

Dave Roberts, Head of Primary Care Information
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Leeds
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1 July 2021

Dear Dave and Arjun,

General Practice Data for Planning and Research (GDPR)

Thank you for your open and helpful contributions to our June webinar, 'Trust and transparency: GP Data for planning and research'.

As you know, the webinar was arranged following the announcement about the planned GDPR. We wanted to give patients, relatives and carers the opportunity to communicate directly with those in charge of the programme and with the wider panel with different perspectives. We wanted a dialogue about the GDPR, to ensure there is a balanced debate about anticipated benefits versus potential risks.

The webinar was well-received by attendees, and their questions and contributions produced a series of key themes and associated next steps, for which commitment and action is required from NHS Digital. We have shared these results with all who attended and have published them on our website [here](#).

We are now writing on behalf of delegates and the Membership of [use MY data](#) to seek information from NHS Digital on the proposed next steps.

Key themes and associated next steps

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

[use MY data](#) believes that patients can only make an informed decision when clear, complete and comprehensible information is available to them, in an accessible form, including information about how to opt out and what this means, both for them as individuals but also the potential impact on research and on our NHS. If patients opt out to the sharing of their data, this should be respected.

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

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

- 2. 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**

[use MY data](#) agrees with the decision taken by NHS Digital to delay the implementation of the GDPR. But the September 2021 deadline is still too short to ensure patients have enough time to consider their options and make an informed choice, and do not feel forced to opt out by August 2021. Opt outs will continue to rise if people are not given the time to make an informed choice.

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

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

We welcome the commitment made in the recent Adjournment Debate that the GDPR data would be managed within a Trusted Research Environment. [use MY data](#) believes that Trusted Research Environments should become the default mechanism to ensure patient data is managed and used safely, in a way which is auditable and transparent. We are optimistic about their role in driving forward health research more rapidly and widely than other data access methods. Our [principles of transparency](#) should be adopted.

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.

- 4. Governance, safeguards and reporting should be clearly defined**

[use MY data](#) believes that only approved users should be able to access the data. The access approval process, and the role of patients in this process, should be clear and published, as should the results of any application, including whether they are approved once or for multiple access, whether successful or not. The GDPR data should be used only for approved purposes to benefit the public. It should never be used for marketing or insurance purposes. If a commercial company uses patient data, the NHS must benefit fairly from any revenues generated.

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

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

5. 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

use MY data believes that a robust communications plan should be developed and delivered, involving patients throughout this process. The benefits of uses of patient data for research and planning need to be emphasised. We suggest that patient stories and patient spokespersons have a role to play in this.

A poll of the webinar delegates showed that by far the largest source of information available to delegates about the GDPR had been from the media. The commitment from NHS Digital to launch “a substantial campaign to publicise this activity” was welcomed, but the contents of that communication need to be clear and balanced.

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 look forward to your response, particularly how use MY data can help to bring patient voices to the design and delivery of the communications plan. We hope that patients will be comfortable sharing their data for planning and research.

We are happy for the contents of this letter to be used or shared without restriction. We will publish the letter on our website for transparency.

Yours sincerely,

Richard Stephens

Richard Stephens
Chair
use MY data Advisory Group



Alison Stone
Coordinator
use MY data

Dave Chuter

Dave Chuter
Vice Chair
use MY data Advisory Group



Chris Carrigan
Expert Data Adviser
use MY data

The only UK independent movement of patients, relatives and carers
focussed on the use of patient data to save lives and improve outcomes

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

Our mission statement

- **use MY data** is a movement of patients, carers and relatives.
- **use MY data** endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.
- **use MY data** aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.
- **use MY data** supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

What we do

- We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.
 - We work to bring a patient voice to all conversations about patient data.
 - We have developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are available [here](#).
 - We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
 - ❖ We provide learning resources for patient advocates on patient data issues, including:
 - Hosting events for patients and the public, focussing on patient data topics
 - a library of resources of data security, consent
 - narratives from individuals about the value of collecting and using patient data.
 - ❖ We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.
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