

Health in Hackney Scrutiny Commission 8 th July 2021 Secondary use of GP patient identifiable data – verbal update	Item No 8
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OUTLINE

The Chair has asked the CCG to provide a verbal update after concerns were raised about planned changes to how NHS medical records from every GP patient in England will be shared with third parties.

The issue has received significant media coverage nationally including for example this article in the Guardian
<https://www.theguardian.com/society/2021/jun/01/gps-urged-to-refuse-to-hand-over-patient-details-to-nhs-digital>

Here also is a news story on it from an industry publication which provides context and attempts to summarise both sides:
<https://www.medicaldevice-network.com/features/nhs-data-grab-gdpr/>

What is the NHS ‘data grab’?

By Chloe Kent 17 Jun 2021

The NHS recently delayed plans to share NHS medical records from every GP patient in England with third parties.

“The medical records of NHS England’s 61 million users are set to be gathered in a new centralised database as part of a new scheme called the General Practice Data for Planning and Research (GDPR). According to NHS Digital, the data will be used to: inform and develop health and social care policy, plan and commission health and care services, take steps to protect public health such as managing the Covid-19 pandemic, enable research, and provide individual care in exceptional cases.

The database will not include names or addresses, or any other data that could directly identify a patient like their NHS number, date of birth, or postcode. NHS Digital claims this will allow the information to remain confidential when it’s accessed by third parties in the healthcare industry. It also says that the data will only be accessible to organisations with a legitimate need for it who match up to stringent criteria, and that the database will never be used for insurance or marketing purposes, promoting or selling products or services, market research or advertising.

But while the scheme was in development for three years, patients were given just over a month to be made aware of the project and opt out if they wished to do so. NHS Digital released the plans on 12 May this year and gave a deadline of 23 June for people to omit data from the GDPR, which has since been pushed back to 25

August following pressure from the Doctors' Association UK (DAUK). If patients do not opt out by this time, they will not be able to do so in future.

The information set to be included in the database includes data about: sex, ethnicity, sexual orientation, diagnoses, symptoms, observations, test results, medications, allergies, immunisations, referrals, recalls and appointments, including information about physical, mental and sexual health. Notably, it includes details about which staff have treated patients.

Those in favour of the initiative believe the database could be a big help in advancing understanding of medical issues, but critics have described the move as an "NHS data grab". Writing into the Guardian, University of Manchester emeritus professor of medical informatics Alan Rector described the assurances of anonymity as "worthless" and that "[f]ew people realise how easy it is to identify individuals from medical records, even if obvious personal details are removed."

All 36 doctors' surgeries in Tower Hamlets, east London, have agreed to withhold patient data when the collection begins.

Patient data confidentiality

While it is worth acknowledging that "most people would be happy for the NHS to have their health data", it doesn't change the fact that the NHS has been involved in some pretty dodgy data dealings in recent years which have damaged public trust. In 2014, the Care.data initiative proved so unpopular public outcry led to the scheme being scrapped in 2016.

In 2015, the health records of NHS patients at the Royal Free London Trust were transferred, without explicit consent from patients and in a way that did not comply with the UK's Data Protection Act, to Google DeepMind. In 2019 it was revealed that international pharmaceutical companies had obtained access to NHS patient data, while the recent involvement of big data company Palantir with the NHS Covid-19 datastore has ruffled more than a few feathers."

Attending for this item will be:

Dr Mark Rickets, CCG Clinical Chair for City and Hackney
Siobhan Harper, Director of CCG Transition for City and Hackney

ACTION

The Commission is requested to give consideration to the briefing.