

DE 500876 : Victoria Dacey : Internal Review

Points to make/references to cite by Q number

2. The original reply was not 'speculation', but a simple statement of policy - that all patients will be sent information in writing, advising them of their available choices, to the address held by the NHS locally, when Summary Care Records are to be introduced into their local area. We hold no information on instances where SCR's have been created in contravention of this policy, and know of no evidence to suggest that it has ever been contravened.
4. There was no single 'decision maker'. The decision was a corporate one. The public information programme was developed following extensive consultation, and advice from patient and citizen groups, and the Office of the Information Commissioner. It was launched with the agreement of Ministers. The particular aspect to which you take objection, non-inclusion of an opt-out form in the information pack, was decided in the light of a risk assessment by Gilliam Braunold, the Department's clinical Director for the SCR and HealthSpace, that the alternative, that is, including an opt-out form, was likely to have significant downsides. Greatest among these was that people would believe they had opted out of having a SCR by putting the completed form into, and sending it in, the reply-paid envelope, albeit the latter was included for altogether different purposes. This assessment was borne out in experience with early adopters. The previously-referenced document explains this.

Alternatives for accessing opt-out forms are legion, and are described at Q6 of the Gilliam Braunold letter.

- 5&6 An act that you, rather oddly, interpret as an attempt to siphon off requests to opt out ie. inclusion of a reply paid envelope in information packs, was in fact a measure genuinely intended to facilitate requests for further information. The fact that some recipients of information packs used it for purposes for which it was not intended (including 'returning' opt-out forms) was the very reason why opt-out forms were not included in the pack – see 4 above.
9. SCR's will be deleted if a patient asks for this to be done, excepting only where the SCR has been used by a healthcare professional in the course of treatment, or should have been so used. The key issue here is a medico-legal one - the potential need to be able to demonstrate the reasons for treatment decisions. In the event that a SCR was accessed as part of someone's healthcare, a record of that access needs to be kept in case there was a subsequent investigation of the performance of a clinician or a dispute about the facts – this is in the best interests of both patients and clinicians. This can be a matter of vital importance

where, for example, clinical negligence is alleged, and where the unfettered right of a patient to have the SCR deleted could leave clinicians exposed to false accusations of incompetence or wrongdoing.

The 'mechanism' for deletion in these circumstances involves a physical cleansing of the relevant hard drive by 'back office' IT staff.

10. We had thought the original reply was perfectly clear. For avoidance of doubt, there has been no alteration to the 'original plans', as described, for rollout of SCRs such that rollout should now happen more quickly.
12. It is one thing to assert, and to adduce evidence to demonstrate, that having a SCR could be life-saving. It is quite another to seek to put a precise figure on the number of deaths in a defined period that have resulted from the absence of a SCR. That would indeed be 'speculation'.

For a discussion, citing evidence, of how the new NHS IT systems, including the SCR, will contribute to greater patient safety and reduction in avoidable deaths, please see the attached Appendix (based on a paper created some 2 – 3 years ago for another purpose).

13. The NHS Care Record Service (NHS CRS), of which the SCR forms only one component, comprises a number of national services and compliant local applications. Costs specific to the individual components of the NHS CRS are not separately identified within the relevant contracts.
14. The decision was made in 2004 by the then relevant Department of Health Ministers, and subsequently re-affirmed by successive Ministers from that date.
16. Controls currently in place are as described. Any confusion is due to choice of language in the earlier reply ie. use of 'will' ('will need to') to describe all occasions and circumstances.
17. See above re use of language. You are right that the process involves 'logical' rather than physical deletion of records. As existing SCRs currently contain only GP summaries, this is most easily achieved by the GP 'overwriting' the existing SCR with a blank record.

The consequence of doing this is that they are made inaccessible to all staff who would otherwise have access to SCRs for the purpose of providing, or managing the provision of, care. They would not then be made accessible other than in exceptional circumstances. See the Parliamentary reply given to Norman Lamb MP of 29 January 2009 at : <http://www.publications.parliament.uk/pa/cm200809/cmhansrd/cm090129/text/90129w0015.htm#090129118000017> for a discussion of what these might be.

18. The intention from the outset has been that the SCR should be potentially available to all staff responsible for providing NHS care where access is capable of contributing to improved clinical outcomes for their NHS patients. This naturally includes community pharmacists. A pilot to provide SCR access to community pharmacists is currently under way in Bradford. The purpose of the pilot is to explore potential benefits, to address practical issues surrounding information governance, to consider changes in clinical or business processes, and to assess acceptability to patients. Decisions about extension of these arrangements more widely will only be taken when the lessons of the pilot have been carefully considered.