

# Net Assessment of decisions regarding NHS patients' data

## Executive Summary

The information given to patients and to NHS decision makers is incomplete, and promises made to patients are systematically undermined. It is beyond the scope of this Net Assessment<sup>1</sup> to determine whether what patients are told about the use of their data is more than misleading.

NHS Digital's choice to deem the linked, life-long medical records of all NHS patients to *not* be "confidential data" does, and will continue to, undermine confidence in every other decision the rest of the NHS makes on data and digital. Influence operations to avoid scrutiny are at best only a short-term approach – leaving significant problems for institutions that expect to be around after such communications end.

The need for accurate information to be provided to patients is vital if research using data acquired in the course of care is to be maintained and effective in the long term. And the harms of some number of patients believing the data system is unsafe and actively dissenting are far wider and of far greater consequence than the same number of patients believing 'medical research' no longer has the integrity it requires for public confidence.<sup>2</sup>

We presume all stakeholders agree it is desirable to avoid the same public perception of controversy for data projects as exists for vaccines. Replicated by NHS Digital, independent public opinion work by the Wellcome Trust<sup>3</sup> has shown a 40% dissent rate is possible under scenarios being considered. A narrative of "remember the 97%" is untenable should 3% become 4.<sup>4</sup>

As one of the principal NGO actors championing medical confidentiality, we have a strong practical commitment to the accuracy of all information provided to patients, and note wider concerns about statements from the Secretary of State,<sup>5</sup> and other DHSC ALBs.<sup>6</sup> Public reaction in an emergent policy debate will likely be even more unpredictable if significant stakeholders have not been fully and accurately briefed on the scope of policy intent – they haven't – most notably around "potential future decisions", even if HMG commitments are only broken "in a very specific and limited way".<sup>7</sup>

Many policy decisions covered below were justified without consideration of new data uses. At this point, only the 3% of people who had dissented from their data being used for purposes beyond their direct care have even been told directly that the new opt out exists; the remaining 97% of the population in effect know nothing;<sup>8</sup> the assumption that they are supportive remains untested.

While it may be as logical for DWP to seek to build a shadow medical record for its own purposes<sup>9</sup> as it is for DHSC to want to take a copy of patients' medical records for its own purposes, outside of public scrutiny, neither approach supports the integrity of direct care.

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<sup>1</sup> <https://www.comw.org/qdr/fulltext/06bracken.pdf>

<sup>2</sup> As demonstrated consistently throughout years of research into public attitudes around health data, collated at <https://understandingpatientdata.org.uk/sites/default/files/2019-08/Public%20attitudes%20study%20summary.pdf>

<sup>3</sup> 'Public attitudes to commercial access to health data', 2016: <https://wellcome.ac.uk/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf> - UPD's launch report.

<sup>4</sup> Perhaps the slogan for consent around GP collections should be "remember the 87%"?

<sup>5</sup> <https://fullfact.org/health/>

<sup>6</sup> <https://twitter.com/medConfidential/status/1204434773063733249>

<sup>7</sup> <https://www.theguardian.com/politics/2020/sep/08/government-admits-new-brexit-bill-will-break-international>

<sup>8</sup> Launching NDOP with similarly-worded communications at the beginning of GDPR did not create public awareness; removing GPs' ability to offer Type-2s may have manipulated the opt-out figures, but reveals nothing about public views.

<sup>9</sup> [https://www.theregister.co.uk/2019/02/19/dwp\\_health\\_data\\_tool/](https://www.theregister.co.uk/2019/02/19/dwp_health_data_tool/)

## The things NHS Digital chooses to tell patients...<sup>10</sup>

*“The national data opt-out allows a patient to choose if they do not want their confidential patient information to be used for purposes beyond their individual care and treatment - for research and planning.”<sup>11</sup>*

Four types of exception to the opt out are listed:<sup>12</sup>

- 6.1: *Consent*
- 6.2: *Communicable diseases and risks to public health*
- 6.3: *Overriding public interest*
- 6.4: *Information required by law or court order*

Each of which is reasonable, and for most of which we see no evidence of systemic misuse.

### ...but also the things it doesn't say

NHS Digital's page for patients contains a clear commitment that “By 2020 all health and care organisations are required to be compliant with the national data opt-out policy”,<sup>13</sup> but omits to say there is currently no mechanism in place to ensure or even check compliance.

Even where they should be applied, NHS Digital's own figures show opt-outs are widely disregarded – for every one data release for which opt-outs are respected, there are around ten which have not. There were 4,434 disseminations in November 2019,<sup>14</sup> of which 87% had opt-outs disregarded without sufficient approvals.<sup>15</sup>

While DHSC / NHS Digital has no readily accessible mechanism for a patient to be able to know their wishes are being disregarded 87% of the time, it is not a stable situation to believe that patients will perpetually remain ignorant.

