

31st July 2024

Rt Hon Peter Kyle MP
Secretary of State for Science, Innovation and Technology
House of Commons
London SW1A 0AA

Dear Secretary of State,

Congratulations on your new role as Secretary of State for Science, Innovation and Technology.

I am writing to offer Understanding Patient Data's support and expertise to you and your officials to ensure that health data is used in a trustworthy way to kickstart economic growth, from collaborating with the UK's life sciences industry and supporting our excellent research institutions to delivering data-driven public services.

At Understanding Patient Data, we have been pleased to see how much health data has already featured in the new Government's work, from references in the King's Speech about a new data bill to securing additional public and private sector funding for UK Biobank. Health data is an important enabler of new products developed by SMEs that can help modernise the NHS, enhance the life sciences industry's ability and willingness to invest further across the UK, and aid the development of appropriate AI to increase productivity and keep the UK at the forefront of global innovation.

Understanding Patient Data's vision is that health outcomes for all are improved through the responsible and trustworthy use of patient data. We do this by convening and supporting the patient data community, acting as a critical friend to governments and the NHS in the development of policies and practices, commissioning research to understand public attitudes, and developing resources to help members of the public understand how health data is collected and used.

We work closely with the Government and the NHS, particularly in England, but also across the UK and internationally, with civil society, academia, medical research charities and industry. We are hosted within the NHS Confederation, which keeps us close to health leaders whilst maintaining our independence and expertise in health data policy and research.

We are supportive of the new Government's aims to make it easier for legitimate researchers doing scientific research in commercial settings to make equal use of the UK's data regime, proposed in the new Digital Information and Smart Data Bill. The private sector, particularly in life sciences, plays an important role in the health data ecosystem. Whilst there is, understandably, limited information available about the bill

at the moment, we are concerned about the possibility of diluting individuals' rights and removing safeguards that prevent unethical, non-transparent research that isn't in the public interest.

We were also disappointed by some of the assumptions and misconceptions in the recent Times article about your plans to “make money from NHS data”, and the focus on technical problems and privacy concerns¹. Whilst it is true that there are some concerns about privacy when it comes to the use of data for research, this is just one area of concern. Others include concerns about discrimination (intentional or unintentional), enforcement action, direct marketing, surveillance capitalism, the value exchange between the public and private sector, and whether working with particular organisations aligns with NHS values.

Furthermore, whilst Secure Data Environments and privacy-enhancing techniques are part of the solution in making individuals' data less identifiable, this doesn't 'fix' the privacy problem; it reduces the risk to an extent, but we know that many people still view this data as theirs and it is usually impossible to keep data useful but entirely anonymous. Data sharing is also a complexity, trust and cultural problem, based on the factors above, rather than one specifically caused by data protection legislation.

More needs to be done to co-design appropriate policies and practices with the public as a whole as well as specific communities affected by particular data projects. The Government and NHS must demonstratively prove that their uses of health data are trustworthy, as well as third parties' uses of data. Some recent initiatives have been making very helpful inroads to understanding public opinion, at a national and regional level, for example via the Large-Scale Public Engagement programme and the Data for Research and Development programme, and as an organisation we have appreciated being invited to groups such as the Health and Social Care Data Strategy Advisory Panel and the Federated Data Platform Check and Challenge group. However, these initiatives are all one-off, rather than ongoing structures that can be used to meaningfully co-design change. Such initiatives don't have to be expensive or slow progress down; in fact, they can reduce the likelihood and extent of backlash and legal challenges.

Achieving these goals whilst maintaining and improving public trust isn't impossible. The Goldacre Review from 2022 sets out how a lot of this can be achieved. The National Data Guardian and her team do an excellent job, and there are many passionate and knowledgeable civil society organisations alongside Understanding Patient Data that are willing to help.

¹ <https://www.thetimes.com/article/800ba103-3a6d-409e-9953-df70f16adf76?shareToken=1317698c9ee61d5b274a1f69cf98b56c>. We do not believe it is correct to say that, “at the moment, people can apply for access to data relating to one very, very specific type of cancer” and not access a “broader set of cancers”, or that if people are struggling to access this data, it is entirely a result of data protection legislation.

I would welcome the opportunity to meet with you or your officials to discuss how we can support your work on common areas of interest, such as the Digital Information and Smart Data Bill, the National Data Library manifesto commitment, and health data for research and development plans. If this would be of interest, your office can get in touch via hello@understandingpatientdata.org.uk.

Yours sincerely,

Nicola Hamilton

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Head of Understanding Patient Data

Cc: Lord Patrick Vallance, Minister of State for Science, Research and Innovation,
Sir Chris Bryant MP, Minister of State for Data Protection and Telecoms
Feryal Clarke MP, Parliamentary Under-Secretary of State for AI and Digital Government
Baroness Jones of Whitchurch, Parliamentary Under-Secretary of State for the Future Digital Economy and Online Safety