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[by e-mail]

Dear Prime Minister,

You will be aware that an NHS England official, using the imprimatur of the Prime Minister's Challenge Fund, attempted last month to acquire details of many millions of people's GP appointments, going back to April 2013. That they were unsuccessful is beside the point.

The official served notice of this "specification and request" to the GP IT software suppliers, which are data processors, rather than approaching the GPs (the data controllers for their patients' records, with a professional, ethical duty of confidence) or their professional representative bodies.

medConfidential completely agrees that your Challenge Fund requires an evidence base; one should be developed. However, it cannot be started by going behind GPs' backs to grab copies of their appointment book. Patients also deserve to know what is happening to their GP records, not to find details of their visits to the doctor have been 'snuck out the back door' during summer recess.

Judging by NHS England's reconsideration this week, and the aggregated practice-level counts they now say will satisfy, it is quite obvious that the information required never actually needed to be sucked up, patient by patient, from GPs' appointment books.

The problem with NHS England's approach to gathering evidence for your Challenge Fund relates to issues underlying the ongoing care.data catastrophe; a 'cultural' flaw within NHS England which, although it has statutory powers, does not always deploy them appropriately. This "collect it all, decide what to do with it later" attitude spawned what is acknowledged to be a flawed specification for the care.data GP data set, as it so clearly also influenced this latest attempt to acquire data.

There are procedures and mechanisms by which such a request could be honoured, in an effective and ethical way. The HSCIC's 'GP Extraction Service' was designed to do almost exactly this, for example: "*HSCIC has established data collection and approval processes for collecting data such as this, which NHS England are aware of*" (HSCIC, 22 July 2015¹) but NHS England chose not to use that process, and instead invoked your Office.

As with care.data, NHS England chose what it thought was politically expedient in the short term, but will end up taking longer to do anything.

¹ <http://central-government.governmentcomputing.com/news/nhs-england-denies-seeking-patient-data-from-software-groups-4628862>

In September, NHS England is proposing to send a letter to a large number of people (but not everyone) in up to six Clinical Commissioning Group areas across England, offering them an 'opt out' from the use of their medical information for purposes other than their direct care.

Not only is it unclear exactly what the opt out will cover, or whether it meets the Secretary of State's promises from 2013 and last year, it is unclear whether patients will even understand what "the NHS" is talking about. (They didn't seem to following a segment on BBC Radio Somerset this Monday, but that could have been due to NHS England's refusal to appear.)

Even more confusingly, many thousands of people in those CCGs who did opt out last year² will be sent the same letter offering them to opt out - but with a choice they made last year removed. This is no way to fulfil promises NHS England continues to break, some 18 months after making them. It is most definitely no way to "rebuild trust"³.

In essence, NHS England and other DH Bodies will grab data because they can request and, in some cases, *require* data without statutory, independent oversight. Arbitrary data grabs are not a sound basis for either an integrated care system or "a Life Sciences economy", both of which can only thrive in an environment of transparent decision-making, full information and public confidence.

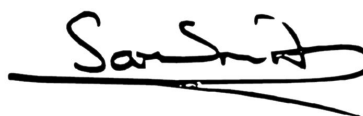
To this end we welcome the Secretary of State for Health's undertaking to put the National Data Guardian onto a statutory footing "at the earliest opportunity". To avoid further corrosion of trust in the meantime, it is vital the Bodies for which he and your other Ministers are responsible all seek and attend to the advice of the relevant scrutiny bodies⁴ when requesting or requiring data.

It has been stated there should be "no surprises" for people about what's done with their medical records; good advice with much broader application. For only when citizens can *know* who has had access, why, and for what purpose the information they have shared with the public services - or with government itself - is being used will the 'data trust deficit'⁵ be bridged.

Yours sincerely,



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² That is "many thousands" in the pathfinder areas. DH's latest estimate suggests that up to 2.5% of the population, possibly more, have already opted out (roughly double HSCIC's previous "700,000" estimate): <http://www.theyworkforyou.com/wrans/?id=2015-07-16.7710.h&s=care.data#g7710.r0>

³ As Baroness O'Neill and others point out, you cannot "build trust" - you can only demonstrate that you are *trustworthy*, by being "competent, honest and reliable". How many of these do NHS England's actions meet?

⁴ For avoidance of doubt, we are referring to the Confidentiality Advisory Group at HRA, DAAG / IGARD at HSCIC, and whatever replaces the currently obscure arrangements of the SCCI sub-committee of the National Information Board. SCCI in its present form is clearly not appropriately constituted.

⁵ <http://www.statslife.org.uk/news/1672-new-rss-research-finds-data-trust-deficit-with-lessons-for-policymakers>

Cc: HMG Chief Data Officer; NHS Chief Data Officer; HSCIC Chief Exec.