And while NHS Digital does publish its release data, it publishes it as one large spreadsheet per month, which is fundamentally impenetrable to regular people. (medConfidential restructures the Excel files' content as a set of webpages at <https://TheySoldItAnyway.com>)

Neither NHS Digital<sup>16</sup> nor NHS England makes public reference to the opt-out mechanism for GP data, which is managed by GPs and not by NHS Digital. Patients are no longer told it still exists, and NHS England guidance is at best 'unclear'.

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<sup>10</sup> <https://digital.nhs.uk/services/national-data-opt-out>

<sup>11</sup> <https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out>

<sup>12</sup> <https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/when-does-a-national-data-opt-out-not-apply>

<sup>13</sup> <https://digital.nhs.uk/services/national-data-opt-out>

<sup>14</sup> <https://digital.nhs.uk/services/data-access-request-service-dars/register-of-approved-data-releases/release-register-archive>

<sup>15</sup> For July 2020, the last month for which data is currently available, such reasons were given as:

- 3805 No - data flow is not identifiable
- 480 Yes - patient objections upheld
- 164 No - Birth data is not considered as personal confidential information - however when handling applications for the data we treat these data as identifiable, even though patient opt outs do not apply
- 82 No - deaths data flowing to Local Authorities does not require the application of patient opt outs
- 57 No - consent provided by participants of research study
- 30 No - NHS Digital are statutorily obliged to provide the data to the CQC
- 8 No - legal basis permits flow of identifiable data
- 8 No - flow to PHE under a memorandum of understanding

<sup>16</sup> E.g. the COVID-19 GPES extract info states only “national data opt-outs will be considered on a case by case basis”, being mute on Type-1s:

<https://digital.nhs.uk/coronavirus/gpes-data-for-pandemic-planning-and-research>

## The national online opt-out process

The online opt-out process is built to serve only individuals and to relate to existing national data collections; a ‘digital service’ without even a basic conception of family life.<sup>17</sup>

While a single individual over the age of 13 can opt out online or using their mobile phone, should a parent wish to express their wish for their child, they must post (i.e. with a stamp) a 7 page form, along with copies of passports, birth certificates and other ID documents, to NHS Digital’s offices in Leeds – there is no official online option for children.<sup>18</sup>

This process is unlikely to prove tenable when subject to wider public scrutiny.

At the time of its withdrawal, the previous ‘Type-2’ GP-mediated dissent mechanism was used by around 5,000 patients per month or roughly 0.01% of patients, as compared with around 100 patients a month using NHS Digital’s new online system.<sup>19</sup> We submit these figures represent a restriction of patients’ rights and choice – not a communications success, as some have claimed.

NHS Digital has ceased publishing regular statistics on opt-outs, appearing to publish them when there is a net change of 0.1% of the population, or in annual updates – administratively hoping it never need publish any ‘irregular’ statistics, but confirming high-profile bad news events when it does so.

## Organisations make mistakes...

NHS Digital routinely audits its data recipients, to assess whether they are following the rules in their contract.<sup>20</sup> It regularly finds major breaches by organisations,<sup>21</sup> which are allowed to continue to receive data even after they break their contracts.<sup>22</sup>

According to NHS Digital’s own data release register, some 38 non-NHS organisations received multiple copies of data from the *same* dataset in the *same* month, one copy having opt outs respected, and another copy with dissenting patients’s data included. The only thing preventing a direct comparison between those two files being a contract which does not allow for any such comparisons to be discovered.<sup>23</sup>

While the NHS remains reliant on pseudonymisation to avoid legal controls around personal data, the law and the ICO are clear: “pseudonymisation is effectively only a security measure. It does not change the status of the data as personal data.”<sup>24</sup>

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<sup>17</sup> <https://digital.nhs.uk/services/national-data-opt-out>

<sup>18</sup> NHS Digital makes database checks (against PDS) to confirm an individual’s identity; it does not then use the information it just verified to check whether that individual has any children for whom to offer a dissent choice.

<sup>19</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/care-information-choices> and

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

<sup>20</sup> <https://digital.nhs.uk/services/data-access-request-service-dars/data-sharing-audits>

<sup>21</sup> <http://theysolditanyway.com>

<sup>22</sup> [http://theysolditanyway.com/organisations/harvey\\_walsh\\_ltd/](http://theysolditanyway.com/organisations/harvey_walsh_ltd/)

<sup>23</sup> And without a statutory basis for the ‘single strike’ sanctions for misuse of patients’ data that were promised as far back as 2014, NHS Digital considers itself powerless to act.

