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 Disagree**

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

Strongly Disagree

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

Unsure

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 Disagree**

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

No

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?

Neither agree nor disagree

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?

It is weak

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?

Disagree

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?

Disagree

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?

Neither agree nor disagree

11 – Comments are in an attached document. You can publish and contact us further

medConfidential

[redacted]

medConfidential response to ICO consultation on Transparency in Health and Social Care

“Social Care”: is that Adult Social Care, Child Social Care, or both?

1. The title of this consultation implies it covers all social care, but the text of the draft implies only adult social care, and omits child social care entirely despite seeming to be covered by the title and text itself. The word “adult” does not appear in the guidance once, the word child only appears as part of consulting with representative cross-sections of the public. That there is nothing discussing the differences between adult social care and child social care suggests that the text is far from fit for purpose.

2. It is hard to see where the Department of Health in England would find conflict with this guidance, as it appears to have been drafted to be entirely subservient to their wishes and practices. In practice, this guidance will be “interpreted” for the intended audience by the joint data policy unit in DHSC and NHS England, and rarely referred to directly. As a statutory regulator, the ICO should be checking details carefully, not allowing others to mark their own homework. The general lack of clarity creates the opportunity for the ICO’s well meaning good intentions to be watered down to irrelevance and patient harm in practice, and organisations to evade any accountability.

Non-Necessary Data Processing is dissentable – but the guidance omits that

3. The guidance seems to imply that the Department of Health in England[1] saying to patients “your data or your life” is fine under the DPA as long as they put it in a transparency notice on a webpage no one knows exists.

4. Processing data within a “secure data environment” is still processing; putting data into a

SDE/TRE is still processing; running data through a PET is still processing; and each so is dissentable where not necessary.

5. The guidance is silent on this topic.

The guidance only covers DPA within the ICO’s remit – the NHS is wider than that

6. It is impossible to satisfy the DPA Transparency obligation when not satisfying other legal or ethical obligations in health and any social care.

7. The guidance should make much clearer that it is guidance only for issues within the ICO’s remit – principally DPA. Given the narrow ownership, it can not and does not include anything else, such as the scope of the non-statutory NHS National Data Opt Out, or the common law duty of confidentiality, etc. Also out of scope are “best practices” – the guide is

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[1] The collective name for DHSC, NHS England, and various parts which sit within and adjacent to them around the DHSC ALB hierarchy. See also paragraph 16a

focussed upon *minimal practices not to break the law*, hence is polluted throughout with “shoulds” not “musts” from the ICO’s perspective.

8. The fact that the law and guidance say you must be transparent about obligations, but can not state what those obligations might be, or even where they may be found, suggests that this guidance is structurally unsound by design.

Transparency Information

9. Take the case study of FDP, can NHS England’s actions regarding the Federated Data Platform in early 2023, it’s unclear whether the weasel words in the draft guidance are worthwhile – they can be read as met without any regard for the substance.

10. For example, where there’s an obligation to publish, do the guidance authors consider publication of this file satisfies the DPA principle and original policy intent? A PDF has been published, the transparency box can be claimed as ticked, and the extent that data subjects have more information than before is largely limited to the count of pages which are entirely redacted.

11. Given the policy intent of the guidance, and of NHS England and DHSC, together acting as the Department of Health in England, there should be a way to see appropriate transparency information together in the NHS app. If some information is made available through the app, then transparency information should also be made available in an equivalent manner.

12. The current text of the guidance allows the Department of Health in England to dump all legal obligations onto General Practice, and the language used in the draft implies that such burden shifting can always absolve all national bodies of their obligations to do anything at all.

“Assess transparency”

13. We are aware that NHS England has previously considered medConfidential’s interventions as counting towards their goal of raising public awareness of their catastrophes, and thereby justifying their continuation of a flawed project.

14. It’s utterly perverse that the guidance suggests that a catastrophe of public trust that gets plastered across the media would count as increasing the level of awareness and be considered a positive thing by the ICO under this guidance.

15. Everyone at the Department of Health in England, and everyone working with them, including Baroness Mone, believe that they are doing a good thing to “help patients”. This guidance will empower the incompetent and the egotistical as justification for whatever they wanted to do, irrespective of any degree of non compliance with legislation.

Topic that are entirely missing

16. There are various topics that are entirely missing.
    a. The various tentacles of the Department of Health in England are complex and confusing. The guidance makes no mention of any obligation upon data controllers to **provide clear, honest, accurate information** that gives a data subject an understanding of how overlapping and interoperating data controllers have used data, and what their *legal* choice are about those data are used.

    b. The guidance could have talked about the distinction between **direct care** and secondary uses. Given the flawed safeguards and limited processes around direct care, there should be higher standards of transparency for direct care, in practice these should be available via the NHS app.

    c. The guidance is entirely silent on the many issues around the mandated implementation of prospective access to medical records. This document will be published by us in early 2024, so the consultation team should speak to their various policy and breach response colleagues.

    d. Larger systems with remote access show far greater risks than smaller systems without remote access.

17. The guidance and context is also entirely lacking that all DPA principles continue to fully apply – transparency alone is not enough. Claiming transparency of illegality is not an excuse.

18. Transparency of untrustworthy acts are still untrustworthy acts, and the mere availability of more coercive power of the state does not justify overriding the wishes and powers of data subjects. The guidance seems to imply that the Department of Health in England saying to patients “your data or your life” is fine under the DPA as long as they put it in a transparency notice on a webpage no one knows exists. Is that the policy intent of the guidance?

Timescales

19. As this consultation closes in early January 2024, it is unlikely that any future stage of this work will appear before the Federated Data Platform goes live in “spring”. As that mess plays out, the team reading these consultations response would do well to assess what wasn’t clear enough or said at all in this guidance, which we don’t doubt the Department of Health in England will assert they follow closely – no raindrop believes it is to blame for the flood.

medConfidential
January 2024