

For the attention of: The Independent Inquiry into Child Sexual Abuse

Letter via email

Dear Ms Chaloner

Thank you for giving me the opportunity to provide a submission to the Independent Inquiry into Child Sexual Abuse.

I was appointed to the role of National Data Guardian for Health and Care by the Secretary of State for Health in 2014. In this role I help to ensure that the public can trust their confidential information is securely safeguarded and that it is used to support citizens' care and to achieve better outcomes from health and care services.

Prior to being appointed as the National Data Guardian I was asked by previous governments to undertake two reviews, both of which I hope will also inform the work of this inquiry team.

The first of these, the Review of Patient-Identifiable Information, was commissioned by the National Health Service Executive in 1996 owing to increasing concern about the ways in which identifiable patient information was being used in the NHS in England and Wales, and the need to ensure that confidentiality was not undermined. Such concern was largely due to the development of information technology, and its capacity to disseminate information about patients rapidly and extensively.

In undertaking the review we recognised the importance of confidentiality not impeding the provision of prompt and effective patient care. But we also recognised that there was a tension between the needs of the health and care service for information and the expectation of patients that information about them would be kept confidential. We concluded that health and care professionals could balance these conflicting needs by adhering to explicit and transparent principles of good practice, which we published in the review report in 1997. These six principles subsequently became known as the 'Caldicott principles'.

This review also led to the creation of 'Caldicott Guardians' in NHS organisations, and then later in Social Care organisations. Caldicott Guardians are responsible for advising organisations on the appropriate use and sharing of information. They are responsible for ensuring that the organisation follows good guidance and for ensuring that patients' rights in relation to their personal information are observed.

In 2013, I led a second review, the Information Governance Review, which recommended an additional Caldicott principle setting out that the sharing of information can be as important as the duty to protect patient confidentiality.

Appropriate confidentiality and sharing of information within the NHS is, I am sure, a matter of relevance to the Independent Inquiry into the NHS. The role of Caldicott Guardians is of particular importance to the NHS. I have drawn Caldicott principles of good practice from the first and second reviews.

After being appointed as the National Data Guardian, I was commissioned by the Secretary of State for Health in 2015 to propose a new set of security standards to prevent malicious or accidental data breaches and a new opt-out, which gives patients a choice about how personal confidential information about their health is shared beyond their own care. This report was published in July 2016.

It lays out expectations and good practice on the security of patient information, particularly by leadership. These recommendations have just been agreed by government and are being implemented, not least through the new CQC.

So I hope that the findings contained in the three reports, which have been incorporated into standards for practitioners and leaders in the NHS over the last 20 years, are helpful in informing the work of the Independent Inquiry into the NHS.

If I can be of further assistance on this important matter, please do not hesitate to contact me.

With kind regards



Dame Fiona Caldicott, MA FRCP FRCPsych

**National Data Guardian**

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Report on the Review of Patient-Identifiable Information  
The Information Governance Review  
Review of Data Security, Consent and Opt-Outs