



T: 0207 611 8235

E: n.banner@understandingpatientdata.org.uk

5th December 2018

Dear Rt. Hon. Matt Hancock MP,

We are pleased that the *Life Sciences Sector Deal* and *Code of conduct for data-driven health and care technology* take positive steps to ensure the UK can unlock the value of health data and drive exciting healthcare innovation. You and others^{1,2,3} have acknowledged that public trust and confidence are essential to underpin these advances, but this trust is fragile.

Patients and the public can be powerful advocates for better use of technology in health and care, but they have to be brought along the journey. The National Data Opt-Out has provided a good basis for people to express their choice. However, with increasing commercial partnerships to drive innovation, such as the *Accelerating Detection of Disease* programme, public anxieties present a significant challenge: there is a very real risk of a backlash⁴ or of some people being left behind.

The Sector Deal and Code provide a fantastic opportunity. They set the groundwork to engage meaningfully with patients, publics and clinicians on how to ensure a fair exchange of value for the NHS and patients when dealing with technology developers and the use of patient data.

The UK has led the world on embryonic stems cells and mitochondrial donation: success underpinned by extensive engagement with patients and the public, resulting in a thriving gene and cell therapy sector for UK plc. The same could be true for data-driven technology, if we get the engagement right.

In partnership with your department, we are keen to jointly lead and support research with publics, patients and health professionals to explore attitudes to the different models for NHS data use. This would help shape policy decisions and guidance on data-driven technology in a way that ensures nobody is left behind by the technology revolution. The recent Academy of Medical Sciences report "*Our data-driven future in healthcare*"⁵ provides an excellent springboard.

We would be happy to discuss our concerns and proposed ways forward in more detail.

Yours sincerely,

Aisling Burnand
Association of Medical
Research Charities

Prof. Sir Robert Lechler
PMedSci Academy of
Medical Sciences

Natalie Banner
Understanding Patient
Data

Nicola Perrin
Wellcome

¹ <https://publications.parliament.uk/pa/ld201719/ldselect/ldai/100/100.pdf>

² [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)32942-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)32942-8/fulltext)

³ <https://www.ft.com/content/1e83be40-4e3b-11e8-ac41-759eee1efb74>

⁴ <https://www.thetimes.co.uk/article/google-poised-to-profit-from-nhs-patient-records>

⁵ <https://acmedsci.ac.uk/policy/policy-projects/use-of-patient-data-in-healthcare-and-research>

