

ICO consultation on transparency in health and social care

24 November 2023

The Information Commissioner's Office (ICO) has announced that it is conducting a public consultation on transparency in health and social care.

The ICO's draft guidance is aimed at public sector organisations, although it will be of interest to the independent sector and the third sector organisations delivering health and care services. The guidance is focused on:

- what data protection transparency means for health and social care organisations;
- how to develop effective transparency material;
- how to provide transparency and privacy information to patients, service users and the public; and
- the factors to consider when assessing levels of transparency.

View the [ICO's consultation survey](#). The closing date for the survey is **07 January 2024**.

The ICO has developed the guidance to help health and social care organisations understand their expectations about transparency, setting out what organisations must (organisations are legally required to meet these requirements), should (the ICO expects organisations to meet these requirements), and could (optional to meet these requirements) do to comply. It adds to the ICO's existing guidance on the principle of transparency and the right to be informed, as such guidance is believed to be high level and not sufficient enough to provide clarity on ICO expectations regarding transparency.

The guidance makes clear that health organisations must:

- be open and honest about the data they are collecting and how it will be used, to ensure they process data transparently and comply with the right to be informed,
- operate transparently and provide specific privacy information to individuals, this information must also be easy to find, and
- assess their transparency based on the circumstances of their data use and their transparency measures.

The ICO's intervention in this area reflects its growing concern about transparency, particularly in light of the increased use of new technologies like Trusted Research Environments (TREs) to support direct and secondary care. The ICO is rightly concerned that a lack of transparency creates a risk of harm to patients and undermines public confidence in the healthcare system. Research demonstrates that there is a direct link between a lack of confidence in the health sector with negative health outcomes for patients.

Browne Jacobson have an expert team of public, health and data lawyers that can assist you with any queries you have about the ICO's consultation, or help you conduct an audit of your data protection compliance to ensure you are meeting your transparency obligations.

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