

Matthew Gould  
Chief Executive, NHSX

Simon Bolton  
Chief Executive, NHS Digital

2 July 2021

Dear Matthew and Simon,

**RE: General Practice Data for Planning and Research**

We are writing jointly to set out areas that we believe must be addressed urgently, prior to data being collected under the GP Data for Planning and Research programme (GPDPR).

In response to our extensive joint lobbying on the matter, we were relieved to see the announcement on the 8<sup>th</sup> June of a delay to the first scheduled collection of data as part of GPDPR, with the new scheduled date set as the 1<sup>st</sup> September. As you will know, the delay to the program is something the profession had called for as a minimum, after exhausting all other avenues to securing the changes we believed were needed to be able to progress the programme with the confidence of the public, our patients. The foremost of these changes was the development of a full national communication and engagement campaign.

Since the original delay announcement was made by the Minister for Prevention, Public Health and Primary Care, Jo Churchill, in the House of Commons it has become clear that there are a number of areas within the programme that require further work and are supplemental to the need for an improved communications campaign. These areas include policy, implementation and technical architecture development, where further improvements should be made in order to inspire, as much as possible, confidence in the programme and ensure that robust safeguards are put in place around data collection, analysis, any onward dissemination and deletion.

We have been clear that we support secure data sharing for legitimate purposes that can improve public health, however our role, as representative bodies for general practice is to ensure that data moving from the control of general practice to NHS Digital (NHSD) is sufficiently protected and that NHSD's responsibility for communicating thoroughly and openly with the public and the profession is accepted. With that in mind, we have outlined below the steps that we believe are necessary prior to any data being collected by NHSD under the GPDPR programme:

## Communications

- A public engagement campaign must be conducted by NHSD:
  - This should include the use of national help desks and local champions to whom GPs can signpost patients.
  - Communications should include information about merits and safeguards built into the programme.
  - Communications must be accessible to all individuals and groups with a GP medical record with consideration given to different languages, reading ages, access needs and any other needs.
  - It should also be made clear to patients what the different opt-outs mean, including where their data will and will not flow as a result and which services will still be accessible to them based on their opt-out preferences.
  - Material to support patients should also be provided to GP practices to use should they have capacity or opportunity to share this.
  - Reassurances must be provided that data will not be sold for purely commercial purposes.
  - The government and NHSD 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.
  - A lay-person's guide to the type of anonymisation that will be used should be provided, and reassurances given over the measures in place to prevent reidentification, particularly for those groups for whom this is of particular concern, such as victims of domestic abuse.
- Communication with the profession to support understanding and confidence:
  - Regular, formal communications should be issued to practices via the CQC registered manager list and Central Alerting System alert list.
  - Webinars, FAQs and explanations tailored for a clinical audience which address the questions and concerns raised since the launch of the programme must be provided.

## Opt-outs:

- Opt-out processes must be simplified and Type 1 Opt-outs should be centrally managed, whilst maintaining confidentiality and privacy as was originally intended when the Type 1 Opt-out process was created:
  - To support patients in exercising their rights to opt out, or back in, in a simple and accessible fashion, we propose that options be provided via a web interface or the NHS app to toggle on and off both Type 1 and National Data Opt-outs.
- The ability to delete data that has already been collected by NHSD prior to a patient registering a Type 1 Opt-out must be developed.
- NHSD must collect and openly publish the total number of Type 1 Opt-outs.

## Data security:

- A Data Protection Impact Assessment (DPIA) Template must be provided for practices with sufficient time prior to collection for practices to consider and complete this.
- Confirmation must be provided that the NHSD DPIA has been shared with the ICO, and the response from the ICO should be shared with the RCGP and the BMA.
- NHSD must withdraw, update and reissue the Data Provision Notice to reflect updated dates and changes to the programme.
- NHSD should only share data within a comprehensive Trusted Research Environment (TRE), as committed to by the former Secretary of State, Matt Hancock, in the House of Commons (24/6/21).
- Data should not be collected by NHSD until it is clear a suitable TRE is operational.

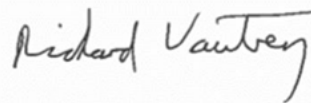
- Greater clarity over which companies and organisations will gain access to patient data through GDPR must be provided – there remain concerns over continued involvement in NHS of private data companies.
- Provision must be made for patients and GPs to be able to see what data will be shared, and has been shared to date, in appropriate, tailored formats and levels of detail.
- Secondary uses of data from other sources such as shared care records should be descoped once the GDPR programme goes live given that an all-encompassing solution for secondary uses will be available.
- An independent evaluation should be undertaken of NHSD's governance procedures for managing encryption solutions, key management and safe haven data access to health data for researchers and NHS Planners as an essential step towards obtaining public and professional trust in the GDPR programme. This was specified as a requirement by the Faculty for Clinical Informatics as part of their review of the scheme.

We have welcomed the weekly meetings where our teams are working collaboratively to help inform NHSD developments, however progress to date has been slow with decisions being handed down from elsewhere. Unless significant progress is made with regards to the areas we have outlined, we remain concerned that the programme will not carry the confidence of the profession or the public.

Yours sincerely,



Prof. Martin Marshall  
Chair, Royal College of General Practitioners



Dr Richard Vautrey  
Chair, General Practitioners Committee  
British Medical Association