

BLOG

What's the difference between the national collection of GP Data for Planning and Research and the OneLondon Local Health and Care Record?

25 June 2021

Chief Clinical Information Officers (CCIOs) from across the OneLondon collaborative highlight what we know about the General Practice Data for Planning and Research (GPDPR) and explain the key differences between this national data collection and the work we've been doing in London as part of the OneLondon Local Health and Care Record (LHCR).

In the last few weeks we've been contacted by Londoners and local colleagues with questions about the national collection of [General Practice Data for Planning and Research \(GPDPR\)](#), and if this is connected to the work we're doing in London to join-up and use health and care data as part of the [OneLondon Local Health and Care Record \(LHCR\)](#).

Essentially, these are two separate data sharing initiatives. GPDPR is being led nationally by NHS Digital. OneLondon is a regional initiative, responding specifically to London-based policy. In this blog we will direct you to more information about GPDPR - available on the [NHS Digital website](#) - including what this means for the public and patients, and GP colleagues. We'll then detail what's happening in London as part of the OneLondon LHCR - including how we've shaped local policy around data use through a [Conversation with Londoners](#).

Here's what we know about the national collection of GP Data for Planning and Research

[NHS Digital](#) is responsible, nationally, for standardising, collecting, analysing, publishing, and sharing data from across the health and social care system. Patient data from GP surgeries has been collected (where a patient has not opted out) for over ten years via the General Practice Extraction Service (GPES). GPDPR is [planned to replace GPES over the course of the next 18 months](#). It is planned that this new approach to data collection will be more efficient and effective, aiming to reduce the burden on General Practice.

Data collected via GPDPR is pseudonymised, so it is not directly identifiable. It includes data about diagnoses, symptoms, observations, test results, medications, allergies, immunisations, referrals, recalls and appointments, including information about physical, mental, and sexual health but not free text conversations or images, letters or documents. In certain circumstances, and where there is valid legal reason, NHS Digital (as the data controller) can re-identify patients. This national data collection is used for the purposes of planning and research - not for an individual's direct care. This is also referred to as secondary use of data. It will be used for things such as:

- Managing and planning demand for services, such as how many people are diagnosed with particular illnesses
- Analysing the outcomes of services to ensure the health service delivery is getting results
- More recently, [managing the coronavirus pandemic](#) (this is currently under a separate data provision legal basis)

Information about GDPR is published on the [NHS Digital website](#). This includes a [transparency notice](#) that sets out what happens to the data at each stage and the safeguards in place. It also details how patients can complete a [Type 1 Opt-Out](#) to prevent their information being shared outside of their GP practice for purposes other than direct care. This is different to the [National Data Opt-Out](#), which allows patients to opt-out of their data being used for planning and research.

For more information about GDPR visit: www.digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research

Concerns voiced by health and care professionals and the public

Media coverage has indicated that concern from patients, the public, and health and care professionals, largely relates to transparency about GDPR. The response from advocacy groups and health and care organisations, including [Understanding Patient Data](#) and [use MY data](#), has highlighted the need for NHS Digital to actively engage the public about what is happening, and to allow appropriate time for people to understand the different choices available to them. As such, NHS Digital has confirmed that the [collection of GDPR will be deferred from 1 July 2021 to 1 September 2021](#).

As a OneLondon collaborative, made up of London's five health and care partnerships (or Integrated Care Systems) and the London Ambulance Service, we welcome NHS Digital's decision to defer the collection of GP Data for Planning and Research to "provide more time to speak with patients, doctors, health charities and others to strengthen the plan".

It is also important that relevant information governance documentation that supports the updated process for GDPR is published by NHS Digital as soon as possible. This includes the Data Protection Impact Assessment, or DPIA.

The benefits of using data for planning and research are only possible if we have the support, confidence, and trust of our communities. OneLondon has detailed some of these benefits using [stories and case studies, available on the website](#). Transparency and an open, authentic dialogue are key to this. In London, we've engaged extensively with our local population to understand their expectations for the join-up and use of data, and are continuing to use their recommendations to shape local policy.

'You said, we did': what's happening in London?

The work we've done in London to develop and implement local policies for using health and care data is separate from the work being undertaken nationally in relation to GDPR. That said, it offers valuable insight and could be used as a model for a national conversation with the public. All materials and stimulus from our engagement with Londoners is publicly available on the [OneLondon website](#).

