

Annex 7B: Anecdotal data on digital disconnection (or how we filled post boxes¹ by posting offline-only opt-out forms to people without printers)

On 12 May 2021,² the NHS in England, led by DHSC's NHSX, announced imminent plans to collect for dissemination (i.e. sale) the GP records of all patients in England. It was delayed on 8 June³ and suspended on 19 July.⁴

To opt out, patients had to deliver a paper form to their GP to prevent their GP data being extracted, in addition to using a different online form for their non-GP data – as well as posting a third paper form to an office in Leeds for any dependent children, or for anyone for whom the online service didn't work.

The plan was a complete mess, and it didn't survive a month.⁵

The initial approach, led by NHSX, had been that this was a digital programme so it would only offer digital methods,⁶ and no offline methods could be offered. That exclusion initially included no mechanisms for patients without access to a working printer to print the forms.

medConfidential therefore told all parties we would post forms to anyone who requested them, no questions asked. This was an entirely manual operation on our part⁷ – people e-mailed us,⁸ and we put the relevant forms in an envelope for them and posted it out.

With NHS Digital now publishing a dashboard of daily opt-out figures and graphs,⁹ we can measure the digital divide where printed forms were required.¹⁰ (While we sent forms without asking questions, people did sometimes include some details in their e-mails, which we deleted on sending the forms they had requested.)

The effect of an offline only process for dependent children is visible in the age breakdown statistics, with the opt out rate being noticeably lower and the changes showed a delay because of the postal-only expression of dissent for dependent children.¹¹

¹ Given that completely filling a post box would have potentially caused problems for others, we mostly filled a couple, and then found a double-slotted post box for the remaining half.

² <https://digital.nhs.uk/news/2021/improved-collection-of-gp-data-launched>

³ <https://www.pulsetoday.co.uk/news/technology/mass-gp-data-extraction-delayed-to-september/>

⁴ <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/secretary-of-state-letter-to-general-practice>

⁵ <https://medconfidential.org/whats-the-story/gp-data-2021/>

⁶ They only said they would accept National Data Opt-out forms via e-mail after we pointed out that not to do so was obviously stupid.

⁷ Even at peak, it was never feasible to automate the process. We simply asked people to tell us the number of adults/children for whom they needed forms, and posted them the forms they needed. It was fundamentally unreasonable for NHSE/X to expect patients to figure out the arcane processes of different entities simply in order to express their wishes.

⁸ We also offered a text message equivalent, which had unclear results and was far more awkward.

⁹ <https://digital.nhs.uk/dashboards/national-data-opt-out-open-data>

¹⁰ NHS and others have analysed the impact of opt out rates, and apart from a couple exceptions of very carefully crafted questions about a couple of small "housing estate" sized places that have very high rates of patients making their choice, respecting the opt out makes no difference on analysis – ie they had to very carefully contrive a question to find any effect anywhere at all. Many other statistics are published here: <https://digital.nhs.uk/services/national-data-opt-out/national-data-opt-out-numbers>

¹¹ Gender breakdown: <https://digital.nhs.uk/dashboards/national-data-opt-out-open-data> (see appendix)

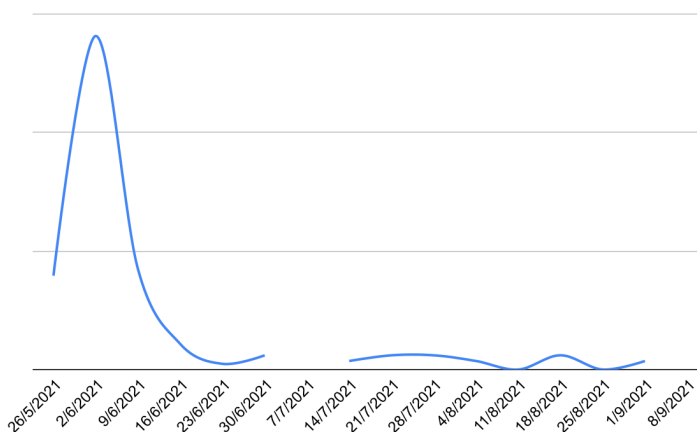
There are many reasons why people wanted us to send them a form: there was a lawyer whose printer was broken and made a significant donation; there were families without the resources for a computer; those whose printers had no ink, etc. that day; and those for whom their local library no longer existed.

NHS Digital also offered to post out forms – when we did, it had to – but it is unclear how many requests it received¹², how many forms it actually posted,¹³ and at some point it appears NHSD silently stopped sending out forms or even replying to requests. (Contributing to the “backlog of opt-outs” referred to in the Minister’s 19 July letter to GPs and the NHS Digital board papers.)

