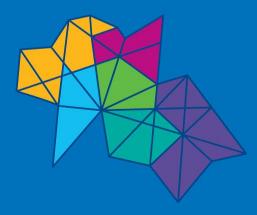# NHS Digital GP Practice Data Sharing

Bringing together Croydon, Kingston, Merton, Richmond, Sutton and Wandsworth

Background

- NHS Digital is **making improvements** to how data is collected from general practice, with a new framework for data extraction called the **General Practice Data for Planning and Research (GPDPR) collection.**

- The data held by GPs is **used every day** to support health planning and research in England.

- Each practice has between 10 and 100 existing data sharing agreements – which go to national organisations like NHS digital and PHE, NHSE and research organisations, CCGs and ICSs.

- NHS digital is set up in statute to **be custodian for NHS data.**

- The current NHS Digital GP extraction service is **over 10 years old and needs to be replaced**.

Latest update

- **There will NOT be specific start date for the collection of data**.

Instead, NHS Digital commit to start uploading data only when the following is 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 Trusted Research Environment has been developed and implemented in NHS Digital

- There will be a campaign of engagement and communication

Misinformation

- NHS Digital **does not sell data** – only available for health and care benefits.

- Use of data held by NHS Digital is **licenced for specific periods of use, constrained to data necessary and proportionate for approved purposes.**

- A licence fee is levied to recover only the costs of data processing **for selective access and use.**

- NHS Digital does **not** collect the whole record, **only the computer coded bits that are needed and in use today by NHS planners and health researchers**.

- **NHS Digital is not the government**. All organisations or agencies requesting to use GP data will have to apply through the same process for approval for specific purposes that must include health and care benefit.

- Only parts of health records are shared relevant to **planning and research.**

- All data is **pseudonymised** at source.

GP data saves lives

- **Oxford University RECOVERY Trial** – Data from general practices was crucial in identifying dexamethasone to treatment patents with COVID-19 patients. This reduced deaths by one-third and by April 2021, the drug had saved 22,000 lives in the UK and one million more worldwide.

- **Development of the Shielded Patient List** – GP data rapidly identified those people most likely to be at high risk from COVID-19 to implement protection and shielding measures.

- **Vaccine prioritisation** – Data from GPs was used to identify those most at risk from COVID-19 according to JCVI criteria and ensuring they were prioritised for vaccination.

- **Long COVID** – Data from GPs was used to provide the evidence to support the urgent commissioning of appropriate new services to meet the needs of those with long term symptoms

Facts

- **The data already collected has been used to save lives**.

- The new data collection is from GP practices in England into **NHS Digital.**

- The new service will only collect **coded and structured data** (e.g. where the GP or Nurse has recorded a blood pressure reading, prescribed a new medicstion, or coded a diagnosis for a condition) not whole records.

- This coded and structured data from GP records is **used every day and is vital for the running of the NHS.**

- This new collection will over time **replace multiple other collections and channels** – applying consistent protection and governance, transparency and application of patient preferences.

Data Security and Governance

- Access to GP data will only be via a **Trusted Research Environment** (TRE)

- The data will **never be copied** or **shipped outside the NHS secure environment**, except where individuals have consented to their data being accessed e.g. written consent for a research study.

- There will be a **transparent approach**, including publishing who has run what query and used which bit of data.

Opt Outs

•**Patients do not need to register a Type 1 opt-out by 1 September** to ensure their GP data will not be uploaded

•NHS Digital will create the technical means to allow **GP data that has previously been uploaded to the system via the GPDPR collection to be deleted when someone registers a Type 1 opt-out**

•**The plan to retire Type 1 opt-outs** will be deferred for at least 12 months while we get the new arrangements up and running, and will not be implemented without consultation with the RCGP, the BMA and the National Data Guardian

Both Type 1 and National Data Opt-outs are respected

- Patients can register two different types of opt-out with respect to the sharing of their personal data.
- These opt-outs serve different purposes as they apply at different stages in the data flow.
- Patients can register both types of opt-out and the new General Practice Data for Planning and Research collection honours both.

| GP Practice Clinical IT System | Type 1 Opt-out | NHS Digital Data Processing Service - GPDPR Collection | National Data Opt-out | Consumer (e.g. research organisation) |

- Prevents sharing of data outside GP practice for anything other than individual care for patients

- Available since summer 2013

- Links provided in GP Practice Privacy pages & NHS Digital transparency pages and form

- Signalled for consideration of retirement by DHSC, although no firm plans or agreement yet in place

- However, devalues the data set, especially for certain communities, and prevents whole population reflection in commissioning and research opportunity

- Prevents use of identifiable data by NHS Digital for purposes other than individual care, subject to exemptions outlined in the National Data Opt-Out Policy, e.g. legal obligation to share and public health

- In place since May 2018

- Links provided in GP Practice Privacy pages & NHS Digital transparency pages

- Does not prevent sharing of anonymous and aggregate data.

Questions

- Is the information we have provided from NHS Digital clear?

- Do you have further questions?

- What kinds of misinformation is out there?

Link to further information

- General Practice Data for Planning and Research (GPDPR) - NHS Digital

- If you have any questions, you can contact the programme at enquiries@nhsdigital.nhs.uk.