

Simon Bolton
CEO, NHS Digital
Chief Information Officer, NHS England

cc:

Matthew Gould, National Director of Digital Transformation, NHS England
Tim Donohoe, Director of Delivery, Assurance and Operations, NHS England

09 February 2022

Dear Simon,

General Practice Data for Planning and Research (GPDPR)

Thank you for your letter of 01 February in response to the concerns we raised about the lack of transparency for the development and planning work for the General Practice Data for Planning and Research (GPDPR) programme, including seeking publication of the existence and roles of the oversight groups.

As we highlighted, the concerns of our members about the lack of transparency continue to grow and we were disappointed that your letter provides neither clarity nor urgency to address this.

We would like to emphasise that use MY data wants the GPPDR to happen and for patient data to be used for research, to save lives and improve outcomes. We are keen to remain on the GP Data Patient & Public Engagement and Communications Advisory Panel in order to provide constructive challenge to NHS Digital. However, transparency is essential for patients having confidence in the use of their patient data in this way and therefore for the GPDPR to be a success. Our position is based on the core principles and values of use MY data, which underpin our work, and which have been established by our members.

Your letter asks us to bear with you whilst you “unblock this issue”. However, it is difficult to understand what the issue is. We do not understand why the existence of the oversight groups cannot be made public.

We continue to highlight the need for NHS Digital to act in a transparent manner by, as a minimum, publishing the existence of the GPDPR oversight groups, their terms of reference, their membership and meeting notes. The guidance from the Information Commissioner’s Office¹ is clear on this last point saying:

“It is good practice for public authorities to have a process that ensures minutes related to regular meetings are published reasonably soon after the meeting has been held”.

NHS Digital’s own website² states:

“The HSCIC is an open organisation that will carry out its activities transparently”.

¹ <https://ico.org.uk/media/for-organisations/documents/1156/minutesandagendas.pdf>

² <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/nhs-digital-s-annual-reports-and-accounts/nhs-digital-annual-report-and-accounts-2016-to-2017/department-of-health-hscic-framework-agreement/transparency>

We request that publication of the existence of the GDPR oversight groups, their terms of reference, their membership and meeting notes takes place by close of business on 28 February. If this date is not met, with regret we will need to step down from the Panel for the time being, to inform our members that we have done so, and to explain to them why. If it would be helpful for you to meet with us and discuss any queries, please do not hesitate to let us know; we would welcome a discussion. Please note however that at this point, we regard this request and deadline as a minimum standard that NHS Digital should be aiming for and achieving.

We equally emphasise that if we do leave the Panel, we will be very happy to return when the necessary steps for transparency have been taken: publishing the existence of the GDPR oversight groups, their terms of reference, their membership and meeting notes.

Please share or use the contents of this letter in any ways that you wish to. We will publish the letter on our website for transparency and so that our Members know that we continue to act on their behalf in accordance with the aims and values of our organisation, which they have set. We will of course publish any reply we receive from NHS Digital.

Yours sincerely,

Richard Stephens

Dave Chuter

Richard Stephens
Chair
use MY data Advisory Group

Dave Chuter
Vice Chair
use MY data Advisory Group

Chris 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.
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