

Opt out rates over time

- **As of March 2025,¹ 5.6%² (3.464m) of patients have a National Data Opt Out (NDOO)³ and 3.3% (2.0m) have a GP Data Opt Out (GPDOO, also known as a ‘Type 1’ opt out)⁴.**
- When NDOO numbers more than doubled in 2021 (2.2% to ~5.4%⁵), GPDOO numbers went up by roughly a quarter (2.59% to 3.3%). (The full timeline is in the annex).
- **Practices with high opt out rates appear to be asking their patients to make a choice in their local new patient registration process, but the “national” process – controlled entirely by NHS England – refused to ask the GPDOO question, resulting in unpredictable outcomes that are now becoming visible:**
 - The interactions of these two systems was untested; NHSE dumped the system onto practices and did not meaningfully engage about its flaws
 - **A single digit number of practices are responsible for 10% of the GPDOO in England, without any clear or consistent reason as to why – some of them use NHSE’s GP registration process exclusively.**
- medConfidential welcomes any effort to help every patient be aware that they can make the right choice for themselves and their loved ones. That includes the ~17% of survey respondents who say they have opted out but who have not (20% think they have, only 3% have, which leaves 15+% surprised/unhappy).

Public perceptions

The real opt out rate today is 5.36%⁶ for NDOO and 3.3% for GPDOO, but various polling over time has shown that around 20% of people when asked believe they have opted out.⁷ Clearly, the biggest discrepancy is between people who think they have opted out and those who actually have – not, as [some special interests](#) argue, between those who didn’t want to be opted out but *are*.

In addition to this, when current NHS data rules are *neutrally and independently* described to people, the number of people who say they would opt out of that system approaches 50%.⁸ This figure was around 40% in 2014,⁹ and has risen to approach 50% in 2025.¹⁰

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¹ All figures used in this note are cited, but not all figures are disclosed for all months. We have picked dates to match official statistical disclosures, rather than for narrative simplicity. The figure is unchanged in October

² Note this figure is probably rounded up by the dashboard from 5.56%, but it is the past figure given in the NDOO open data dashboard <https://digital.nhs.uk/dashboards/national-data-opt-out-open-data>

³ <https://digital.nhs.uk/dashboards/national-data-opt-out-open-data>

⁴ Latest NHS England monitoring figures for GP, field 2024-25/NCD/HI18 published in March 2025 digital.nhs.uk/data-and-information/publications/statistical/mi-network-contract-des/england-march-2025 .

⁵ <https://digital.nhs.uk/dashboards/national-data-opt-out-open-data>

⁶ Dashboard: <https://digital.nhs.uk/dashboards/national-data-opt-out-open-data>

⁷ This question has been asked with different wording over time.

⁸ <https://understandingpatientdata.org.uk/what-do-members-public-think>

⁹ e.g. 6.2 at <https://cms.wellcome.org/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf> or appendix of <https://understandingpatientdata.org.uk/sites/default/files/2020-10/Public%20attitudes%202010-2018.pdf>

¹⁰ The system described being the state of things today, not what has been proposed in the 10 Year Plan

The best evidence is that opt outs have no material effect

Some data users consistently argue that the 3% (or the 5%) who have opted out ‘irreversibly damage’ research – though this argument is always hypothetical. Some argue that opt outs are biased by deprivation – the NDOO dashboard shows they are not as it is broadly flat.¹¹

Whenever projects have gone looking for actual evidence, they rarely publish that they did not find any – so the next consideration can again argue that the NDOO would irrevocably damage them.

The Cancer Registry in England (formerly of PHE, now NHSE) insisted that the NDOO would catastrophically destroy their dataset; it hasn't. What *did* destroy PHE's ownership of the data was handing data to a “causes of cancer” study run by a tobacco company.¹²

If the opt outs *had* had a material effect on patients, then we would have seen it in the use of the pandemic dataset – and the research community would have shouted any such findings from the rooftops. Even NHS England, which used the “Planning” only dataset to help determine who got Covid booster vaccines – temporarily, but even so still against stated bounds – argues GPDOO had no effect.

The coming awareness campaign

It is unclear to medConfidential why UK Biobank, HDRUK et al. believe an ostensibly upfront public awareness campaign will get the opt out rate to go down from the level it is at now, rather than going up towards the 20% of people who believe they have already opted out.

