

Simon Bolton
CEO
NHS Digital

cc:
Matthew Gould, CEO, NHSX
Tim Donohoe, Director of Delivery, Assurance and Operations, NHSX

18 January 2022

Dear Simon,

General Practice Data for Planning and Research (GDPR)

We are writing to follow-up about our letter to you, sent on 30 November 2021. We have not yet received a reply and although we recognise that this is a busy time for you, we had hoped to have had some form of response by the start of the New Year.

Our letter highlighted our Members' concerns about the lack of transparency for the development and planning work for the General Practice Data for Planning and Research (GDPR) programme and sought a publicly-declared date of publication. These concerns continue to grow and, to date, there are still no published updates about progress, programmes or oversight groups. As stated above, there is no reply to our emailed letter either.

As a patient led movement, we keep our Members updated on any work that we do on their behalf. However, in this instance we have not been permitted to do this, at the request of NHS Digital. We are not allowed to share the notes or work from the GP Data Patient & Public Engagement and Communications Advisory Panel, on which we have a place. The continued and prolonged lack of transparency is in danger of making our place on the Panel untenable, and the lack of communication to us on top of the lack of communication to the public is greatly concerning.

As highlighted in our previous letter, 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 we 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. But we need the same commitment from NHS Digital. At present it feels as though the patient voice in relation to the use of their patient data, is not being heard.

We would welcome a reply to our 30 November letter, so that we can update our Members. 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 have acted on their behalf to reflect their growing concerns on this matter and 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
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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