

Sir Sabaratnam Arulkumaran  
President  
British Medical Association  
BMA House  
Tavistock Square  
London WC1H 9JP

9 June 2014

Dear Sir Sabaratnam

### **Use of patient data for research purposes**

It has come to our attention that York's Local Medical Committee is bringing a motion to your Annual Representatives Meeting 22<sup>nd</sup>-26<sup>th</sup> June, which proposes that extraction of patient data for NHS England's care.data roll-out should only take place with the explicit and informed consent of patients opting-in.

The Royal Statistical Society (RSS) is a learned society for statistics, a professional body for statisticians and a charity which promotes statistics for the public good.

We support data linkage for reputable statistical and research purposes, including the use of personal data with sufficient privacy protections. We are also of the view that public trust in the use of personal data needs to be hard earned, and regrettably has not been in the care.data case.

While we share the LMC's approval that care.data be put on hold, we have grave concerns that creating an 'opt-in' system would be an excessive response to the recent problem. Sharing data only on an opt-in basis means that the data collected is far less representative of the general public. An opt-in approach would make any shared GP dataset remarkably less useful for statistical and medical research, and for healthcare commissioning.

To preserve value for research, work instead on improving privacy safeguards would be far more valuable. In April we published a statement to share some suggestions in this regard, which can be found on our website<sup>1</sup> and which I enclose with this letter.

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<sup>1</sup> [http://www.rss.org.uk/uploadedfiles/userfiles/files/RSS\\_Position\\_Care\\_data\\_Apr2014.pdf](http://www.rss.org.uk/uploadedfiles/userfiles/files/RSS_Position_Care_data_Apr2014.pdf)



We also have some concerns as to the LMC proposal that data should be pseudonymised or anonymised before it leaves the practice. The earlier that data is anonymised or pseudonymised, the more limited the data become for data linkage purposes.

We hope that this letter and our earlier statement could be shared with the Annual Representatives Meeting in advance of a vote on this motion.

With thanks and regards,

A handwritten signature in blue ink, consisting of several overlapping horizontal and vertical strokes, appearing to be the name 'Roeland Beerten'.

Roeland Beerten  
Director of Public and Professional Affairs

## Royal Statistical Society position on personal health data in England

The Royal Statistical Society strongly supports the use of personal data for research where the purpose is to gain new statistical insight into a population, and the identity of the individual is not needed for the research. Data that arises from individual participation in health services is of great and proven value for this. It has been used both in the public sector and in public private partnership, for example to make improvements in healthcare and in medical treatments.

We favour efficient, transparent and ethical access to such data for statistical research in the public interest. However it is imperative that the gathering of these insights also respects the rights of individuals, including their right to privacy.

In recent months we have seen legitimate public concerns raised regarding the management of personal health data in England. These have led to proposed amendments to the Care Bill which will be presented on the 7<sup>th</sup> May. Our view is that some improvements may be possible in the short term, but that robust responses to restore public confidence should be developed and consulted on over a longer time period. It is imperative that new health data sharing initiatives such as care.data are not brought into practice on a basis that does not address public concerns.

In our view, there are several broad principles that could help to restore the trust of the public, experts and research stakeholders.

1. Transparent accreditation of data uses and data users. The criteria for this should be consulted on, publicly available and consistent. Criteria for use could include a clear case that the research question requires analysis of personal health data, a public interest purpose for the research, and commitment to publish the results publicly. Criteria for users could include that they would be personally legally liable for confidentiality breaches.
2. Consistent, transparent roles and responsibilities for 'safe havens' and safe settings, which gate-keep researchers' access to personal health data. The Health and Social Care Information Centre is a designated safe haven, however their role in data sharing and data protection were not set out in the 2012 Health and Social Care Act. The role of safe havens in data protection should be clarified.
3. Public consent for GPs to share their data in the public interest should continue to take place, on an opt-out rather than opt-in basis. Switching to an 'opt-in' system would greatly reduce the extent to which the data represents general practice across England. This would compromise its value for statistical and medical research, and for healthcare commissioning. However, there is a need for dialogue with the public regarding the legitimate purposes of data sharing. Public understanding of medical and research purposes should be promoted, and public views should inform the criteria for approval of research that makes use of personal data.



4. Rules against re-identification must be backed up with effective protocols, procedures and sanctions that command public trust. There is a sound legal basis for these enforcements in 1998 Data Protection Legislation and the 2006 NHS Act, but oversight and public trust in enforcement could improve. A new statutory body is likely to be needed to fulfil this role.

28<sup>th</sup> April 2014

