



NDG's Review of Data Security, Consent and Opt-Outs
Room 2N12
Quarry House
Quarry Hill
Leeds, West Yorkshire
LS2 7UE

7 September 2016

Dear Sir/Madam,

Re: National Data Guardian for Health and Care's Review of Data Security, Consent and Opt-Outs

I am writing in response to the National Data Guardian's consultation on the review of data security, consent and opt-outs. I welcome the opportunity to respond to this call for evidence on behalf of the Royal College of Physicians (RCP).

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 almost 32,000 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.

We support the proposed ten data security standards and welcome the balance that has been struck between individual privacy and public benefit. We welcome the review proposals for greater clarity and transparency about the use of data for secondary purposes. We are also pleased to see that data flows for existing collections, such as HES, will continue unchanged.

The current procedures for data processors are quite onerous and we would welcome any progress towards a new simplified process for data sharing whilst aspiring to the broader principles set out in the consultation.

We would like to raise that opt outs present a risk in skewing data in national clinical audit programmes, especially if there are specific cohorts of patients who opt out. Clear communications about benefits of data sharing will be key to reducing this risk. In this respect, we would be grateful if consideration could be given to whether there could be a process whereby patients choosing to opt out in life could consent to their data being released after death for secondary use purposes if they so wished.



We have concerns that the ten data security standards should not simply replace the current Information Governance Toolkit. This would leave out key elements of information governance such as consent management, confidentiality, data protection, data sharing and records management.

We recognise the need to review and update the NHS IG Toolkit and would welcome an approach that enabled those completing it to use it as a tool to help manage information governance within the organisation, rather than simply as a reporting exercise. We also consider that it should refocus to support key developments in integrated care and data sharing.

We have concerns that smaller organisations providing health care such as care homes, GP Practices, dentists and other small providers find it difficult to cope with current IG Toolkit requirements and would struggle with Cyber Essentials, thus making it difficult to share information to achieve integrated patient care.

We would like to see the review take into account the increased opportunities individuals will have to manage their own data in the future. As individuals get access to their data through online access to GP and hospital records and as they record their own health information in personal health records there will be an opportunity to improve the quality of data through patient feedback on inaccuracies and to increase the richness of the data by patient-provided information (e.g. from monitoring devices). The review needs to take account of patient recorded data and whether this would be subject to the same restrictions on type one objections related to the collection of data in the HSCIC safe haven. It should also take account of the opportunity for patients to record consent decisions through their personal health records.

The opt out model differentiates between use of data for local purposes connected with providing local services and running the NHS and social care system and use of data for research and to improve treatment and care. As structured and coded data is increasingly being recorded and used by clinicians in electronic health records in healthcare organisations this distinction is becoming increasingly blurred, for example with local clinical audit, quality improvement, collecting evidence for appraisal and revalidation, etc. It may be difficult for both patients and clinicians to draw a clear distinction.

Communication is going to be an important element of implementation to ensure that patients are aware of the choices and implications available to them. The RCP has an active patient advisory group in the form of the Patient Carer Network and as such would be happy to provide further support and advice.

I would be delighted to discuss these issues in more detail with you. Please contact policy@rcplondon.ac.uk to arrange a further conversation.



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Summary

- The RCP welcomes the proposed security standards and the balance between individual privacy and public benefit.
- The RCP recommends that the ten data security standards should be complementary to the Information Governance Toolkit in order to fully encompass data governance issues, however recognise the need to review and update it.
- There is the concern that smaller organisations may struggle with Cyber Essentials, making it difficult to share information for integrated patient care.
- The review should note the impact that increased opportunities for individuals to manage their data will have in future.
- The opt out model differentiates between the use of data for running the NHS and social care system and for research, however this is not a clear choice as these purposes can overlap, for example in local clinical audit.
- Progress towards a simplified system or data sharing would be welcomed.

Yours faithfully,

A handwritten signature in black ink, appearing to be 'A. Goddard'.

Dr Andrew Goddard
Registrar