NHS England ignores data protection law to test Palantir's Foundry Platform and strengthen central control

KONP data WG November 2022

Brief reminder: The Health and Care Act 2022[1] gives sweeping powers to NHS Digital to share data in connection with health or adult social care. It gives the Secretary of State the powers 'to require data' from any NHS or social care, or private organisation involved in health care in a specific, standardised form so that it is readable and useful for any NHS provider or commissioner to use for whatever purpose. The Act also enables organisations to be merged: NHS England is to take over the roles and powers of NHS Digital, including the management of NHS data, but this will not be completed until early 2023.

Introduction

According to a recent report,[2] the government, on behalf of NHS England, is directing NHS Digital to pilot test the collection and sharing of patient data for what is called the 'Faster Data Flow Acute Data Set'. This will collect patient level identifiable data (including NHS number, date of birth and postcode) about admission, inpatient, discharge, and outpatient activity from acute providers. Until now, this kind of data has been collected weekly (at most) and sometimes only annually: now, these data will be brought together in one daily collection[3]. The aim is to carry out this collection and processing in Real Time. Such an ability will empower the managers of the systems to rapidly identify and make decisions about levels of performance, variations in practice, costs and outcomes and where limited money should best be allocated to maximise value.

Why is this happening?

The reasons given for this data swoop are to help with elective waiting list recovery, support health commissioning and planning, and achieve better health outcomes for individuals and populations. Teasing out more detail from the document, it is clear that there are aims to enable:

- the 'effective' use of independent sector capacity to help with the NHS backlogs;
- improved efficiency in inpatient services by identifying 'patients who are blocking beds' (their words) for actioning by services;
- the use of data to drive improvement within the NHS, through using consistent measurement of performance; and
- working with regions and systems, to understand and address the reasons behind 'performance variation'.

[1] https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted

[2] Minutes of NHSD Board meeting, 1st November 2022 https://digital.nhs.uk/about-nhs-digital/our-organisation/nhs-digital-board/board-minutes-and-papers

[3] The Data Protection Impact Assessment for this project has been approved by NHS Digital's Data Protection Officer but was not available with the report.

The data, software, and processing

The software to be used is the Foundry Data Platform developed by Palantir, which is 'owned' through contract and managed by NHS England. A data processing agreement is already in place setting out the terms for the provision of the Foundry Services by NHS England to NHS Digital to enable the daily collection, processing and pseudonymisation[4] of data for health commissioning and planning purposes, with Palantir as sub-processor. NHS England has directed NHS Digital not to publish any of the data collected, but instead provide an 'anonymised' version of the data set for them, which they will in turn disseminate to Integrated Care Boards and acute providers.[5]

Avoidance of any opt-out

Ideally, to meet the aims listed above, or for any further data analysis or algorithm development, the data set needs to be complete i.e. have minimal opt-outs. If this project were to be performed later next year, then NHS England would have acquired NHS Digital's powers with respect to data management. NHS England's current lack of these powers probably explains the convoluted and contradictory suggestions in the report about who takes the role of data controller and who is the data processor. This is very much NHS England's project. They have chosen and own the Platform to be used, the data and processing required, and the method of dissemination: they are indeed the data controllers. However, NHS England have set it up so that it appears as if NHS Digital are the prime movers who supply them with 'anonymised data[6] for commissioning and planning'. *With the data categorised as anonymous, patients cannot opt out of the use of their data*!

The only way that patients will even know that their personal data is being collected and processed (courtesy of Palantir) on a daily basis, is if they seek out acute providers' 'privacy notices' - NHS England have advised Providers to include information about the Faster Data Flow collection and subsequent processing of their patient's data in these notices. Of course, NHS Digital will provide a Data Provision Notice as well, wherever that can be found.

Comments

1. The use of Real Time data by NHS England, that is also made available via dashboards to Integrated Care Boards, has become a major part of their plan to improve the elective care and cancer care back logs- this possibility has probably been boosted by Palantir's now 30 contracts to provide software to Trusts to reduce

[4]Unlike anonymisation, pseudonymisation techniques will not exempt controllers from the ambit of GDPR; Recital 26 provides that "Personal data which have undergone pseudonymisation, which could be attributed to a natural person by the use of additional information should be considered to be information on an identifiable natural person."

