

Simon Bolton
CEO
NHS Digital

cc:

Matthew Gould, CEO, NHSX

Tim Donohoe, Director of Delivery, Assurance and Operations, NHSX

30 November 2021

Dear Simon,

General Practice Data for Planning and Research (GDPR)

We are writing on behalf of use MY data, to highlight our Members' continued and growing concerns about the lack of transparency for the development and planning work for the General Practice Data for Planning and Research (GDPR) programme and to seek a publicly-declared date of publication.

In July 2021 the Parliamentary Under Secretary of State for Primary Care and Health Promotion wrote to all GPs in England to pause the GDPR collection. The letter committed to a set of four areas to be addressed, including ensuring that patients are made more aware of the scheme through a campaign of engagement and communication. Part of this commitment was for a centrally driven communication campaign with clear messages. However, since July 2021 there has been no further publication about the work, which has included the appointments of and recruitment to oversight groups who are working on the next steps for the programme.

We wrote to NHS Digital in July 2021 seeking information about the remit and membership of the oversight groups and asking that details of these groups be published for transparency. Three months later, in October 2021, we received information from NHS Digital about the two formal oversight groups for the GDPR and an invitation to join the GP Data Patient and Public Engagement and Communications Advisory Panel.

NHS Digital advised that "to ensure transparency, the terms of reference for each group as well as appropriate meeting input/output will be captured and published for full public visibility. Again the publication location is being confirmed and will be included in the terms of reference as they are finalised". We were given 27 October as an intended date of publication (ahead of our first panel attendance on 28 October). Publication did not happen on 27 October and we have continued to push for publication. We were informed on 09 November that publication of information on the panel and on the GDPR was "going through the approval process". A publication date is still awaited.

use MY data has principles for transparency around using patient data, created by our Members. The principles include **being timely with communication** and **being as proactive with 'bad news' as with 'good news'**. We find ourselves in a difficult position of being part of a panel of which the public is unaware and about which nothing is published. Whilst some discussions and decisions around the GDPR will be complex, it is difficult for us to understand why overview details and meeting minutes of the oversight groups have not been published.

The lengthy delays and apparent secrecy around the next steps for GDPR are doing nothing to allay public suspicion about the project and the motives behind it, and indeed may well contribute to enhancing it.

use MY data exists to ensure that patient data is used to benefit patients and the NHS. We are the only independent movement of patients, relatives and carers in the UK focussed on patient data and aim to bring the patient voice to build confidence in the use of patient data to save lives. We would like to reiterate our commitment to this principle and to working supportively with NHS Digital.

Please share or use the contents of this letter in any ways that you feel will help to set a date for publication. 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 growing concerns on this matter.

Yours sincerely,

Richard Stephens

Dave Chuter

Richard Stephens
Chair
use MY data Advisory Group

Dave Chuter
Vice Chair
use MY data Advisory Group

C. Carrigan

Alison Stone

Chris Carrigan
Expert Data Adviser, use MY data

Alison Stone
Coordinator, use MY data

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** supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.
- **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.

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.
-