

Simon Bolton  
CEO, NHS Digital and  
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

01 March 2022

Dear Simon,

### **General Practice Data for Planning and Research (GDPR)**

We would like to thank you and your team, for the publication on 21 February of information on the oversight groups for the GDPR programme. This included the details identified by our Members as essential for transparency. Publication of the names of the groups, their terms of reference, membership and meeting notes/action points (with notes post-January awaiting publication) is a positive step towards transparency and confidence in the GDPR.

We look forward to helping the programme going forward, not least as part of the GP Data Patient and Public Engagement and Communications Advisory Panel. Our representatives will continue to monitor progress, including about transparency, at the meetings. We will continue to offer constructive suggestions to support this aspect of your work.

As ever, 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.

Yours sincerely,

*Richard Stephens*

Richard Stephens  
Chair  
use MY data Advisory Group

*Dave Chuter*

Dave Chuter  
Vice Chair  
use MY data Advisory Group

A handwritten signature in black ink, appearing to read 'Chris Carrigan'.

Chris Carrigan  
Expert Data Adviser, use MY data

A handwritten signature in black ink, appearing to read 'Alison Stone'.

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**

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## **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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