[5] There is of course an artificiality to all of this-it is general knowledge that NHS England are in the process of taking control of NHS Digital and this is to be completed at the beginning of next year

[6] According to the Information Commissioner's Office, anonymous information is defined by the ICO as information that does not relate to an individual. Anonymised data is data that has identifying elements removed so that a third party should be unable to de-identify it. This means the data is no longer personal data and therefore not protected by data legislation.

elective care waiting lists[7]. One hopes that such an action aimed at resource management is not going to stand instead of the increase that most staff in the NHS, plus many commentators, feel is essential to help to manage these lists as effectively as possible while maintaining usual NHS activities.

2. The idea that only anonymised data will be disseminated from this process in the future seems to run counter to its ultimate aims, namely, not only to speed up access to data, but rapidly to identify the situation of particular patients who are: i) slowing down the system; ii) receiving procedures of 'low-value'[8] or iii) being cared for by individuals or teams working in any 'unwarranted' way[9].
3. Our data is to be used to drive improvement, and ensure uniformity of performance within the NHS. The new imperative to collect data, and the need for all clinical decisions or actions to be entered onto a computer, will enable data collection about the care provided to every patient from every healthcare worker. With the granular detail of the associated PLICS[10] costings currently being developed,[11,12] NHS England will be aware of every penny spent. This is a Performance Manager's dream.
4. The obfuscation used in this study in order to avoid Data Protection Law -and therefore consultation and the provision of an 'opt-out' - is deplorable and will not engender public confidence. The population is being treated with contempt while complete transparency and proper consultation are assigned to the bin.
5. Further, there is a worrying tone to parts of this report, such as the idea that there are 'bed blockers'- a terrible, pejorative term for frail older people stuck in hospital through no fault of their own because there is nowhere else safe to be. This situation is due to gross underfunding of social care and health care by serial governments. The use of such a term reveals a mindset of blame at the centre of the health service that may perhaps extend in the future to identify 'financially profligate physicians', 'responsibility averse GPs' or 'shirking nurses'. It is of course much easier to blame individuals than to take the difficult decisions that run counter to the current ideology of low state spend, especially if these may hamper career progression.

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[7] https://www.healthcareitnews.com/news/emea/nhs-teams-palantir-tackle-elective-care-waiting-lists

[8] The NHS in England decided to stop funding clinical procedures it considered 'low value' or unnecessary, to save money and eliminate clinical variation across the country. The list of procedures continues to grow. https://www.bmj.com/content/362/bmj.k2903

[9] It is stated that 'Some types of variation can sometimes be unacceptable and harmful for patients, their families and carers, and the health services that support them. Variation that is judged to have harmful consequences is known as 'unwarranted variation''. https://www.england.nhs.uk/rightcare/2017/01/04/matthew-cripps-3/

[10] The Patient Level Information and Costing Systems (PLICS) data collection records activity and cost information for acute, mental health and ambulance services in England. https://www.nuffieldtrust.org.uk/files/2017-01/patient-level-costing-summary-web-final.pdf

[11] https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/patient-level-information-and-costing-system-plics-data-collections

[12] NHS costing is going through a massive transformation, moving from costing based on averages to costing the actual care individual patients receive. Patient-Level Information and Costing Systems (PLICS) bring together healthcare activity information with financial information in one place. PLICS provides detailed information about how resources are used at patient-level, for example, staff, drugs, and diagnostic tests. https://www.hfma.org.uk/our-networks/healthcare-costing-for-value-institute/what-is-plics

APPENDIX

From MedConfidential: THE PLANS FOR OUR PERSONAL DATA ACCORDING TO NHS England from 'Enabling Evidence based continuous improvement; the target architecture[13]'(circa 2017)

POSTSCRIPT

> The use of Palantir's Foundry, if it is found to be capable of collecting and processing Real Time data for all the ICSs, will surely serve to settle the question of who will get the contract for the NHS England Federated Data Platform[14]. This at a time when Palantir is drumming up trade in the development of Lethal Autonomous Weapon Systems in NATO, with Imperial College London as the European Headquarters[15].

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[13] https://medconfidential.org/wp-content/uploads/2017/09/2017-07-13-Target-Architecture.pdf page 14
[14] https://www.theregister.com/2022/09/15/nhs_data_platform_procurement_delayed/
[15] https://newleftreview.org/sidecar/posts/looking-east