There are only a single digit number of GP practices with continually high GPDOO rates, each of which use NHS England's (now mandatory) registration form – on which NHSE refused to allow GPDOO to be offered – so that question continues to be asked elsewhere by some individual practices. There are some consistencies between these practices, which generally ask patients a straight question on GPDOO when they sign up through the practices' own sign-up process. However, given that process is now owned by NHSE, which refuses to include the GPDOO question, it may be that the “take what you're given” approach of NHSE has interacted badly with some existing practice processes. The number of affected practices is in single digits; a number so low NHS England will not have cared at all.

What's clear is that in all of the NHSE-run registration processes, no patients are getting to express their GPDOO wishes as a result of NHSE choices. Given the importance of this process, it may be that NHSE's tone-deaf approach resulted in GPDOO being set by default, simply because NHSE refuses to ask patients the question – and some GPs previously treated the question as a required decision, to be made on a safety first basis. (A Professional supportive conversation with about 7 GP practices might save a great deal of other effort...)

It is the position of UK Biobank, of Genomics England, and of Our Future Health that the pandemic GP dataset is so valuable that the “pandemic only” promise about uses of it should be torn up, while at the same time contending it is worthless because it respects GPDOO. This position is

¹¹ <https://digital.nhs.uk/dashboards/national-data-opt-out-open-data>

¹² [telegraph.co.uk/news/2018/01/14/medical-records-thousands-patients-handed-us-firms-connected/](https://www.telegraph.co.uk/news/2018/01/14/medical-records-thousands-patients-handed-us-firms-connected/)

clearly incoherent. Patients who have consented to be in a research study should have that data about them used how they wish, but shortcuts for 'administrative expediency' should not be taken at the expense of breaking promises made to all other patients.

Many of the follies of failed data grabs – past and present, and perhaps future – come from “leaders” who believe patient choices shouldn't impact on anything they personally care about, because their priorities must be imposed on others. The shared culture of HDR / Biobank, which manifests as 'efficiency' in the Department of Health for England; doing things *to* patients not doing things *for* patients.

The impact of patient objections is exaggerated by inward focussed researchers and institutions who feel that anything less than 100% of the data is an insult to their priorities. It is unlikely that such feelings can ever be reconciled with patients having choice.

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medConfidential
November 2025

Annex: Timeline

2014: The first widespread use of the GP Data Opt Out was in 2014, and when statistics were first disclosed in 2016,¹³ the GPDOO reached “1,461,877 instances” (2.59%¹⁴) and NDOO¹⁵ reached 2.2% (1,228,832 people¹⁶). Both opt outs were expressed on a single form to the practice, a single form covering an entire family, and contemporary assessments showed that almost everyone with a GPDOO had a NDOO and vice versa, but there were a minority who only requested one.

2018: The NDOO came into operation with its current name and exceptions, and DH/NHSE/NHSD wrote only to those patients with an NDOO telling them that it was all fine now and would they please opt back in. According to the July 2018 NDOO statistics,¹⁷ “There were 1,602,910 national data opt-outs as at the 1st July 2018.” NHS England decided that “If you had a type 2 opt-out in place on or before 11 October 2018 and were aged 13 or over you will have been sent a letter to tell you that your opt-out has been converted to a national data opt-out”.¹⁸ While NHS England has anecdotally said people did opt back in, the National Data Opt Out Statistics show month on month increases in the opt out count.¹⁹ No communication was sent to the other 55m patients who had not previously opted out. NHS England has made consistent claims that GPs “opted all their patients out without telling the patients” yet this exercise produced no evidence of patients reporting surprise or objections at these letters – if they had, the numbers would show it; they don’t.

By policy decisions of DH/NHSE/NHSD, the NDOO did not incorporate the full range of GDPR rights, but those NHSE was willing to give patients. Indeed, at the time, NHSE service leadership told medConfidential that “GDPR doesn’t apply to us”,²⁰ to which we suggested they check with the ICO, which resulted in the HSJ headline: “[Patient data flow suspended amid 11th hour GDPR confusion](#)” and a deal with the ICO that the NHS would sort itself out over the grace period (it’s unclear if they expected that to be 7 years and counting).

The launch of NDOO took away the single form for the whole family for both GPDOO and NDOO, and created a three (or more) step process

- Paper form for the whole family for GPDOO to the GP
- Online process (each individually) for those over 13 for NDOO
- Different NDOO paper form posted to the NHS D/E “contact centre” for under-13s

which was an improvement only for NHS England who made the entire process more difficult for patients. Punishment by paperwork in classic bureaucracy style.

