Available next steps for a trial of post-COVID SCR

During the pandemic, additional information was added without consent and with very little transparency to 55.7 million patients' Summary Care Record for the purposes of COVID-19 response. There is now a reasonable debate to be had about where we go from here.

Some will argue that more information is useful – they may even be right. Others will argue that patients have given no meaningful information about the change and therefore no real opportunity to dissent – and they are right. There is, however, a dearth of meaningful and *necessary* data at this point.

Nonetheless, we are starting from where we are, with significant changes in place as a result of the pandemic.

It will likely take several months for any decisions to be made, and that time can be used to collect more information from patients whose SCR has been accessed, as they will be in the best position to know what *should* have happened, and to give a real world view.

Given these changes are in place, the time before the COPI Notices expire can be used to run a trial to collect patients' views on what should happen after the Notices expire.

Every patient should know how data about them is used, and there is a clear prioritisation available – for those whose SCR has actually been used – while what should happen about everyone else is considered.

On a trial basis, based on the logging information it already receives, NHS Digital should automatically generate and send a letter to a patient when their 'post-COVID' SCR (i.e. containing Additional Information) is accessed for the first time. This letter should notify the patient (a) that they currently *have* a post-COVID SCR, (b) from where it was accessed, (c) what information is in *their* record, (d) how to dissent from future use if they wish, and (e) how to respond to a consultation on the process.

The letter need be no more than a single sheet of A4, with references to further information.

Such a trial will create space for informed debate and provide an evidence base from patients, including measures of informed dissent, as well as informing longer term decisions in 6-12 months.

If the letters are shown to be unnecessary, then they can be ended after the trial period; if they are shown to be useful, the process can be left to run indefinitely. (Each patient only ever gets one letter; this solves the 'one off' communications problem, as patients only get a letter as needed – if someone's SCR is never used, barring breaches, they should not need to know about it). And when NHS.UK rolls out data release statements to cover SCR accesses, this proposal could be subsumed into that notification process.

As with all direct comms to patients, the letter should also have a paragraph about the National Data Opt-out, and how to differentiate between direct care and secondary uses.

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