

## 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

