

# Your Personalised Health & Care Data Usage report

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This should be produced for you by NHS Digital & available via NHS.UK,  
instead, designed and printed by medConfidential at TheySoldItAnyway.com

**January 2022**



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# From NHS Digital: Here's what we did with your data

NHS Digital runs the computer systems at the heart of the NHS; we treat no patients, we run no hospitals, but we support those who do with data systems and modern infrastructure.

As custodian of the confidential medical information of you and millions of other NHS patients, we at the statutory safe haven for health and social care data in England believe you should know how your information has been used, and by whom – and what resulted from those uses. Our aim is to build confidence by providing knowledge about hundreds of data projects around and across the NHS each month. This report therefore itemises who has accessed **your** data, and for what reasons, in the past 3 months.

Data is vital for planning and monitoring, for research, and to help run and improve the services on which we all depend. You have the right to [choose whether your information is used for any purpose beyond your direct care](#). We hope this and future reports show how beneficial choosing to be included can be, and that knowing how your information is used supports your ongoing confidence in allowing your data to be used for those purposes. The choice to be included is a gift from you; yours to share or not, as you decide.

Our [dashboards](#) are public, our [data usage registers](#) are public, and our [Board meeting minutes and papers](#) showing the performance of every service we run are public too. Our audits – both [clinical](#) and [data](#) – are public, and we publish both [what we have been directed to do](#) and [the data people are requesting to access](#) as part of our public accountability. We also openly [publish information](#) that shows where our [powers to limit high-risk activity by data recipients are limited](#).

It is far safer to provide access to data in a properly controlled Trusted Research Environment, or 'TRE' – though these aren't just for academic research. [Good TREs work](#). Our [release registers](#) show many organisations are already able to use NHS Digital's "system access" for their own authorised purposes, and we continue to expand the range of those for whom our environment is used.

Information you share with your doctors and those who care for you must be kept confidential, but there should equally be no secrets *about how your health records are used*. Earlier this summer, NHS Digital implemented Directions from the Government around the extraction and opt-out process for GP data; we did [as we were Directed](#) regarding the timing of the collection and the lack of public communications as well.

The [Government has notified us](#) that NHS Digital will be abolished "as soon as legislation allows", likely through powers taken by NHS England, who have written the introduction on the next page.

Goodbye.

Mr Simon Nearmanchester  
Not-quite-the Outgoing Interim Chief Executive Officer,  
NHS Digital

# From NHS England: Why do you want to know?

NHS England makes [plans](#) – [lots of plans](#) – then decides how best to “support and assure the performance” of NHS organisations across England. We also drive “system transformation”, for which we need ever more data. We tell [hospitals](#) and [doctors](#) how they should “[best](#)” practice medicine, though we treat no patients and run no hospitals. For the good of the system, we believe we shouldn’t be restricted in what [we say](#), nor on how we use your medical records – even if [others think otherwise](#).

Our focus is on protecting the institution and ensuring communications are consistent, which often means having to make tough decisions about when to enforce the rules, particularly when they’ve been [violated](#) by an institution represented on our own Board. We listen closely to our stakeholders, and to the handpicked organisations we appoint to our advisory boards, who challenge what we say... [but not too much](#). (Nor more than once.)

From the beginning of the pandemic we said we would do everything we could to make our own “single source of truth”, which we did with Palantir and millions of your records. Although now we have our shiny dashboards, we’re not so sure the “[data will either be destroyed or returned](#)” as we promised. Data saves lives, you see.

We also said we’d make the data we collected “openly available”, and that every data use would be approved via a process controlled solely by us. Transparency is important, which is why 12 months later we published details of 18 projects (later [updated to 20](#)) briefly describing some of the less controversial uses. Our Palantir system is advertised as [open, extensible and interoperable](#) with anything – except the systems NHS Digital uses for accountability. NHS England also manages the process for external researchers, to ensure their independent academic research does not contradict our internal line; maintaining standards for us and them.

We are proud of our [track record](#) on steering [large data projects](#). Almost as proud as we are to have embedded Palantir in the heart of the NHS, for ‘[a good analyst can save more lives than a good anaesthetist](#)’. NHS England has hundreds of analysts, all expert at cutting and pasting from Palantir into reports. Then, to help patients, we write letters to hospitals and GPs insisting they must do what we think is best for their patients – or at least, for the [headlines](#) about them.

NHS England is also working with Government to develop AI to help the NHS – whether that’s to prioritise people on waiting lists, reduce staffing shortages, or to play with cool stuff in our ‘[skunkworks](#)’. Having worked closely with [AI mercenaries](#) since before the pandemic, we gladly work with the Home Office [ACE programme](#) – and we are certain commercial entities, and other countries, wouldn’t do to us what this Government’s advisors [suggest we do to them](#).

