<u>New review into use of health data for</u> <u>research and analysis</u>

A new review, launched by the government today, will focus on the more efficient and safe use of health data for research and analysis for the benefit of patients and the healthcare sector.

The review will complement the forthcoming Data Strategy for Health and Social Care which will set the direction for the use of data in a postpandemic healthcare system.

The Secretary of State for Health and Social Care has asked Dr Ben Goldacre to undertake this rapid review and report his findings in April.

Matt Hancock, Secretary of State for Health and Social Care, said:

The pandemic has demonstrated just how important health data is. Ensuring that researchers have secure, transparent and ethical access to health data has the potential to transform health and care and save lives.

Ben has a wealth of experience in working with health data and I am delighted he has accepted my invitation to undertake this review. I am looking forward to working with Ben and seeing his recommendations over the coming months.

Dr Ben Goldacre, Director of the DataLab, Nuffield Department of Primary Care Health Sciences, University of Oxford, said:

The UK has a phenomenal resource in its raw data, and its people. Our challenge is now in the final lap: we need to find safe, secure, collaborative and efficient ways to turn that raw data into insights and action, to improve patient care for all. There is a wealth of expertise around the country, much of it untapped.

I'm excited to talk to people across health, social care and research about their experiences and concerns to help drive better, broader, safe use of health data.

If you would like to get in touch about the review or share your experience of using health data for research, please contact <u>goldacrereview@dhsc.gov.uk</u>.

Terms of reference for the review

1. How do we facilitate access to NHS data by researchers, commissioners, and innovators, while preserving patient privacy?

- 2. What types of technical platforms, trusted research environments, and data flows are the most efficient, and safe, for which common analytic tasks?
- 3. How do we overcome the technical and cultural barriers to achieving this goal, and how can they be rapidly overcome?
- 4. Where (with appropriate sensitivity) have current approaches been successful, and where have they struggled?
- 5. How do we avoid unhelpful monopolies being asserted over data access for analysis?
- 6. What are the right responsibilities and expectations on open and transparent sharing of data and code for arm's length bodies, clinicians, researchers, research funders, electronic health records and other software vendors, providers of medical services, and innovators? And how do we ensure these are met?
- 7. How can we best incentivise and resource practically useful data science by the public and private sectors? What roles must the state perform, and which are best delivered through a mixed economy? How can we ensure true delivery is rewarded?
- 8. How significantly do the issues of data quality, completeness, and harmonisation across the system affect the range of research uses of the data available from health and social care? Given the current quality issues, what research is the UK optimally placed to support now, and what changes would be needed to optimise our position in the next 3 years?
- 9. If data is made available for secondary research, for example to a company developing new treatments, then how can we prove to patients that privacy is preserved, beyond simple reassurance?
- 10. How can data curation best be delivered, cost effectively, to meet these researchers' needs? We will ensure alignment with Science Research and Evidence (SRE) research priorities and Office for Life Sciences (OLS) (including the data curation programme bid).
- 11. What can we take from the successes and best practice in data science, commercial, and open source software development communities?
- 12. How do we help the NHS to analyse and use data routinely to improve quality, safety and efficiency?

Dr Ben Goldacre Biography

Ben Goldacre is a doctor, researcher and author. He runs the DataLab at the University of Oxford, building tools and services from large health datasets, and advises government on better uses of data and technology.

He leads various technology projects including:

- <u>OpenSAFELY.org</u>, a new model of secure analytics platform that runs across unprecedented volumes of linked primary and secondary care electronic health record data
- <u>OpenPrescribing.net</u>, an open data explorer for NHS primary care prescribing with over 130,000 users a year
- <u>TrialsTracker.net</u>, an open tool that monitors clinical trial reporting performance

His books, including 'Bad Science', have sold over 700,000 copies in more than 30 countries. His online lectures have over 5 million views.