The way we measure the service medConfidential provided is by the amount we spent on stamps.¹⁴ We know that some purchases were missed, but generally the stamps we had were used within days (requiring yet more stamps). Our figures will therefore if anything be an understatement of the situation; it is likely many who are fully offline may have heard nothing at all about the programme, and certainly not about the opt-out.

Data

Week of	Envelopes posted out
26/5/2021	396
2/6/2021	1408
9/6/2021	424
16/6/2021	108
23/6/2021	24
30/6/2021	60
7/7/2021	No data
14/7/2021	36
21/7/2021	60
28/7/2021	60
4/8/2021	36
11/8/2021	0
18/8/2021	60
25/8/2021	0
1/9/2021 ¹⁵	36



¹² Compare page 35 of September 2021 Board papers

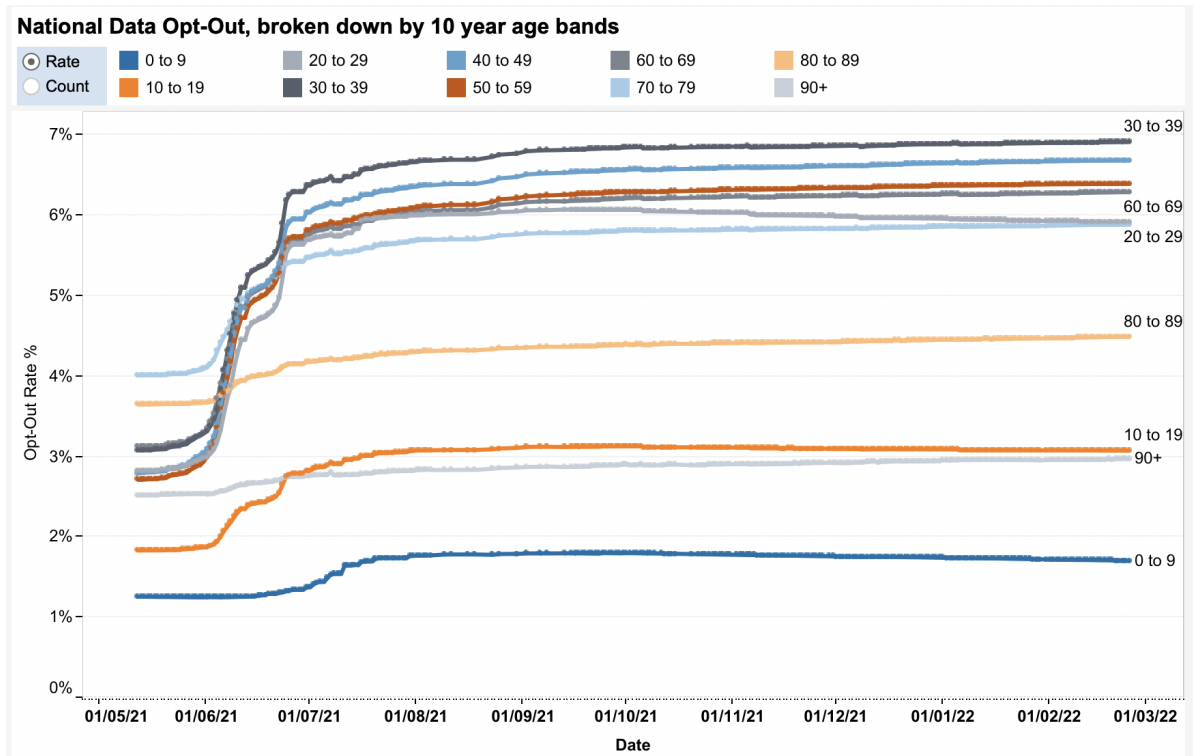
<https://digital.nhs.uk/binaries/content/assets/web-site-assets/corporate-information/board-meetings/2021/20210922-public-board-web-pack.pdf#page=35> and page 57 of December 2021 Board papers <https://digital.nhs.uk/binaries/content/assets/web-site-assets/corporate-information/board-meetings/2021/20211201-public-board-web-pack.pdf#page=57>

¹³ Comparing “contacts” with “transactions” in the NHS Digital board papers suggests very few forms were posted out by NHS Digital.

¹⁴ All stamps were second class (ie 66p each), date was collected from the receipts on expenses claims.

¹⁵ From mid-september, the figure has been between one and three envelopes a month.

Appendix:



National Data Opt Outs for those under 13 were only possible by post.