

Use MY Data

16 September 2021

Dear Use MY Data

General Practice Data for Planning and Research (GDPR)

Thank you for your letter dated 01 July 2021, my apologies for the delay in responding before now. In your letter you raised several questions relating to the key themes and associated next steps for the General Practice Data for Planning and Research programme.

Many of the points that you raise have been flagged by other valued stakeholders and on 19 July 2021, Parliamentary Under Secretary of State Jo Churchill MP wrote to all GPs in England to respond to this feedback. A copy of the full letter can be viewed on this webpage:

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/secretary-of-state-letter-to-general-practice>

I have answered your questions inline below and referred to specific points in the Parliamentary Under Secretary of State's letter where appropriate.

The mechanism of opt out is unclear to people and difficult in the current situation -we have seen over 100,000 new National Data Opt-outs in a month, despite these not being the route required to express a GDPR opt out.

Action: NHS Digital to provide clearer information on the types of opt out available, and the effect of the different opt outs.

The GDPR programme is undertaking work to identify user needs, and design and implement improvements to the opt-out user journey. Please refer to Jo Churchill MP's letter of 19 July 2021 section on opt-outs and the government's pledge to make the process of opting-out simpler:

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/secretary-of-state-letter-to-general-practice#opt-outs>

We do not know the number of Type-1 opt outs made via GP practices.

Action: NHS Digital should publish the numbers and breakdown of Type-1 opt outs.

NHS Digital does not currently collect data on the numbers and breakdown of Type 1 opt-outs which are held by GP Practices. The Secretary of State would need to instruct NHS Digital to put in place systems to collect and analyse this information via a Direction. The GDPR programme will work with partners to identify how this is best achieved.

The timing of the proposed 'go-live' date is too short. Effective communication with patients and the public is needed, so that they have enough time to make an informed choice. Our 160 delegates on the webinar posted nearly 120 questions during the webinar, most of which we did not have time to answer.

Action: NHS Digital should extend the go-live date to allow time for the development and rollout of a formal communications strategy.

As per Jo Churchill MP's letter of 19 July 2021 we are not setting a specific start date for the collection of data. Instead, we 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 Trusted Research Environment has been developed and implemented in NHS Digital.
- Patients have been made more aware of the scheme through a campaign of engagement and communication.

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/secretary-of-state-letter-to-general-practice#general-practice-data-for-planning-and-research>

The GDPR data should be managed safely and transparently inside a Trusted Research Environment.

Action: NHS Digital should confirm that the access to the GDPR data will be within a Trusted Research Environment. Any exceptions to this should be clearly highlighted, with the reasons published.

The Government has committed that access to GP data will only be via a Trusted Research Environment (TRE) and never 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. This is intended to give both GPs and patients a very high degree of confidence that their data will be safe, and their privacy protected.

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/secretary-of-state-letter-to-general-practice#data-security-and-governance>

Governance, safeguards and reporting should be clearly defined.

Action: NHS Digital to enhance the reporting of access requests to include requests which are refused.

Minutes of IGARD discussions are already publicly available and include details of applications which are not recommended for approval or where amendments are required. These minutes include details of the considerations involved in the decision which is important context since there are many reasons why an application might not be recommended for approval.

Action: NHS Digital to publish, in a more accessible format, the benefits assessment undertaken when access to data is given to a commercial company.

Changes to the NHS Digital Data Uses Register have been made since GDPR initially went live. These changes have been implemented with a view of improving the visibility of data uses. NHS Digital will keep this register and its use under review and will continue to make improvements as part of our commitment to be transparent about data access. This will also be informed by further dialogue with patients and the public.

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/secretary-of-state-letter-to-general-practice#protecting-patient-data>

The proposed public campaign is welcomed, but more detail is needed about design, content, mechanisms and timing. The messaging about the GDPR needs to be managed positively, not just left to the media.

Action: We see the communications plan as a critical piece of work. NHS Digital should publish details about the plan.

Action: We believe it is essential to involve patients and the public in the design of the communications and the overall plan, and in its delivery. We would like NHS Digital to take steps to include the patient voice as an equal in the development and rollout of the communications campaign.

We agree that it is essential to involve patients and the public in the design of the communications and overall plan, which is why we have the four-phase approach to communications and engagement, described in Jo Churchill's letter here:

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/secretary-of-state-letter-to-general-practice#transparency-communications-and-engagement>

As per our discussion on 15th September, we will be sharing details of this plan with you shortly for feedback and remain keen to agree how best to involve UseMYData to support ongoing review and feedback into the programme - either Vicky or I will be in touch to take this forward.

I hope that I have answered your questions, however please feel free to contact me again should you have any further queries.

Yours faithfully



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