



Notice for Patients -

General Practice Data for Planning and Research Scheme – collection and use of patient information.

Dear Patient

The Local Medical Committee has produced by the LMC on behalf of GP Practices in the Borough so that patients can be aware of an important change in the way patient's information will be extracted from GP records ,stored and utilised centrally under new arrangements being introduced in July 2021.(1)

NHS Digital which organises the data systems for national collection and storage of information generated in the course of NHS activities – including patient related information- is about to introduce a new scheme. This will widen the scope of access and utilisation by internal NHS planning bodies , medical research agencies, and non-NHS organisations and corporations both in the UK and overseas.

You may have seen various reports in the Press about this scheme.(2)

The Government has recently enacted a law requiring GPs to send copies of their patient's records to NHS Digital, where they may be used for research and planning. The scheme will collect information on people's treatments, referrals, and appointments over the past 10 years, alongside other data from medical records held on GPs' systems.

The way in which the scheme is being introduced assumes that all patients will have automatically consented to the use of their medical records unless they explicitly opt out by notifying their GP that information must not be extracted from their records.

Patients who are happy with this use of their medical information need do nothing: patients who wish to exclude their information from being extracted at the start of the scheme must notify their GP by no later than 23 June 2021. After this patient can opt out at any time but data extracted prior to the opt-out will not be expunged.

NHS Digital has confirmed this information will be stored and made available to internal and non-NHS agencies in an 'anonymised ' fashion which will keep the identities of individuals confidential.

There is nothing unusual about the use of anonymised data generated by the NHS. Appropriately consented patient information has been used by NHS organisations and

Medical Researchers to help run and improve health services. It's also used to research and develop cures for serious illnesses: for example, it was critical in the University of Oxford's recovery trial which identified that treatment with Dexamethasone improves the chances of survival for people hospitalised with COVID-19.

Concerns have been raised about particular features of this new scheme and the very short timescale for its introduction, especially the lack of consultation with Patients and the Public, and the security of access to the information in the long term. It is claimed by some expert IT organisations that the 'anonymisation' can be readily reversed and there are fears about hacking.(3)

The British Medical Association and Royal College of GPs are not convinced that all of this data is needed for planning and research, but the law must be complied with. They have called for a postponement of the introduction of the scheme so that Patients can be fully informed and consulted and the reservations about security of the information can be addressed. At this time, it cannot be predicted that more time will be granted.(4)

GPs are the legal and ethical controllers of patients medical information contained in GP records and they value the trust which patients place in their collection and storage of this data. It is important that patients are aware of the changes being made to the national data collection and management system and the options regarding patient consent to it which are being applied.

As mentioned above, patients who are happy with the new scheme, need do nothing, their consent is already deemed to have been given.

Patients who think they should 'opt out' of the scheme should complete the Type one 'opt out' form and give to their GP Practice this will stop the automatic extract from your GP patient record- you can find the form here-



Type+1+Opt-out+for
m.docx

Patients who think that should opt out of the Scheme in connection with their non- GP records ie Hospital treatments and appointments, can

[use NHS Digital's online National Data Opt-out process](#)

and If you are opting out and have children under 13- use this form



nhsd-both-postal-for
m.pdf

For dependents who may be unable to complete the opt out-



Make_and_manage_a
_choice_for_someone.

The Sefton Local Medical Committee is the body established by NHS Act to be advise and represent GPs in the Sefton Borough. If you have any queries about the content of this notice you can get in touch by e mail at Seftonlmc@seftonlmv.co.uk

or by phone on 07984 160601

J Chattin

Honorary Secretary

LMC

1) [General Practice Data for Planning and Research \(GDPR\) - NHS Digital](#)

2) [GPs are fighting plans to share your NHS records with private firms | Express.co.uk](#)

[NHS Digital national data opt-out deadline: When do you have to opt out by? | UK | News | Express.co.uk](#)

[The Guardian view on medical records: NHS data grab needs explaining | Editorial | The Guardian](#)

[The NHS data grab: why we should be concerned about plans for GPs' records | Letters | The Guardian](#)

3)

<https://www.infosecurity-magazine.com/news/nhs-share-patient-data-third/#:~:text=%EE%80%80NHS%EE%80%81%20patient%20data%20in%20England%20will%20be%20shared,England%20who%20are%20registered%20with%20a%20GP%20clinic.>

4)

[BMA calls for delay in roll-out of patient data sharing programme - BMA media centre - BMA](#)

[College writes to Health Secretary calling for immediate delay to patient data proposals \(rcgp.org.uk\)](#)