<sup>24</sup> <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/what-is-personal-data/what-is-personal-data/>

## **...but the process of disseminating data is always unsafe**

The current approach to the dissemination of health data began in the early 1990s with what are now called the Hospital Episode Statistics (HES), and the scope of dissemination has been expanded repeatedly over time.

No fundamental recounting has been made of significant changes in the data environment, and the law – despite the *first* Caldicott report in 1997, which defined the list of identifiers in health data,<sup>25</sup> and the Data Protection Act 2018, which made it explicit that pseudonymised data is identifiable.

HES pseudonymises the NHS number, while maintaining the link between all of the health records for a particular individual, which are themselves defined events with dates attached. While it is unlikely one could guess a target's NHS number or pseudonym, knowledge of a combination of or even a single health event in their life allows their pseudonym to be discovered – and thereby all other health events linked to that identifier to be read off.

In practical terms, while NHS Digital claims to protect the date of birth of a child, it does not protect the dates attached to 'maternity events' of the mother, nor does it take account of those who (are expected to) make public, high profile statements about their health events.<sup>26</sup> It is for this reason that we have recommended and supported the creation and use of safe settings, and specifically NHS Digital's Trusted Research Environment<sup>27</sup>. But while health and research bodies now appear conversant with the Five Safes, their practical application lags behind – currently at best on a 20:80 basis (access through safe setting vs dissemination) when in 2020, the reverse should be true.

While public concerns about commercial exploitation are well-known – though poorly grasped – taking copies of individual-level data to inform funding decisions could prove equally unwise. As the pandemic has shown, the NHS 'branding' on a programme or organisation does not guarantee the trust of a public who are becoming more sophisticated in their understanding of the use and abuse of data and its derivatives with every passing month. Nor are things helped by systemic lack of transparency, including the failure to publish records legally required to be kept by the COPI Notices.

## **Pre-COVID, the public context was about to change**

While the assessment above is for currently held data, NHS England, NHSX, and DHSC were planning a new collection of GP data in early 2020.

The last attempt at a mass GP data collection was 'paused' in 2014 and finally abandoned in 2016, but not before having made a commitment to send a letter to each patient telling them about the programme and how to opt out. Subsequent undertakings were given that any new GP data extract would be made available exclusively via safe setting. It is as yet unclear whether these promises will be maintained for any new initiative. Since that period, NHS Digital has also implemented a

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<sup>25</sup> Appendix 7, [https://webarchive.nationalarchives.gov.uk/20130124064947/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4068404.pdf](https://webarchive.nationalarchives.gov.uk/20130124064947/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4068404.pdf)

<sup>26</sup> For further worked examples, see 'Misunderstanding the Birthday Attack': <https://medconfidential.org/2015/medconfidential-response-to-nhs-england-response-to-sky-news-nhs-security-story-and-research-by-the-oxford-internet-institute/>

<sup>27</sup> <https://digital.nhs.uk/coronavirus/coronavirus-data-services-updates/trusted-research-environment-service-for-england>

programme that collects data from private providers about the care they provide. The data of any non-NHS patients collected is not covered by the opt out,<sup>28</sup> a fact which is likely to widen and intensify interest in any new programme.

The care.data debacle is now seen inside Government as something no longer salient to tomorrow's data projects – it is most often dismissed as simply a “communications” failure. It is therefore reasonable to expect there will be communications and influence operations for any new programme replicating those of the political party that was successful in the 2019 UK general election.

How this will play out within the context of an ongoing Government or NHS data programme is unclear; have any such actions been meaningfully contested and sustained for even one Parliament, as opposed to the environment of a political campaign with a predefined end date and an objective measure of success?

In any event, the consequences for those health institutions whose active support is not only required but necessary will remain long after any Government communications campaign ends.

## Conclusion

To paraphrase this Net Assessment in a single tweet:

As a patient, if you find out - which you probably won't;  
& if you are informed (but @DHSCgovuk doesn't tell you)  
& if you opt out, which @NHSDigital makes hard;  
& if you take the extra steps for your kids, which are harder;  
then this Government will be selling your data anyway...

medConfidential, August 2020  
sam@medConfidential.org

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<sup>28</sup> <https://digital.nhs.uk/services/national-data-opt-out/understanding-the-national-data-opt-out/who-must-comply-with-the-national-data-opt-out-policy#organisations-not-covered-by-the-national-data-opt-out-policy>