



Department  
of Health &  
Social Care

*From the Lord Bethell  
Parliamentary Under Secretary of State for Innovation*

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The Rt Hon Damian Hinds MP  
By email to: [damian.hinds.mp@parliament.uk](mailto:damian.hinds.mp@parliament.uk)

29 July 2021

Dear Damian,

Thank you for your correspondence of 30 June on behalf of one of your constituents, about NHS Digital and the sharing of patient records. I apologise for the delay in replying.

The COVID-19 pandemic has shown the incredible role that data, and data-driven technologies, can play in health and care. Without this weapon in our arsenal, we could not have identified people at high risk from COVID-19 and prioritised them for vaccinations, and we could not have discovered COVID-19 treatments such as dexamethasone, which has now saved more than a million lives across the world.

We need to build on this pioneering work and look at where we can go further. GP data has been used to improve services for many years, but the current service – GPES – is more than ten years old and needs to be replaced. We are proposing a new system – GP Data for Planning and Research (GPDPR) – so that we can do more to unlock the intrinsic benefits of the data while still maintaining the highest possible standards of security.

More than 200 prominent scientific and medical researchers have endorsed a statement supporting this mission, and we have developed it together with doctors, patients and experts in data and privacy.

This new and improved system will reduce work for GPs, so that they have more time to focus on patient care, and ensure that data is collected, stored and accessed in a secure and consistent way. It will replace 300 separate data collections with one single, daily collection. This more accurate data will mean that we can view trends as they happen and adapt services as a result, and we can use higher quality data in life-saving research into new treatments.

This system will be underpinned by the highest standards for safety and security, building on the huge advances we have seen around trusted research environments (TREs). TREs are secure spaces bringing together multiple datasets, where researchers can access data while maintaining the highest standards of privacy.

The Government has committed that access to GP data will only be via a TRE and never copied or transferred out of the NHS secure environment, unless people have consented

to their data being accessed; for example, by giving written consent for a research study. This will give both GPs and patients a very high degree of confidence that their data will be safe and their privacy protected.

We have also put in place a rigorous and independent approvals process before anyone can access data, and audits are carried out to make sure that it is only being used for legitimate purposes.

We are determined to give patients control over their data. If, despite the strong safeguards we have put in place, patients would prefer to opt out, then we have given them the option to do so.

If a patient does not want their directly identifiable data to be shared outside their GP practice except for the purposes of their own care, they can apply to their GP to opt out. This is known as a 'type 1 opt-out' and NHS Digital will not collect patient data for any such patient. There is also a 'national data opt-out', which indicates that a patient does not want their confidential patient information to be shared for purposes beyond their individual care across the health and care system in England. Details of both types of opt-out are available on the NHS Digital website at [www.digital.nhs.uk](http://www.digital.nhs.uk).

It was confirmed on 19 July that we are no longer setting a specific start date for the collection of data for the GDPR programme. Instead, NHS Digital commit to start uploading data only when we have the following in place:

- the ability to delete data if patients choose to opt out of sharing their GP data with NHS Digital, even if this is after their data has been uploaded;
- the backlog of opt-outs has been fully cleared;
- a TRE has been developed and implemented in NHS Digital; and
- patients have been made more aware of the scheme through a campaign of engagement and communication.

The Government is aware there has been a great deal of concern regarding the lack of awareness about this work among the healthcare system and patients. We recognise that we need to strengthen engagement, including opportunities for non-digital engagement and communication.

Since the programme has been paused, we have been developing an engagement and communications campaign, with the goal of ensuring that the healthcare system and patients are aware of and understand what is planned and can make informed choices.

Through this new communication campaign, with clear messages, we will seek to ensure that the introduction of this data collection does not impose an additional burden on GP practices.

One of the central lessons from this pandemic is that data makes a difference. This important work to improve our GP data collection will help us to draw on what we have learnt from this crisis, so we can build back better and save lives.

We recognise that it is important that we have a UK-wide data focus and response, making sure that people have confidence that the health and care system will support them, regardless of where they live or work in the UK. This means making sure that health and care data can be shared safely and effectively across the UK to support individual care and to improve outcomes for everyone.

This is why we have published a draft data strategy, *Data saves Lives: Reshaping health and social care with data*. As part of this strategy, we set out that we need to work with officials across the devolved administrations, noting the devolved nature of health and care policy, and build on the work of units such as the Joint Biosecurity Centre and the newly established UK Health Security Agency. This will also help us collaborate to solve public health issues, improve disease surveillance, and to overcome any behavioural or structural obstacles to appropriate data sharing across our respective health and social care systems.

If your constituent would like to know more about this strategy, further information is available on the NHSX website at [www.nhsx.nhs.uk](http://www.nhsx.nhs.uk) by searching for 'Data saves lives'.

I hope this reply is helpful.

A handwritten signature in black ink that reads "Bethell". The signature is written in a cursive style with a large initial 'B'.

**LORD BETHELL**