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Your reference FS50201819

Dear Mr Jarman

Thank you for your letter of the 9th June 2008.

My application for a decision notice under the above reference is outstanding. Under the Freedom of Information Act, I am seeking publication of a counsel's opinion obtained by the Department of Health in respect of the NHS database proposals. I would be grateful if you could clarify the progress of that decision.

I am writing to request that two new further developments be considered in respect of this application. These have arisen subsequent to my complaint.

Firstly, I note the recent judgement from the European Court of Human Rights re I v. Finlandⁱ (enc). The court has confirmed that health care staff who are not involved in the care of a patient must be unable to access that patient's electronic medical record. "*What is required in this connection is practical and effective protection to exclude any possibility of unauthorised access occurring in the first place.*"

Even if they can be made to work as intended, the other security features in the NHS system, such as organisational "legitimate relationships", role based access controls and "sealed envelopes", will still leave data for enormous numbers of patients accessible to large numbers of staff who are not involved in their care. Because of this, the Department of Health's reassurances about data security have very much been based on the value of the audit trail facility.

The NHS database relies on deterrent laws and retrospective employment sanctions on staff who access records inappropriately. The judgement is clear that, though important, such legal mechanisms do not provide sufficient protection, even if misusers might be identified retrospectively by an audit trail.

Secondly, I note that the Information Commissioner has now confirmedⁱⁱ, in conjunction with Dr Mark Walport, that long published Connecting for Health intentions are not in fact lawful but can only proceed if new primary legislation is enacted to override the common law requirement for patient consent.

The discussion paper I wrote in January 2006ⁱⁱⁱ questioned the lawfulness of CfH proposals in respect of both the Human Rights Act provisions and with regard to common law requirements. The counsel's opinion was commissioned by the Department of Health in response to my paper.

These latest developments completely support an over-riding public interest in publication of the legal advice upon which CfH has relied to date. Publication of the counsel's opinion is essential to clarify the justification for new primary legislation as the information commissioner has recommended.

Connecting for Health's "Summary Care Record Advisory Group"^{iv} (SCRAG) has met recently and is reported as having recommended that the NHS adopts "a refined consent model, simplifying decisions for patients without removing the choices available." Connecting for Health has declined to describe the advisory group's preferred consent model in detail and a decision is not scheduled until September.

SCRAG includes independent members and representatives of other organisations. Such group members are outwith the Department of Health as a legal entity. They cannot make an informed decision in this essential matter without full access to the department's legal advice. If these SCRAG members are to be adequately informed, legal privilege in the counsel's opinion must either be waived by the Department of Health or over ridden by the FOIA provisions. In either circumstance it must be published.

I am concerned at the suggestion in your letter of the 9th June that this complaint may not be addressed for several months. Is there a mechanism by which this could be expedited? Otherwise, the medical records of a large number of patients may be unlawfully disseminated.

Yours sincerely,

Dr Paul Thornton

ⁱ **CASE OF I v. FINLAND** (*Application no. 20511/03*)

<http://cmiskp.echr.coe.int/tkp197/viewhbkm.asp?action=open&table=F69A27FD8FB86142BF01C1166DEA398649&key=71800&sessionId=11881439&skin=hudoc-en&attachment=true>

ⁱⁱ <http://www.justice.gov.uk/reviews/datasharing-intro.htm>

ⁱⁱⁱ <http://www.ardenhoe.demon.co.uk/privacy/NHS%20database%20proposals%20unlawful.pdf>

^{iv} <http://www.pulsetoday.co.uk/story.asp?sectioncode=23&storycode=4120259&c=2>