

# Dr Paul Thornton DCCH, MPH, MRCP

---

03 June 2007

Dr Nigel Watson,  
Chief Executive  
Dorset Local Medical Committee  
59 Tower Street  
WINCHESTER  
Hampshire  
SO23 8TA

390 Cromwell Lane  
Burton Green  
Kenilworth  
Warwickshire  
CV8 1PL

Phone 024 7646 2927  
Mobile 07711 698918

Email [drpaulthornton@nhs.net](mailto:drpaulthornton@nhs.net)

Dear Dr Watson,

I note the report in "Pulse" last week that plans for the rollout of summary care records in Dorset might be proceeding using the same consent model as has been used in Bolton, Bury and elsewhere.

Before the first "early adopters", The Medical Defence Union (MDU) published guidance<sup>i</sup> for its GP members (enc). It was possible at that time to argue that the requirements to inform patients that were identified by the MDU might be met by local publicity and by the letters that would be sent to all patients.

However, the recent report<sup>ii</sup> produced for CfH by Professor Trisha Greenhalgh and colleagues at University College London (UCL), has clearly shown that the criteria set out by the MDU are not met by the CfH strategy.

In SCR pilot areas, only about 1% of the people who were sent information about the proposals actively "opted out". But the UCL report suggests that as few as 1 in 7 people whose address was printed on an envelope had actually received, read and remembered it. The true opt out rate could be 7 times higher i.e. 5 percent (7 x 0.9) of the people who are fully informed would not want a summary care record.

This is supported by greater detail in the paper<sup>iii</sup> from the same authors published in the BMJ this week. e.g. *"Around one in 12 people thought that the SCR was a bad idea "on principle", viewed the intention to create one as an infringement of their rights, and drew explicit parallels with government plans to introduce identity cards and the clamp down on social security fraud..."*

The evidence in this report supports concerns that the CfH proposals are not lawful. The researchers have shown that patient awareness and understanding in the "early adopter" areas among people who did not "opt out" remains uninformed. Doctors can no longer assume that the common law requirements for implied consent ("opt-out") for the uploading of information are met. On the contrary, as a consequence of this study, we now have to assume that implied consent ("opt out") in these circumstances is unlikely to be valid.

At the same time, the Department of Health is refusing to publish the entire legal advice that it obtained in respect of the Summary Care record. Ministers obtained a counsel's opinion in response to a previous paper<sup>iv</sup> that was submitted to the Ministerial working party by Mr James Johnson, then chairman of the BMA. The department's summary<sup>v</sup> of that opinion is referenced in the MDU advice. An appeal to the Information Commissioner has recently been submitted seeking publication of the Counsels opinion under the Freedom of Information Act<sup>vi</sup>.

The UCL suggestion that an explicit contemporaneous "consent to view" mechanism should operate might assist the ethical use of the system. However, once data is out-with the exclusive control of the GP practice, mechanisms exists for the data to be released (or accessed) by others without patient consent (both lawfully and unlawfully). Accordingly, "consent to view", on its own, would not seem to be sufficient

to circumvent the obligations on GP's that were identified in the MDU guidance. It would appear that these can only be met through explicit consent to create a summary care record –“opt in”.

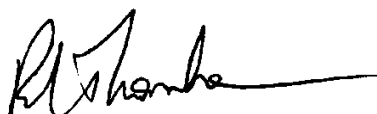
Connecting for Health are reported to be seeking review of the UCL report by their “Summary Care Records Advisory Group”. Any further uploads should have been deferred, at least pending the outcome of those deliberations. In the interim, Dorset GPs have been placed in an invidious position.

I am sure that the Dorset LMC is already formulating recommendations to GP's. I hope this letter is helpful. I would be content for you to disseminate it more widely. Please do not hesitate to contact me if I can assist further.

I shall copy this letter to the various relevant professional bodies as below with a request that it is circulated to relevant Ethics, IT and other subcommittees in each organisation. I hope they will support the request for publication of entirety of the legal advice obtained by the Department of Health so that it can be subjected to expert scrutiny.

Kind regards,

Yours sincerely,



Dr Paul Thornton

cc. Dr Hamish Meldrum, Chair of Council, BMA  
Professor Steve Field, Chair, RCGP,  
Ms Jane O'Brien, Head of Standards and Ethics, GMC  
Dr Stephanie Bown, Director of Education and Communications, Medical Protection Society  
Dr John Holden, Medico-legal Advisor, Medical Defence Union

---

<sup>i</sup> MDU Guidance  
[http://www.ymcentre.freeserve.co.uk/download/MDU\\_NCRS2.pdf](http://www.ymcentre.freeserve.co.uk/download/MDU_NCRS2.pdf)

<sup>ii</sup> UCL report  
<http://www.ucl.ac.uk/openlearning/documents/scrie2008.pdf>

<sup>iii</sup> BMJ article by Greenhalgh et al  
[http://www.bmj.com/cgi/content/full/bmj.a114v1?q=rss\\_home](http://www.bmj.com/cgi/content/full/bmj.a114v1?q=rss_home)

<sup>iv</sup> Previous paper seeking review of legal basis for CfH proposals  
<http://www.ardenhoe.demon.co.uk/privacy/NHS%20database%20proposals%20unlawful.pdf>

<sup>v</sup> DH Guidance to GP's re SCR  
<http://www.ymcentre.freeserve.co.uk/download/gpguidance.pdf>

<sup>vi</sup> Letter of Appeal to Information Commissioner  
[http://www.ardenhoe.demon.co.uk/Bradshaw%20correspondance/PT\\_IC\\_13\\_05\\_08.pdf](http://www.ardenhoe.demon.co.uk/Bradshaw%20correspondance/PT_IC_13_05_08.pdf)