We remain a huge supporter of TREs. Quite aside from Palantir, we used to approve dozens of “Accredited Safe Havens”, filling them with “[weakly pseudonymised](#)” data and hoping no-one noticed. Our trust model is simple: you must just trust us.

The rest of this report covers NHS Digital’s activities.

Mr Simon Nearmanchester

Not-quite-the Incoming Chief Information Officer, [reporting](#) to the Director of Transformation, Transformation Directorate, who [reports](#) to the National Director, Strategy and Innovation  
NHS England



## Direct Care Accesses

From participating institutions<sup>1</sup>, your medical record was accessed since 1st July 2021 at:

15th December 2021:  
Your GP practice, Coventry.

11th, 13th December 2021:  
LTH Pathology Ltd

10th-13th December 2021:  
Leeds Teaching Hospital.

9th-10th December 2021:  
York Hospital, including SCR via non-consented A&E.

3rd December 2021:  
Your GP Practice, Coventry



There have been no reported breaches or losses of your medical records from your doctors or hospitals this quarter.

<sup>1</sup> for details and an explanation <http://www.nhs.uk/sharedcarerecords/whoaccessedyourdata>

# Knowledge Created with your contributions

Your data is distributed as part of Hospital Episode Statistics (HES). Academics and researchers use them to try and learn more about health and illness. The research below may have been conducted in any of the last several years, on any health event since 1988 - when HES was first collected. You may have been included as a healthy person unaffected by the condition, as part of a comparison group to examine differences to the general population.

## Knowledge from Academic Research

[Risk prediction for poor outcome and death in hospital in-patients with COVID-19: derivation in Wuhan, China and external validation in London, UK](#) H Zhang, T Shi, X Wu, X Zhang, K Wang, D Bean... - 2020 - [papers.ssrn.com](#) ... *[open access]*

Accurate risk prediction of clinical outcome would usefully inform clinical decisions and intervention targeting in COVID-19. The aim of this study was to derive and validate risk prediction models for poor outcome and death in adult inpatients with COVID-19.

[Features of 20 133 UK patients in hospital with covid-19 using the ISARIC WHO Clinical Characterisation Protocol: prospective observational cohort study](#)

AB Docherty, EM Harrison, CA Green, HE Hardwick... - *bmj*, 2020 - [bmj.com](#) *[open access]*

In study participants, mortality was high, independent risk factors were increasing age, male sex, and chronic comorbidity, including obesity. This study has shown the importance of pandemic preparedness and the need to maintain readiness to launch research studies in response to outbreaks.

[Estimating excess mortality in people with cancer and multimorbidity in the COVID-19 emergency](#) AG Lai, L Pasea, A Banerjee, S Denaxas, M Katsoulis... - *MedRxiv*, 2020 - [medrxiv.org](#) *[open access]*

We provide the first estimates of potential excess mortality among people with cancer and multimorbidity due to the COVID-19 emergency and demonstrate dramatic changes in cancer services. To better inform prioritization of cancer care and guide policy change, there is an urgent need for weekly data on cause-specific excess mortality, cancer diagnosis and treatment provision and better intelligence on the use of effective treatments for comorbidities.

[Student-teacher curriculum learning via reinforcement learning: predicting hospital inpatient admission location](#) R El-Bouri, D Eyre, P Watkinson... - *on Machine Learning*, 2020 *[open access]*

Accurate and reliable prediction of hospital admission location is important due to resource-constraints and space availability in a clinical setting, particularly when dealing with patients who come from the emergency department. In this work we propose a student-teacher network via reinforcement learning to deal with this specific problem. A representation of the weights of the student network is treated as the state and is fed as an input to the teacher network. The teacher network's action is to select the most appropriate batch of data to train the student network on from a training set sorted according to entropy. By validating on three datasets, not only do we show that our approach outperforms state-of-the-art methods on tabular data and performs competitively on image recognition, but also that novel curricula are learned by the teacher network. We demonstrate experimentally that the teacher network can actively learn about the student network and guide it to achieve better performance than if trained alone.

[Impact of the COVID-19 pandemic on the detection and management of colorectal cancer in England: a population-based study](#)

EJA Morris, R Goldacre, E Spata, M Mafham... - *The Lancet* *[open access]*



There are concerns that the COVID-19 pandemic has had a negative effect on cancer care but there is little direct evidence to quantify any effect. This study aims to investigate the impact of the COVID-19 pandemic on the detection and management of colorectal cancer in England.

How do patients with malignant brain tumors experience general practice care and support? Qualitative analysis of English Cancer Patient Experience Survey (CPES) ...

