

Ebulletin 166 – June 2021

General Practice Data for Planning and Research programme

Dr Patricia Wilkie, president of N.A.P.P. was dismayed to read in the Times that NHS digital plans to data share patient GP medical records. This is based on the patients' understanding that these will be used only for their own health care and will not be disclosed to others without the prior consent of the patient. Patients were being given till 23rd June to opt out of this.

Dr Wilkie, and our Patron, Sir Denis Pereira Gray submitted the full letter below to the Times in response. According to the Times, the letter was published in an abridged form due to space. We have their permission to publish the full version here.

N.A.P.P.'s Letter to the Times

Letters Editor - *The Times* - 31 May 2021

Sir/Madam

Medical records

You report (Plan to share medical data 'risks eroding trust', 31 May) that the Department of Health, through NHS Digital, has put the medical records of all living adults and children in the English NHS who are registered with GPs into a database (GDPR). This is to be de-identified and made available widely to commercial firms and others. This will include the whole of the GP medical record including abortions, marital problems and mental illness, all information given by patients with a clear professional and common law expectation that it will be kept confidential. The fundamental principle is patient consent. Emerging forms of artificial intelligence are making it easier to re-identify people. There are now serious questions about whether British GPs will be able to keep confidences in future and the trust of their patients. This proposal is of the highest importance to patients whose information it is. Patient representatives have not been consulted and patients are being given only until 23 June to opt out when most of them know nothing about this proposal.

Professor Sir Denis Pereira Gray, Patron

Dr Patricia Wilkie, President

RCGP response to the plans to data share patient GP medical records:

GP data

There has been a lot of debate and media coverage around the GP Data for Planning and Research (GDPR) programme over the past week. Last week we told you that we had written to NHS Digital,

pushing them to **communicate better with the public about this new collection**. An appropriate level of communication has not yet begun and time is now running out before the 23 June deadline for patients to register Type 1 opt-outs. Today, we have escalated our concerns by writing to Health Secretary Matt Hancock calling for an immediate delay to the programme in order to allow time for a proper public information campaign and for patients to make informed decisions about the use of their data, including the right to opt out.

We've set out previously that the College supports the principle of improved and more secure sharing of data for legitimate healthcare planning and research purposes, but we've also been clear that it is critical that appropriate safeguards are in place to guard against any inappropriate uses of this data. Most importantly, any sharing of data must be transparent and maintain public trust in how general practice and the NHS more widely uses their information.

We have also reiterated that at this time of extreme workload pressures, as well as the focus on the COVID-19 vaccination programme, it must not be left to GPs to communicate with patients, but that this must be done by NHS Digital and thoroughly.

Postponement

As a direct result of the letter from N.A.P.P. along with communications from other quarters, the Health minister Jo Churchill announced, on 08 June, in the Commons that “the General Practice Data for Planning and Research programme would be delayed from 1 July to 1 September, after mounting calls for the scheme to be postponed.”

Type 1 opt-out form

As the Type 1 opt-out form mentioned has been found to be extremely difficult to locate online, we are attaching it as a PDF here. Please feel free to share this with your patient population, and your practice. [Type-one-Opt-out-Form.pdf](#)

More information from the NHS about the National Data Opt-out is here: <https://www.nhs.uk/your-nhs-data-matters/>.

Further information

Further discussion from N.A.P.P. about the complex issue of data sharing will follow as soon as possible.