking to patients where they have concerns about data use but they should not be the primary means of communication. Proper transparency should be the responsibility of the central programme team or those seeking access to data. Frontline staff have a supportive role but they need to be given the tools and education to support them in being able to have conversations with patients.
90	Example	Agree.
91	How do we assess if we are being transparent?	I think in his sentence the distinction between awareness and understanding is particularly important.
92	How do we assess if we are being transparent?	Perhaps also acceptance?
93	How do we assess if we are being transparent?	And communications staff, if it's the DPOs who are 'holding the pen' on the transparency activities. In matters of comms and engagement, it's important to get their subject matter expertise alongside that of privacy specialists. I appreciate that not all orgs are large enough to have comms staff, however.
94	How do we assess if we are being transparent?	Perhaps there should be something about research/evidence-based decision-making rather than just, 'I thought about this in my own head and decided to do it!' :-)