[OneLondon](#) has undertaken a multi-stage process of public engagement to understand people's expectations of health and care services, and to inform how health and care data should be joined-up and used, in a way that is legitimate and trustworthy. This Conversation with Londoners included a four-day deliberative [Citizens' Summit](#), where 100 public participants - reflective of London's diverse population - formed a set of [recommendations and conditions for using data for multiple purposes](#).

This 'mini public' were supportive of a) joining-up and using identifiable information across London to support individual care, and b) using de-personalised (non-identifiable) data to support planning and research, as long as certain conditions are in place, whilst also

respecting the National Data Opt-Out process. Since the Citizens' Summit, OneLondon - with the support of [NHS England \(London Region\)](#) and the [Mayor's Office](#) - has made good progress in developing a consistent set of policies for using health and care data in London, in line with public expectations.

This includes a data sharing framework, developed by the London Information Governance Steering Group, and currently being confirmed through local governance processes. This data sharing framework for London sets out the principles for safely and securely joining-up health and care data in London for the purposes of individual care, planning and research, based on our public recommendations.

Based on these principles, identifiable data will not be shared beyond the purposes of direct care for individuals. Fully de-identified data for planning and research (as agreed by Citizens' Summit participants) is not sold, and is subject to appropriate controls in relation to access, charging, and transparency. This de-identified data for planning and research will only be accessed in an environment that is secure, accredited, monitored, and prevents unauthorised use - in other words, all the requirements of a [Trusted Research Environment](#).

Importantly, with this consistent join-up and use of data in relation to the work of the OneLondon Local Health and Care Record, data controllership remains with local providers - recognising the trusted relationship between patients and health and care professionals.

As work continues to develop a health data strategy for London, OneLondon is working closely with NHS providers and academic institutions to ensure that the recommendations and conditions set out by the public are fulfilled.

For more detail on how public recommendations are being used to shape policy for the join-up and use of health and care data in London [read this blog from OneLondon Chief Officer, Luke Readman](#), published earlier this year. This includes consistent processes for sharing data (consistent with the National Data Opt-Out) and access within a Trusted Research Environment.

The remit of OneLondon is to respond specifically to London-based policy and practice. Thanks to the [recommendations set out by participants involved in the Citizens' Summit](#), for the first time we have clear instruction from the public to local policymakers and health and care leaders as to how we should be using health and care data in a way that builds trust and confidence. This also offers clarity and direction to our frontline health and care staff, and data controllers.

Dr Jack Barker, CCIO for Our Healthier South East London

Dr Osman Bhatti, GP, CCIO for North East London Health & Care Partnership

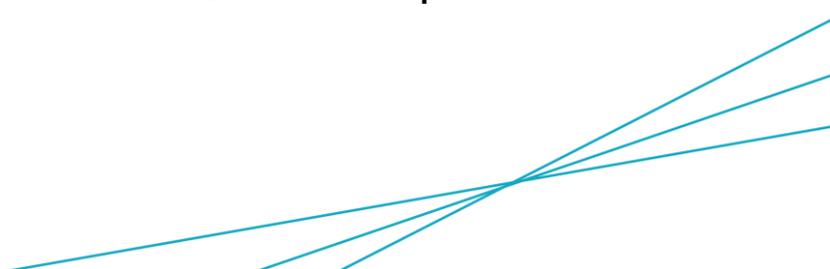
Stuart Crichton, Paramedic, CCIO for London Ambulance Service

Dr Sanjay Gautama, Consultant Anaesthetist, CCIO for North West London Health & Care Partnership

Dr Zuhaib Keekeebhai, GP, CCIO for North London Partners in health and care

Dr Achim Schwenk, CCIO for North London Partners in health and care

Dr Jane Wilson, CCIO for South West London Health & Care Partnership

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Further information and resources

NHS Digital General Practice Data for Planning and Research (GDPR)

- [8 June, NHS Digital press release: Collection of GP Data for Planning and Research to go ahead on 1 September 2021](#)
- [Additional information for patients and the public](#)
- [Transparency notice](#)

Responses to GDPR

- [15 June, Understanding Patient Data: Trustworthy use of GP data: what must happen now](#)
- [10 June, HDR UK: NHS Digital GP Dataset - Joint Statement from the Medical and Social Research Community](#)
- [9 June, ICHP: Response to NHS Digital's announcement to introduce and decision to defer GDPR](#)
- [Position statement from use MY data: GP Data for Planning and Research](#)
- [27 May, Understanding Patient Data: Our perspective on the new system for GP data](#)
- [Statement from the British Medical Association and Royal College of GPs](#)

OneLondon Citizens' Summit

- [Report: Public deliberation in the use of health and care data](#)
- [Citizens' Summit materials and stimulus](#)