

## **BMA and RCGP briefing: Adjournment debate on use of patient data as part of NHS Digital's General Practice Data for Planning and Research programme**

**Thursday 24 June 2021**

### **About the BMA and the RCGP**

The BMA is a professional association and trade union representing and negotiating on behalf of all doctors and medical students in the UK. It is a leading voice advocating for outstanding health care and a healthy population. It is an association providing members with excellent individual services and support throughout their lives.

The Royal College of General Practitioners (RCGP) is a membership body of over 54,000 GPs in the UK that was established to encourage, foster, and maintain the highest possible standards in general practice.

### **What has happened so far?**

- General Practice Data for Planning and Research (GPDPR) data collection was launched by NHS Digital on 12 May 2021.
- GPDPR will move patient data to a central NHS Digital database, to support health and care planning and research in England, to help find better treatments and improve patient outcomes for everyone.
- The new data collection aims to reduce burden on GP practices by extracting data once for many uses, to allow doctors and other staff to focus on patient care.
- The initial announcement from NHS Digital stated a deadline of 23 June 2021 for patients to opt out with the aim of introducing the system on 1 July, however following concerns from many including the RCGP and BMA, this has since been extended to 1 September 2021.

### **What is the BMA and the RCGP's position on GP data sharing?**

The BMA and the RCGP called for the Government to pause the roll out of the new GP data sharing arrangements scheduled for introduction on 1<sup>st</sup> July, due to concerns that the final stages of the programme had been rushed.

It became apparent to us that the communications associated with the GPDPR programme had been insufficient. We raised concerns both privately and then publicly over the lack of communication with the public on this matter and the absence of informed consent. Furthermore, it was unacceptable that without a full public consultation campaign it was being left to GPs to explain what the programme was to patients, despite this clearly being outside of their role and remit. Data sharing must be based on trust, and transparent communication from government is key to maintaining this public trust.

We welcomed the Government's decision to put in place a pause in the roll out to facilitate further public consultation on the programme. With the deadline for first extraction having now been extended to 1 September, we are clear that this pause will only be effective if NHS Digital and government use this time to consult and communicate effectively with stakeholders and patients

about the use of their data, including simplifying the right to opt out. We hope that such an approach will help to maintain public trust in how the NHS more widely uses their confidential health data.

Whilst the RCGP and the BMA have been engaged in discussions on data sharing with NHSD, we jointly continue to have ongoing concerns regarding how the current programme is being implemented.

### **What are the benefits of data sharing?**

We believe that data sharing with the right safeguards built in can play a positive role in supporting the development of new medicines, medical research and future healthcare planning. However, it must be done correctly, with appropriate safeguards, and sufficient information must be provided to the public and NHS workers about how the system will work to allow them to make informed decisions around opting out of sharing confidential health information.

During the pandemic, health services in England and research organisations have benefitted greatly from a tactical GP Extraction Service (GPES) for COVID19 planning and research. This provided a dataset comprised of GP records from across the country to be used for any activities related to planning or research of services, treatments or drugs related to COVID19.

GPES is the existing mechanism for extracting patient data from GP records for the purposes of providing that data to organisations undertaking planning within the NHS or medical research. Any data extracted via GPES is held by NHS Digital before being transferred to organisations given access to it or made available to them in a Trusted Research Environment. GPES is used to extract specific information and usually for a single purpose, extract once, use once and has very strict and stringent parameters within which it functions and works.

### **What needs to happen to next to make an effective and secure data sharing system?**

Since it launched, communications on GP data sharing have been limited to NHS Digital's online platforms, which means that communication of the new data sharing arrangements has only been provided to people already familiar with using digital channels.. We believe that this approach has resulted in large parts of the population, including those without access to digital provision, being excluded from receiving information about the programme. Because of this we consider education about the programme to have been ineffective and insufficient to adequately inform the majority of patients of the changes ahead, transparency has not been met. To address this the BMA and RCGP are calling for:

#### **Communications**

- A comprehensive public information campaign. GDPR is a government programme, and particularly at this time of extreme workload pressures in general practice it is wholly unreasonable and inappropriate for it to have been left to GP practices to communicate the data sharing changes to patients. A public information campaign is crucial to address this, although we are conscious that there is a short time frame until 1<sup>st</sup> September for an effective campaign of sufficient scale to be delivered. We are therefore, calling on the government to provide further details immediately.
  - The communications campaign should include information about merits and safeguards built into the programme.
  - It should also be made clear to patients what the different opt outs mean, such as which services will still be accessible to them based on their opt out choice.
  - Material to support patients should also be provided to GP practices, alongside information specifically aimed at healthcare workers.
  - Reassurance must be provided that data will not be sold for purely commercial purposes.

- The government must take time to genuinely reflect and have conversations about concerns raised by stakeholders and the public, and where necessary make changes to their policy to ensure a safe, secure and effective programme.

**Data security and privacy:**

- It is important that sharing of data is transparent and maintains public trust. Greater clarity over which companies and organisations will get access to patient data through GDPR is therefore necessary. While we are assured by NHS Digital that data will not be sold and will not be used for solely commercial purposes, we have concerns about the continued involvement in the NHS of private data companies and their ability to access confidential patient identifiable NHS data.
- Data must only be made available within secure 'trusted research environment' platforms which allow researchers to log on and access the data they need within NHS Digital's systems, rather than have ownership of data on their own systems. The government must make this commitment clearly and publicly and provide evidence that appropriate systems are in place and that this commitment will be complied with.
- The BMA and RCGP believe that the recording of type one opt out must be simplified and the burden must not fall on the GP practice to record this. A review of opt-out processes is needed to ensure opt-outs are simple, clear and accessible. Under present plans, data collected by NHS Digital prior to an individual registering a 'Type 1' opt-out with their GP will not be deleted. This should be changed so that people have a retrospective right to deletion of their personal confidential health data should they so wish.
- NHS Digital must also provide a Data Protection Impact Assessment (DPIA) Template for GP practices.