¹³ All figures: <https://digital.nhs.uk/data-and-information/publications/statistical/care-information-choices/care-information-choices-may-2016>

¹⁴ Calculated using the 1,461,877 instances across 56,257,680 patients are responding practices.

¹⁵ We use current naming throughout. In 2014 the GPDOO was known as the alias today of the “type-1” opt out, and the “type-2” becoming the National Data Opt Out in 2018 after discussions with patients about clarifying the language. Those discussions excluded medConfidential as, to quote the Head of Stakeholder Engagement for that programme speaking to a coordinator of medConfidential: “you are not a stakeholder”. That individual was last seen with responsibility for some stakeholder engagement for the FDP programme...

¹⁶ [Type 2 Care Information Choices - May 2016: Workbook](#) - NHS England

¹⁷ <https://digital.nhs.uk/data-and-information/publications/statistical/national-data-opt-out/july-2018/ndop-jul18>

¹⁸ <https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/how-we-look-after-your-health-and-care-information/your-information-choices/how-opt-outs-work>

¹⁹ See each month late 2018 / early 2019:

<https://digital.nhs.uk/data-and-information/publications/statistical/national-data-opt-out>

²⁰ At the same meeting as the stakeholder engagement comment was made.

2020: The pandemic of 2020 was largely uncontroversial (at the time when usage was constrained). NHSE created a [GP extract for pandemic-only purposes](#) and it ran without controversy for some years. The pandemic dataset for planning and research respected the GPDOO but not NDOO. Misuse of this dataset were partially hidden from NHS England and the public until 2025. Patients were told they could express a GPDOO to opt out, effectively no one did (NDOO numbers went down²¹).

2021: After the “success” of the 2020 pandemic-only collection, NHSE tried to take a [generic dataset of GP data](#) without the pandemic-only constraints, and the public revolted. The NDOO rate doubled as it was the only opt out clearly signposted by NHS England, but because the GPDOO which materially affects the GP data was not signed posted by NHS England, the GPDOO opt out rate went up by only a quarter, which matches medConfidential’s assessment that our material was seen by a minority of those looking.

2022: The [Goldacre Review of 2022 was clear](#) – patient level data remains identifiable. As of 2025 NHS England agrees saying [“Personal data can be directly identifiable personal data or pseudonymised data”](#), with ICO guidance [saying](#) “Is pseudonymised data still personal data? Yes.” and [further](#): “If we anonymise personal data, does this count as processing? Yes. For the purposes of data protection law, applying anonymisation techniques to turn personal data into anonymous information counts as processing personal data. The end result (the anonymous information) is not subject to data protection law, but the procedure (anonymisation) is”. NHS England practice is not compliant.

2023: The lessons the Department of Health in England took from the 2021 exercise is that NDOO and GPDOO and COPI should be modified to let DH/E do anything they wanted as would later emerge had been done with the pandemic dataset without permission or consent.

In 2023 HDRUK began an undisclosed project (it came out via press release in 2025) which fed all the “pandemic only” data into an AI model because it would assess patients ‘before and after covid19’, because HDRUK decided “pandemic only” didn’t apply to them. (The then Secretary of State seems to have similarly decided he didn’t have to follow the promise of his predecessors because that was easier).

2024/25: DH/E commissioned “public engagement” (parts of which were little more than push polls) to justify the changes they wanted to make to the NDOO+GPDOO. Giving patients their full rights under GDPR was excluded from debate, and NHSE strongly argued that they should be able to do anything they wished with all patient data, especially in the Palantir FDP.

Late 2025? It remains unclear whether taking the public’s GPDOO+NDOO rights away at the same time as creating the “Health Data Research Service” which may get to ignore NDOO which patients are told covers research, and at the same time as creating the “Single Patient Record” as the new brand for Palantir’s FDP is going to survive interaction with reality.

2026? The NDOO could be good, it could allow patients to fully opt out of research and planning, and make uncontroversial the use of data because everyone who doesn’t want to be used in research isn’t having their data used in ways they don’t want. However, NHSE refuses to do that because that standard will apply to NHSE as well for their “non necessary” uses. In practice, DH/E may have to [lose in court](#) to give patients their existing legal rights.

²¹ March 2019 & June 2020 digital.nhs.uk/data-and-information/publications/statistical/national-data-opt-out