

How can we put the UK at the forefront of data science to enable discoveries that improve people's lives? Your ideas and suggestions

[Response to the online SurveyMonkey survey from use MY data](#)

July 2020

Background from HDR-UK

There's an opportunity to understand what has changed during the COVID pandemic and use this to set a new and even more ambitious direction for health data research in the UK. Share your ideas on how we can move this forward!

Research using health data during the COVID pandemic has been more visible and impactful than ever - with high profile leadership in SAGE, daily publications in national and international media on direct and indirect impacts of COVID, and a phenomenal range of new and enhanced data assets created.

We have seen the extraordinary pace and creativity from people using health data, and major advances in creation of new datasets, enhancements of datasets, and new publicly available tools. However, the use of these new data assets is still nascent, and there is an opportunity to radically increase the use of data and place the UK at the forefront of the health data science revolution.

On 20 July 2020, Health Data Research UK and Lord Prior, Chairman of NHS England, are convening a discussion between current and future health data science leaders to consider this opportunity and to think about how we use lessons learnt to shape the future of health data science in the UK. The aim is to create a consensus statement that we will publish on our website. This discussion will be recorded and made publicly available after the meeting.

We would like to inform this important discussion by inviting people from our wider community - whether you are a patient, member of the public or a colleague in the NHS, academia, industry or charity - to submit your ideas and suggestions in advance. We will collate this input and share it as a paper to the attendees of the meeting.

1. In relation to health data science, what have we learnt from COVID-19?

[What we have seen is an unprecedented focus on the use of patient data to drive research. This required a new approach to ensuring that data was available to researchers, with many barriers being removed and legislative support being enabled. In terms of data access, what previously may have taken many months has now taken days. We have learned that this improved data-access is possible - now let's not go backwards in a post-COVID world.](#)

2. Over the next five years, what opportunities could there be for UK health data science?

This will depend on the ability to link different data sources, and to make this data available for researchers in a timely, robust, audit-able and transparent manner. And in a way which maintains and builds public trust, with the patient voice embedded through these processes. We have proved that technology works, but we need far greater emphasis on inclusion of patients and public in this work, and more widely.

3. Where are we now?

This was well summed up by one use MY data member, who said: “My views remain as they always have been; we need a culture change in governance, replacing Guardians with Sharers, Confidentiality with Access, and recognising that the needs of the many outweigh the needs of the one. We do tend to regard the duty of care as being to the individual but there comes a point when public (or even private) bodies have a duty of care to the public and to society, and I wish the guidance given to these bodies would reflect on that.”

4. What needs to happen for us to meet the opportunities you identified?

Much wider patient and public engagement and inclusion. Backed up by clear, high-quality, tested and consistent communications. History shows that whilst we are willing to spend on technology, we seem unable to invest in communications to bring patients and the public with us.

Thank you for your ideas and suggestions. We will collate this input and share it as a paper with those attending the discussion session.

If you have any questions or would like to discuss anything further please email enquiries@hdruk.ac.uk