

Dave Roberts
Head of Product for Arms Length Bodies
NHS Digital
7 and 8 Wellington Place
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West Yorkshire
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21 July 2021

Dear Dave,

General Practice Data for Planning and Research (GDPR)

Thank you for your response to our letter of 1 July 2021 following our June webinar, 'Trust and transparency: GP Data for planning and research' in which we identified key actions around the implementation of the GDPR.

We note the intention to delay the implementation of the GDPR and we support this position. We support and want patient data to be used with the confidence of patients and the public.

It was reassuring to see that three of the key actions that we identified have been addressed and confirmed in the letter from Jo Churchill, Parliamentary Under Secretary of State, to the GP community.

Key actions we identified, which are yet to be addressed:

1. NHS Digital should publish the numbers and breakdown of Type-1 opt outs.
2. NHS Digital to publish, in a more accessible format, the benefits assessment undertaken when access to data is given to a commercial company.
3. NHS Digital to enhance the reporting of access requests to include requests which are refused.
4. We see the communications plan as a critical piece of work. NHS Digital should publish details about the plan.
5. 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 are aware of the response¹ from Dr Nicola Byrne, the National Data Guardian, who was similarly positive about the decision to postpone and the steps being planned. Nicola refers to an oversight group and a group to focus on engagement which are being convened. It is vital that patients and the public are represented and have an equal voice on these groups. Please can you provide details of the groups, their membership and terms of reference. We have been unable to find any information online, suggesting that there is a continued lack of transparency about this project.

use MY data can help to bring patient voices and support to the next stages of the programme and to ensure successful delivery. We look forward to working with you and playing a full part in the next steps. As part of this, we would be supportive of hosting a use MY data webinar on the GDPR in September, open to patients and the public, and in working with NHS Digital on this.

Please share or use the contents of this letter in any ways that you feel will help you take the next steps. We will publish the letter on our website for transparency and so that our members know that we have acted on their behalf to reflect their interests on this matter.

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

¹ National Data Guardian Statement on the GDPR; <https://www.gov.uk/government/news/national-data-guardian-statement-on-the-general-practice-data-for-planning-and-research-gdpr-programme>

The only independent UK 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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