House of Commons Science and Technology Committee Inquiry into Big Data

Royal College of Physicians Submission

Introduction

1. The Royal College of Physicians (RCP) welcomes this opportunity to provide evidence to the Science and Technology Committee inquiry into Big Data. This response is based on the experience of the RCP's members and fellows, mainly hospital doctors and the RCP's Health Informatics Unit.

Summary

- Big data has the potential to improve the quality of patient care and is fundamental to providing new innovative procedures and treatments.
- The current processes for recording and sharing patient information are not sufficient for utilising the potential benefits of big data. Clinical records and information is often not accurate or of high enough quality for big data purposes.
- Clinicians must be supported to develop a better understanding of wider benefits of good patient records and big data to the benefits of patient care.
- The public must be provided with more information on big data to ensure that the benefits of big data can be balanced with individual confidentiality.

Evidence

The opportunities for big data, and the risks

2. Big data offers many potential benefits to improving the quality of patient care. Clinical data can generate knowledge and improve patient care, through providing valuable resources for research, supporting data collection, clinical audit programmes and helping to understand and measure the performance of trusts in caring for patients. Utilising large scale data sets further enables the tracking of diseases and conditions on a national and local basis.

3. Large scale data collection further supports the delivery of the latest treatments and procedures in health such as stratified medicine. Stratified medicine which is a significant breakthrough enables doctors to provide patients with specific treatments according to individual needs. It requires the collection of genotype (information on individual's genetics) and phenotype (lifestyle and environmental information from patients). The benefits of stratified medicine are only possible through the collection of data.

4. However, whilst there are significant benefits to patient care, big data also comes with associated challenges and risks. There are significant problems with the collection of clinical data. Many of our members and fellows have reported that the collection of data can often be costly, inefficient and inaccurate.

5. For NHS collection of information there is often little standardisation of clinical data in source systems, either in the headings under which data are recorded or in the definition of individual clinical terms. This

has led to huge variations in record structures and clinical language, and major problems with the coding of clinical concepts.

6. There is often large inconsistencies with regards to recording clinical data. For example, ICD10 codes used in hospitals (secondary care) contain very high level information. Read codes however which are used in primary care are very detailed, there are 47 read codes for asthma. This makes it very difficult to compare data coded at different levels of care. As a result, epidemiologists and researchers spend a lot of their time trying to make sense of and clean up clinical data, then understanding and compensating for its many hidden biases. Many clinical research studies can often be undermined due to poor quality of data at point of recording or collection.

7. SNOMED CT (Systematized Nomenclature of Medicine--Clinical Terms) is being implemented across primary and secondary care which will help in ensuring that there common coding framework.

Whether the government has set out an appropriate and up to date path for the continued evolution of big data and the technologies requires to support it.

8. There is a widely held view that Big Data can be obtained from current data sources in the NHS, however the problems outlined above regarding the quality of information recorded means that there is not sufficient quality to collect useful information in health care.

9. The Government must set out the requirement for a national record standard for health providers. These include the use of the Academy of Medical Royal Colleges standards for the structure and content of patient records, and SNOMED-CT as the clinical terminology.

10. Definitions of the clinical terms that are used in patient records (and coded through SNOMED-CT) also need to be developed and agreed. These should be consensus based, and it is recommended that specialist societies are commissioned to undertake the work, in collaboration where appropriate.

Where gaps persist in the skills needed to take advantage of the opportunities, and be protected from the risks, and how these gaps can be filled.

11. All clinicians need to develop a good understanding of the wider benefits of accurate record keeping. There is a need to develop skills in health informatics at all levels, from medical trainees to consultants, if a change in culture is to be achieved. This gap needs to be filled both through ensuring health informatics is included in the medical core curriculum and through continuing professional development, revalidation and service accreditation. The RCP's Health Informatics Unit will continue to promote this agenda in conjunction with other Royal Colleges.

12. In addition, there is a need to develop leadership skills so that every care provider has a chief clinical information officer (CCIO) and team, who are able to provide clinical leadership within their organisation on all informatics developments. The RCP and Royal College of General Practitioners are collaborating on developing a case for the establishment of a Faculty of Clinical Informatics to address this skills gap.

How public understanding of the opportunities, implications and the skills required can be improved, and 'informed consent' secured

13. There were significant problems with the public communications surrounding the launch of the Care.Data programme. Many individuals in the public did not fully understand the proposals included in the Care.Data programme and the potential benefits to individual patient care. There is a state of confusion surrounding the Care.Data programme the proposed use of patient information and the safeguards. The impacts of the launch of the Care.Data programme still has implications for other data programmes and initiatives.

14. The risks for big data largely relate to the potential for individuals to be identified, but need to be balanced by the potential benefits from the knowledge generated. The risks can be mitigated by appropriate pseudonymisation at source, and by consultation on, and clarity about, who will have access to the data and the purposes for which the data can be used. It would be very helpful to have a wide and informed debate to agree the principles to utilise the benefits of big data whilst protecting patient confidentiality.

Any further support needed from Government to facilitate R&D on big data, including to secure the required capital investment in big data research facilities and for their ongoing operation.

To increase the value of clinical data as a component of big data, the Government could promote and facilitate the development of Health Informatics as a discipline, to help us to understand and improve:

- Methods for capturing data from patients; the reliability and validity of such data; privacy issues; human computer interaction
- The quality & completeness of clinical data at source, through interventions, including extending the depth in structured and coded data
- Interoperability of records to reduce repetition and to link data across care settings
- The documentation & instrumentation of datasets for re-use (eg. Manchester eHERC's eLabs project)
- The design of tools to browse virtual cohorts etc. (I2B2 etc.) or improve patient recruitment to pragmatic clinical trials
- Better presentation of research results via information design, infographics etc.
- The incorporation of research results into guidelines and practice (knowledge representation, knowledge management, reminders, clinical decision support, apps etc.)

15. We are aware of and support proposals being put together for submission in the Spending Round for an MRC–led institute of health informatics, which aims to improve researcher productivity, reduce research waste and increase funder return on investment. The Government should also support the continued leadership of the development and implementation of standards for the structure and content of clinical records, which is provided by the Professional Record Standards Body (www.thePRSB.org), of which the RCP is a member. In addition, we believe that radical change is needed in the process for central returns, so that data is validated by clinicians during patient care and extracted from the electronic patient record, rather than being a separate data collection exercise.

Background to RCP

16. The RCP plays a leading role in the delivery of high quality patient care by setting standards of medical practice and promoting clinical excellence. We provide physicians in the United Kingdom and overseas with education, training and support throughout their careers. As an independent body representing over 30,000 fellows and members worldwide, we advise and work with government, the public, patients and other professions to improve health and healthcare. Our primary interest is in building a health system that delivers high quality care for patients.

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