Uniting Health Data in the UK Review

Introduction

Professor Cathie Sudlow, Chief Scientist at HDR UK, has been commissioned by Professor Sir Chris Whitty, Dr Timothy Ferris, and Professor Sir Ian Diamond to conduct an independent review of the UK health data landscape *(see Annex 1: Terms of Reference)*

The review, entitled *'**Uniting Health Data in the UK**'*, will map and assess the flows of health-relevant data across the four nations of the UK, offering an opportunity for policy makers to evaluate how data can be better managed to improve the public's health, while maintaining privacy and public trust. **As well as mapping the health-relevant data landscape the Review will also identify barriers to the safe and secure linkage and analysis of data from different sources for public benefit and will recommend solutions**, with an initial focus on England.

Proposed Scope of the Review

1. **Data to consider in mapping the linkable health datasets across the UK**

    - Data in electronic format arising from routine activity **within the NHS:**

        o   Collected and collated at national (country) level e.g., hospital episodes, primary care data – largely structured, coded data

        o   Not available at national level but collected regionally e.g., free text, images, some NHS operational data

    - Health relevant data in electronic format arising from routine administrative activity **outside the NHS**, e.g., Census, education

2. **Make reference to health relevant data generated by the research community (e.g. population and disease-based research cohorts, clinical trials) and data beyond health care/administrative activities** (e.g., mobile phone apps, wearable devices, supermarket loyalty cards, air pollution monitoring, meteorological data). There is considerable potential to enhance the potential of all of these by enabling their trustworthy and consensual linkage to data arising from routine activity within and beyond the NHS (listed above) and to each other.

3. **Plan to highlight:**

    - input from patients and members of the public

    - progress made during the pandemic with data sharing/access and generation of policy relevant insights

    - key gaps that remain

- national scale datasets that exist but remain difficult to link and/or access

- potential to create a more granular picture at national level through federation across regional datasets

- examples of digitally mature regional data linkage and access set-ups and what they can achieve

- need to move beyond COVID-specific use approvals.

4. Addressing barriers and potential solutions will have an English focus but will take into account the need for solutions that will be relevant for all UK nations.

Proposed timelines for the review

- **May – November 2023:** consultation phase with key UK wide stakeholders including members of the public.

- **December 2023– Spring 2024** – drafting of Review

- **Spring 2024** – Publication

Input to Review from key stakeholders

To date, Professor Sudlow and team have received input to the Review (and continue to do so) from a wide variety of stakeholders via a series of consultation meetings and online survey responses, with a public workshop planned in August. Please see below for list of stakeholders who have provided input to date *(please note this is not exhaustive as consultation ongoing):*

Organisations consulted /in process of consulting with to date	
Dept of Health and Social Care UK Biobank Our Future Health UK Longitudinal Linkage Collaboration Generation Scotland Asthma and Lung UK National Institute for Health and Care Excellence Cancer Research UK	• National Speciality Advisor for Pathology NHS England • Royal College of Radiologists • Royal College of General Physicians • Royal College of General Practitioners • British Medical Association • National Institute for Health and Care Research • UK Research and Innovation

British Heart Foundation	• NHSE Regional Secure Data Environments
Medicines and Healthcare products Regulatory Agency, Clinical Practice Research Data Link	• Carnall Farrar
Genomics England	• Precision Life
OpenSAFELY	• Palantir
UK Health Security Agency	• Lane, Clark and Peacock
NHS England, NHS Wales, NHS Scotland, Health and Social Care NI	• Pfizer, AstraZeneca
All four nations CSOs for health	• National Data Guardian
Office for National Statistics	• UseMyData
ADRUK	• Understanding Patient Data
ABPI	• medConfidential
BIA	• Online survey- stakeholders including members of the public submitted responses via an online survey June-July 2023
Association of Medical Research Charities	• Further public involvement and engagement planned (including via workshop in August 2023)
Research Data Scotland	
Health Research Authority	• Numerous senior academics with relevant specific expertise
Royal College of Surgeons	• Input still welcomed via sudlowreview@hdruk.ac.uk
Academy of Medical Royal Colleges	

Annex 1: Review Terms of Reference

1. The Chief Medical Officer for England Professor Chris Whitty, NHS England's National Director of Transformation Dr. Timothy Ferris and the UK's National Statistician Professor Ian Diamond have commissioned Professor Cathie Sudlow to conduct a review of flows of health data. This has the support of the Chief Medical Officers of the four nations of the UK and the Government Chief Scientific Adviser.

2. During COVID-19, we saw the flow of data improve in parts of the health system. Embedding these, other positive changes and enhancing the flow of secure data will help healthcare workers, public health experts, researchers and policy officials to improve patient outcomes.

3. This review should analyse the speed and flow of data within the health system, identify areas where there are barriers and prevent the reversal of progress we have seen to date including what needs to be in place to promote ongoing improvement.

4. Maintaining the principle of patient confidentiality and public confidence is essential.

5. The review should be in two parts:
   - Part A: A mapping of the linkable health data sets across the UK. This includes health data, but also non-health data which has a bearing on health where you think that is relevant.
   - Part B: Outlining any barriers in England, including practical and regulatory, and what we can do to overcome them.

6. The review should cover data related to:
   - Direct care.
   - Population health: de-identified data for epidemiology and identified data for case finding.
   - Operational planning: de-identified data with access by NHS and/or government.
   - Research.

7. Reflections on wider data issues which impact on health inequalities would be welcome.

8. It is assumed you will seek Secretariat support from within Health Data Research UK but if this is challenging then we can seek support from within DHSC, NHSE and ONS.

9. You should assemble either as a permanent refence group or consult ad hoc for specific issues whoever you think would be helpful to progress the work.

10. The report should be concluded within six months if possible and be made publicly available. You may prefer to do two reports, with early findings informing action.