



[coordinator@medconfidential.org](mailto:coordinator@medconfidential.org)

15 October 2018

Dear NDOP advisory group,

NHS Digital should by now have shared with you figures confirming that, during the period since NDOP was introduced, an order of magnitude more people used their GP to opt out than used the new online service you oversee.

Additionally, after sending 1.6 million letters (exclusively) to those who had already opted out, informing them about the new system and signposting changes the NHS has made to improve processes since their decision, NHS Digital's own figures show only one person in every 2500 recipients (or 0.048%) opted back in digitally.

The National Data Guardian has previously suggested that the NHS continues to need to do more to rebuild public confidence in data use – a view the evidence now proves correct.

The system you have advised upon forces any parent to send 4 forms of ID documentation to NHS Digital officials who then decide whether they are a legitimate person to express a choice for their child. There is no digital process for this – again by choice.

Adults who make a consent choice online have, by definition, had their identity verified against the details held by the Personal Demographics Service (PDS). The digital process could therefore ask if they have any dependent children living at the same address for whom they wish to express a choice. It doesn't. Each dependent child will already have an entry in PDS for their NHS number, and the existing address / contact details in PDS for the child can be checked with those recorded for the verified adult.

Despite the NHS Digital website publicly stating "there will be no changes to... extracts that are currently running through GPES"<sup>1</sup>, that was in fact used as justification for removing the GP opt out process in October. DHSC can, and in light of these figures now *must*, direct NHS Digital to continue the GP opt-out process<sup>2</sup>. Did the Department know these figures when it decided not to continue Type-2 GP extractions in September?

The failures outlined above are very public results of the approach taken. Unlike with your predecessor body, the care.data Advisory Group, the decision was taken that medConfidential is "not a stakeholder"<sup>3</sup>.

As members of the advisory group, you were asked – once again – to put your confidence in the delivery of NHS Digital, NHS England, and DHSC. Do these results satisfy your expectations of how they would deploy the institutional confidence you offered them?

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<sup>1</sup> <https://digital.nhs.uk/services/general-practice-extraction-service/planned-changes-to-gpes-in-2018-and-2019>

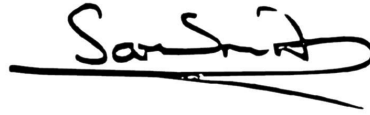
<sup>2</sup> Currently the Type-2 process, but this could be replaced with an interface to the new spine service. Patients' Type-1 opt-outs remain unaffected.

<sup>3</sup> Head of Stakeholder engagement, NHS England.

Yours sincerely,

Handwritten signature of Phil Booth in black ink.

Phil Booth, medConfidential

Handwritten signature of Sam Smith in black ink, underlined.

Sam Smith, medConfidential

Cc NDG, NDG panel, DH, BMA, Ben Heather.