

**From the President**  
**Professor Dame Anne Johnson**  
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6 July 2023

Professor Cathie Sudlow OBE FMedSci  
Lead for the 'Unifying Health Data in the UK' review  
By email: [SudlowReview@HDRUK.ac.uk](mailto:SudlowReview@HDRUK.ac.uk)

Dear Professor Sudlow,

**Re: The Sudlow Review, 'Uniting Health Data in the UK'.**

I was delighted to hear that you are chairing the 'Uniting Health Data in the UK' review, to map the health data landscape in the UK and propose solutions to enhance the use of data for the benefit of patients and the public. I am sorry that the Academy of Medical Sciences will not be able to put together a comprehensive response to your consultation questions by the 7 July 2023 deadline. However, we wanted to bring to your attention relevant past and upcoming Academy work that we hope will be useful for your review.

As you will know, the Academy is the independent, expert voice of biomedical and health research in the UK, and this review speaks to our vision of good health for all supported by the best research and evidence. The Academy has long championed the use of data to improve health care, and has called for **better access to, and linkage and use of, data, supported by capacity building for skills in managing and analysing large data sets**.<sup>1,2</sup>

In 2020, we partnered with Health Data Research UK (HDR UK) and the Centre for the Advancement of Sustainable Medical Innovation (CASMI) to explore how patient and NHS benefits from health and care data could be realised.<sup>3</sup> Our report 'Our data-driven future in healthcare' published in 2018 also set out **a series of principles to guide the development, evaluation and use of data-driven technologies in health and social care** (see box below).<sup>4</sup>

We will soon be publishing an update statement to our 'Improving the health of the public by 2040' report published in 2016,<sup>5</sup> and will set out priorities to improve the health of the public through research. Our statement identifies **better harnessing data and novel methods and technologies for health of the public research and practice** as a key priority for action. At present, data related to the wider determinants of health are not readily captured. This is to the detriment of public health research, which would greatly benefit from the systematic collection of wider demographic data, such as socioeconomic, race and ethnicity data, and its linkage to health records.

In addition, the Goldacre review recommended that Trusted Research Environments (TREs) should be established for the use of health data for research.<sup>6</sup> These provide a secure environment for the storage and analysis of health data, but we have heard that it remains challenging to integrate other datasets on the wider determinants of health within TREs due to complex governance issues.

We agree that there is a unique opportunity to build on the positive developments in data linkage and governance gained during the Covid-19 pandemic. **This must include better collection and linkage of data on the wider determinants of health and health outcomes at the local, regional and national level, as well as improving the quality and availability of social care data.**

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In our upcoming statement on improving the health of the public through research, we call on **the Departments of health and public health bodies in all UK nations to review the existing mechanisms for generating, collecting and linking wider determinants of health data to identify opportunities to enhance the use of public health data, and to work with HDR UK and other data repositories, such as the ONS, to identify how this can be done.** This will need to be supported by investment in skills and research to develop better technologies and methodologies for the generation and use of public health data, and to ensure the public health workforce is equipped with the skills to use such tools.

We emphasise that any initiatives to enhance data collection and linkage will require **consultation with the public**. We are therefore pleased that patients and the public will be consulted and embedded in the governance of your review.

We look forward to reading the outcomes of the review in your final report. Please do not hesitate to contact us if there are aspects of the review where you would value further input from the Academy.

Yours sincerely,



**Box: Principles for using data-driven technologies outlined in our report 'Our data-driven future in healthcare'<sup>7</sup>**

- A. Purpose, value and benefits:** Data-driven technologies should be designed and used for clearly defined purposes that uphold the social values of the NHS and benefit individuals, the NHS, or society.
- B. Privacy and rights:** Data-driven technologies should be designed and used in ways and settings that respect and protect the privacy, rights and choices of patients and the public.
- C. Public engagement and partnership:** Those determining the purpose and uses of data-driven technologies should include patients and the public as active partners.
- D. NHS data stewardship and responsibilities:** The NHS, and those acting on its behalf, should demonstrate their continued trustworthiness by ensuring responsible and effective stewardship of patient data and data-driven technologies in the NHS.
- E. Evaluation and regulation:** Data-driven technologies should be evaluated and regulated in ways that build understanding, confidence and trust, and guide their use in the NHS.

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- <sup>1</sup> Academy of Medical Sciences (2017). *Enhancing the use of scientific evidence to judge the potential benefits and harms of medicines*. <https://acmedsci.ac.uk/file-download/44970096>
- <sup>2</sup> Academy of Medical Sciences, British Academy, Royal Academy of Engineering & Royal Society (2020). *National Data Strategy Consultation – Joint response from the UK National Academies*. <https://acmedsci.ac.uk/file-download/2148827>
- <sup>3</sup> Academy of Medical Sciences, Centre for the Advancement of Sustainable Medical Innovation & Health Data Research UK (2020). *Realising patient and NHS benefits from health and care data – from policy to practice*. <https://acmedsci.ac.uk/file-download/73707502>
- <sup>4</sup> Academy of Medical Sciences (2018). *Our data-driven future in healthcare*. <https://acmedsci.ac.uk/file-download/74634438>
- <sup>5</sup> Academy of Medical Sciences (2016). *Improving the health of the public by 2040*. <https://acmedsci.ac.uk/snip/uploads/5807581429f81.pdf>
- <sup>6</sup> Goldacre B, et al. (2022). *Better, broader, safer: using health data for research analysis*. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1067053/goldacre-review-using-health-data-for-research-and-analysis.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1067053/goldacre-review-using-health-data-for-research-and-analysis.pdf)
- <sup>7</sup> Academy of Medical Sciences (2018). *Our data-driven future in healthcare*. <https://acmedsci.ac.uk/file-download/74634438>

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