I Fraulob, EA Davies - Neuro-Oncology Practice, 2020 - [academic.oup.com](https://academic.oup.com) [open access]  
English Cancer Patient Experience Survey (CPES) data show patients with brain cancer report the least-positive experiences of general practice support. We aimed to understand these findings by identifying the issues described in qualitative survey feedback and suggest how care may be improved.

Risk stratification of patients admitted to hospital with covid-19 using the ISARIC WHO Clinical Characterisation Protocol: development and validation of the ...

SR Knight, A Ho, R Pius, I Buchan, G Carson... - *bmj*, 2020 [open access]  
An easy-to-use risk stratification score has been developed and validated based on commonly available parameters at hospital presentation. The 4C Mortality Score outperformed existing scores, showed utility to directly inform clinical decision making, and can be used to stratify patients admitted to hospital with covid-19 into different management groups. The score should be further validated to determine its applicability in other populations.

Ethnicity and risk of death in patients hospitalised for COVID-19 infection in the UK: an observational cohort study in an urban catchment area

E Sapey, S Gallier, C Mainey... - *BMJ open* ..., 2020 - [open access]  
Those of South Asian ethnicity appear at risk of worse COVID-19 outcomes. Further studies need to establish the underlying mechanistic pathways.

Evaluation and Improvement of the National Early Warning Score (NEWS2) for COVID-19: a multi-hospital study

E Carr, R Bendayan, D Bean... - *BMC* ..., 2021 - [open access]  
NEWS2 score had poor-to-moderate discrimination for medium-term COVID-19 outcome which raises questions about its use as a screening tool at hospital admission. Risk stratification was improved by including readily available blood and physiological parameters measured at hospital admission, but there was evidence of miscalibration in external sites. This highlights the need for a better understanding of the use of early warning scores for COVID.

Linkage of the CHHiP randomised controlled trial with primary care data: a study investigating ways of supplementing cancer trials and improving evidence ...

A Lemanska, RC Byford... - *BMC Medical* ..., 2020 - [open access]  
We provide a set of recommendations on linkage and supplementation of trials. Data recorded in primary care are a rich resource and linkage could provide near real-time information to supplement trials and an efficient and cost-effective mechanism for long-term follow-up. In addition, standardised primary care data extracts could form part of RCT recruitment and conduct. However, this is at present limited by the variable quality and fragmentation of primary care data.

There were 205 articles published in the time period. To read all publicly available scholarly papers that used data, and search by keywords, please see <http://www.nhs.uk/data/whatwelearnt>

## **Knowledge from Commercial Data Use**

Commercial providers are not required to have public benefits for new activity, nor do they report use of the data. Therefore, we have no independently citable evidence of public benefit.

## Where your data went

HSCIC releases data to eligible organisations that meet defined criteria, for the purposes of the provision of health or adult social care, or for the promotion of health. These organisations and releases are not for the purposes of your direct care, but should generate future knowledge of the types covered in the previous section.

**On the 18th June 2021, you enabled the National Data Opt Out preference to dissent from data being used for purposes beyond direct care, such as research and planning. The releases below occurred before that date.**

Your data was included in the following releases, for the following reasons. For more details of any release, the work they wish to do, and the past work of that organisation, see the internet links given below:

### One Off Releases

**Harvey Walsh Ltd - data dissemination.** Harvey Walsh undertake numerous projects utilizing HES on a yearly basis, approximately 120 distinct projects were completed in 2017/18. The outputs produced as a result of the data processing may include (but are not limited to)... [\(more\)](#) **An audit shows unreported data breaches.**

**OpenSAFELY and High Cost Drugs linkage** - NHS England request this data to support their Coronavirus (COVID-19) research platform work. The National Tariff High Cost Drugs List contains the High Cost Drugs which are not covered by national prices under the National Tariff Payment System. These drugs are typically used in a relatively small number of specialist centres rather than across all Trusts. High cost drug data can also be used to answer questions directly related to 'confounders' and those people in the UK who are shielding. NHS England can rapidly review how such specific medications are associated with COVID-19 related outcomes, such as mortality, to help inform clinical and policy decisions on shielding criteria.

**NHIS Ltd (Wilmington Healthcare) — (66 files)**

NHiS is an information intermediary which specialises in applying healthcare data to produce outputs that are used in health and social care to: 1. Raise disease awareness, management and diagnosis through analysing data and publishing reports and tabulations which are available in the public domain; 2. Support the commissioning cycle and enhance patient outcome through understanding disease progression and applying to continual service development improvement A directorate within NHiS is the Neurology Commissioning Service (NCS), an official NHS England (Ref: Map of Medicines), niche commissioning support unit... [\(more\)](#)

**University of Manchester - Self-harm project (8 datasets)**

Reduction in the numbers of suicide following self-harm is an important objective of the National Suicide Prevention Strategy for England, with research showing that suicide prevention is key to achieving this. As well as suicide, self-harm is associated with increased risk of other causes of mortality. Therefore, all-cause mortality is an important outcome to monitor following self-harm.

