

Update on the national planned extraction of data from patient records for planning and research.

Many patients have expressed concern over the extraction of data by NHS Digital. A new system was scheduled to take place on the 1st September but has now been postponed without a date being set for when it will take place. This is to allow NHS England and the government to make changes in the light of concerns that have been expressed and to engage with patients and doctors.

This information is important to the country and has been used to plan the response to the Covid 19 pandemic, including the vaccine roll-out and to understand how to support patients suffering from 'long Covid'.

However, the new data extraction will only now take place, when;

You, as a patients have the means to delete your data from a data upload, *even after a data collection has taken place*. You will be also able to opt-out from any future collections. The way that you will do this is being made more simple.

The present back-log of opt-outs expressed by patients, whether at practice level or on-line (with NHS Digital) have been cleared.

A "Trusted Research Environment" has been developed and implemented within NHS Digital itself. This mean that the data collected will only be accessed within this environment and that it will not be able to be copied or transported outside of the environment. Data can only be copied and transferred outside of this secure environment, if you, as a patient have given your explicit consent; e.g. for a specific research study.

NHS Digital promises that:

- 1) The data extraction will continue to be both pseudonymised, i.e. the data identifying you as you does not reach NHS Digital and will be encrypted by GP System suppliers.
- 2) Wants to improve its communications:
 - a. By continuing to listen to patients and other stakeholders,
 - b. Will consult via series of events that aim to explain the programme and engage in co-design with stakeholders as to how the programme will move forward.
 - c. Will demonstrate how public feedback is being used to shape how the data is collected and how the data informs research and planning across the NHS

Jo Churchill, the under-secretary of State for Primary Care promises that:

"Once the data is collected, it will only be used for the purposes of improving health and care. Patient data is not for sale and never will be for sale."

The full text of his letter is available here.



General Practice Data
for Planning and Rese