**Burdens on public authorities vs citizens**

MedConfidential exists because of bureaucratic secrecy. We formed primarily in response to NHS England’s the care.data project to collate the medical histories of every citizen, which, when the public found out about it, collapsed under the weight of public scrutiny, and as statements by both NHS England,[[1]](#footnote-0) and the Parliamentary Under-Secretary for Health to Parliament,[[2]](#footnote-1) were proved false by FOI request.[[3]](#footnote-2)

Our issue is the access to the nation’s medical records. Both the broad records of the NHS, and also additional studies incorporating medical records such as “Whitehall II”[[4]](#footnote-3). For the purposes of health, the NHS creates a national scale, linked database of everyone’s medical care throughout their life. This is both deeply intrusive on an individual level, but necessary for research at a wider level. The tradeoff being managed by, those in the study, being told what the rules will be as the basis for their involvement - their consent is on that basis.

However, once that is in place, there are many who will wish to circumvent the rules via special pleading[[5]](#footnote-4) that this committee has received. Projects wishing to use data may make public claims of transparency, with statements that papers would be published, but in practice on make such documents available to the public under FOI.[[6]](#footnote-5) At the time of writing, no papers have been published for meetings since May.[[7]](#footnote-6) That’s your medical history being used in ways which are only accessible because of Freedom of Information legislation.[[8]](#footnote-7) The burden on citizens of the need for Freedom of Information is usually exorbitant, the burden responding places on public bodies is comparatively negligible.[[9]](#footnote-8)

medConfidential

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 coordinator@medconfidential.org

1. “every household in England” <https://www.england.nhs.uk/2014/01/06/better-info-better-care/> [↑](#footnote-ref-0)
2. “Royal Mail was contracted to deliver the leaflet to every household in England” <http://www.theyworkforyou.com/wrans/?id=2014-02-11a.186539.h> [↑](#footnote-ref-1)
3. “This means that the leaflet has not been delivered to households that have registered with the Royal Mail’s ‘door to door opt-out’” <https://www.whatdotheyknow.com/request/royal_mail_contract_for_caredata> [↑](#footnote-ref-2)
4. <https://www.ucl.ac.uk/whitehallII> [↑](#footnote-ref-3)
5. <http://bmj.com/content/351/bmj.h5087> [↑](#footnote-ref-4)
6. <https://www.whatdotheyknow.com/request/caredata_programme_board_minutes> [↑](#footnote-ref-5)
7. <https://www.england.nhs.uk/ourwork/tsd/care-data/documents/> [↑](#footnote-ref-6)
8. e.g. <https://mq.b2i.sg/snow-owl/#!terminology/snomed/242614007> [↑](#footnote-ref-7)
9. see comments from Private Eye & others. e.g. <https://twitter.com/rbrooks45/status/665100240702304256> [↑](#footnote-ref-8)