### National Back Office

Your record was included in **3** status checks for repeats of past conditions. Information from it was provided **once** to the 1965 Cohort Study who had lost track of you in 2003 and wished to recontact you to request your continued participation. Access is *temporarily* suspended for the UK Border Agency via their self-assertion of access via the Data Protection Act.

# Ongoing Releases

## Public Sector

**NHS England** - DSfC – 30 different datasets – NHS England will carry out analysis on a variety of pseudonymised datasets. This collection of datasets has been referred to as the “temporary National Repository” (tNR), and is now known as the National Commissioning Data Repository (NCDR). The requested datasets are required to ensure that NHS England can meet its statutory duties (as per NHS Act 2006 and the Health and Social Care Act 2012 s13N,s23) and to meet the requirements of the Five Year Forward View. The objective for processing can be summarized as the provision of an ad-hoc and routine analysis and reporting service to support the work of NHS England (NHSE)... ([more](#))

**NHS England** -National Gastro Intestinal Cancer Audit Programme – HES or SUS - Admitted Patient Care. By auditing the care delivered by cancer services, we can highlight areas where hospitals are doing well, and areas in which the quality of care can be improved. By producing information for all NHS services, it allows cancer services to compare themselves with others in England and Wales and share examples of good practice.

**CSUs, CCGs, NHS England, PHE, LAPH** - Data linkage and processing for Commissioning  
Commissioning activities of: Validation of provider invoices; Pandemic emergency planning; Monitoring and audit; Provider performance management; Strategic delivery planning; Immunisation monitoring

## Commercial Users

**Dr Foster** – direct feed – 11 datasets

Dr Foster use the data provided under this agreement to provide a management information function in the form of analysis and clinical benchmarking for healthcare organisations and to increase the power of predictive models for rare diseases, procedures and events. Dr Foster build standard casemix adjustment models for 259 diagnosis groups and 200 procedure groups which include some rarer conditions. Casemix is a system that measures hospital performance, aiming to reward initiatives that increase efficiency in hospitals. It also serves as an information tool that allows policy makers to understand the nature and complexity of health care delivery. Using all the requested datasets means that Dr Foster have the most up to date information and can inform customers of potential issues around quality and in turn they can make better informed decisions for the improvement of healthcare and outcomes for patients... ([more](#))

## Academia

**SAHSU at Imperial College London** - HES/ONS Linked and GP pandemic file

Evaluation of birth weight trends: Birth weight centiles updated with the data 2012-18 (up to the available year) and small for gestational age centiles to be used as a threshold to define small for gestational age (SGA) outcome in future environmental epidemiology studies 2. Evaluation of stillbirths in relation to birth weight charts: Analysis of the effect of stillbirths in relation to Birth weight centiles. 3. Construction of Birth weight charts sex-specific and ethnic-specific: Birth weight trends to investigate the evolution of trends in England and Wales, (including data from 1986-2012) and to identify change points and analysis in the relation of ethnic differences. 4. Validation of the existing birth weight charts and evaluation of the misclassification rates: Validation of the actual birthweight chart with the most recent data, to investigate based on the birth weight trends if updated are required due to changes in population distribution Maternal residential exposure to aircraft and railway noise and risks of adverse birth outcomes: (2019) A PhD student is the lead analyst working on this study. **An audit shows there continues to be HIGH RISK non-compliance by Imperial College which they have failed to rectify.** [You can find more details of what happened, & how it affects you.](#)

## Concerns

If you haven't questions about where your data was accessed for Direct Care purposes, please use the guide on <http://www.nhs.uk/sharedcarerecords/whoaccessedyourdata> for support in finding answers to your questions.

If you have any other questions about the content of this report, please contact [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk)

## Access to knowledge

From April 2014, all new publicly-funded research was required to be open access, with unrestricted online access to peer-reviewed scholarly research. Research funded earlier, or outside the UK, may require payment of an additional fee per reader. If you would support NHS Digital mandating that all publications using public data be open access, please email a statement of support to [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk)

If you have opted out of your data being included in data releases, we will continue to show you research resulting from releases prior to your objection being implemented.

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Ask NHS Digital where you can get yours.

Or email [coordinator@medconfidential.org](mailto:coordinator@medconfidential.org) for what we may do next