



The Royal College of **Pathologists**

Pathology: the science behind the cure

Response from the Royal College of Pathologists to the Consultation on New data security standards and opt-out models for health and social care

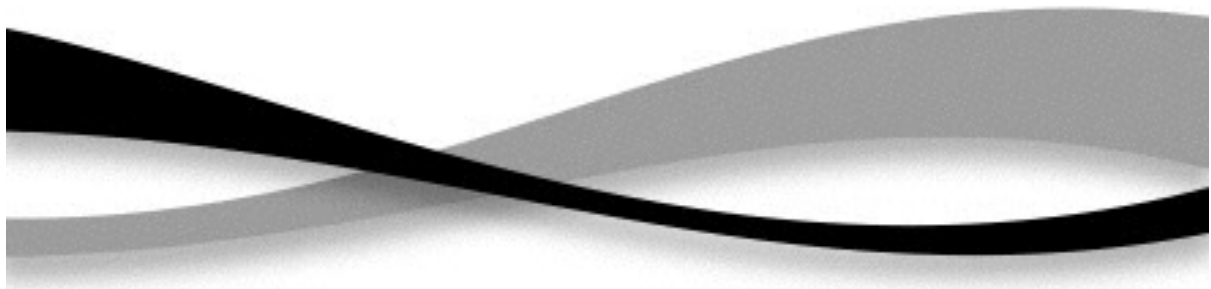
The Royal College of Pathologists' written submission

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For more information please contact:
Rachael Liebmann
Registrar

The Royal College of Pathologists
4th Floor
21 Prescot Street
London
E1 8BB

Phone: 020 7451 6700
Email: registrar@rcpath.org
Website: www.rcpath



1 About the Royal College of Pathologists

1.1 The Royal College of Pathologists (RCPATH) is a professional membership organisation with charitable status. It is committed to setting and maintaining professional standards and to promoting excellence in the teaching and practice of pathology. Pathology is the science at the heart of modern medicine and is involved in 70 per cent of all diagnoses made within the National Health Service. The College aims to advance the science and practice of pathology, to provide public education, to promote research in pathology and to disseminate the results. We have over 10,000 members across 19 specialties working in hospital laboratories, universities and industry worldwide to diagnose, treat and prevent illness.

1.2 The Royal College of Pathologists comments on proposed standards were made by Dr Bernie Croal, Chair of the RCPATH Pathology Informatics Group.

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2.1 Pathology results exist on a number of databases including laboratory LIMS, order comms and clinical databases. For optimum patient safety, a multitude of professionals need to have access, especially in emergency situations. Difficult to access results stored across a fragmented system of providers could also lead to unnecessary repeat testing.

2.2 In addition, much of the interpretation of complex lab results, especially genetics, requires access to associated clinical data - it is vital again that information government restraints do not make this difficult.

2.3 In response to the question 'If applicable, how far does your organisation already meet the requirements of the ten standards? Standard Requirements - Where 0 = Not at all and 10 = Fully Compliant': 5

2.4 In response to the question 'By reference to each of the proposed standards, please can you identify any specific or general barriers to implementation of the proposed standards?': Much of this will require significant funds to expand IT departments across the NHS as well as the necessity to pull in IT staff who will be difficult to recruit.

2.5 The lack of standardisation in pathology will also significantly inhibit attempts to allow safe data sharing, and there will be significant risks associated with this.

2.6 In response to the question 'Please describe any particular challenges that organisations which provide social care or other services might face in implementing the ten standards': As mentioned above much of this will require significant funds to expand IT departments across the NHS as well as the necessity to pull in IT staff who will be difficult to recruit.

2.7 Gaps in standardisation and interoperability will also make data sharing from primary/secondary care to social care difficult.

2.8 In response to the question 'Is there an appropriate focus on data security, including at senior levels, within your organisation?': Yes

2.9 Most NHS Pathology departments will take this very seriously however gaps in standardisation and limitations of budgets and staff will always make this difficult - especially if the standards are considerably increased.

2.10 In response to the question 'What support from the Department of Health, the Health & Social Care Information Centre, or NHS England would you find helpful in implementing the ten standards?': A fully funded National Catalogue for pathology tests is essential for safe data sharing and handling - especially as genetic services are expanded.

2.11 In addition, a consistent program of IT support would be very important, as well as the increased funding required.

2.12 In response to the question 'Do you agree with the approaches to objective assurance that we have outlined in paragraphs 2.8 and 2.9 of this document?': Yes

2.13 If the toolkit works then that is great but there is not a lot of confidence among Fellows that it will be delivered. In addition, the threat of CQC inspection is just that - a threat. Inspection on its own does not necessarily improve compliance if there are still significant budget constraints and a failure to recruit staff.

2.14 Regarding the importance of data sharing and proposed consent/opt-out model in response to the question 'Do you have any comments or points of clarification about any of the eight elements of the model described above?' The use of big data holds much promise - allowing people to opt out of this could seriously undermine or bias the data and the conclusions/actions taken. What proportion of opt outs are expected?

2.15 In response to the question 'Do you support the recommendation that the Government should introduce stronger sanctions, including criminal penalties in the case of deliberate re-identification, to protect an individual's anonymised data?': No

2.16 The issue here will generally not be deliberate identification but accidental or unavoidable as a result of deficiencies in IT systems or IT support and this needs to be taken into account. This should not be a crime but should be detected/corrected.

2.17 In response to the question 'If you are working within health or social care, what support might you or your organisation require to implement this model, if applicable?': Organisation support: huge costs are likely and database maintenance - especially for pathology based data.

2.18 In response to the question 'What are your views about how the transition from the existing objection regime to the new model can be achieved?': The current model is generally anonymous to most patients - the new system needs to be very clear.

2.19 Regarding equality issues in response to the question ‘Do you think any of the proposals set out in this consultation document could have equality impacts for affected persons who share a protected characteristic, as described above?’: Of course - access to information and the understanding of such will always be limited in certain minority groups and the elderly, psychiatric patients and children.

2.20 In response to the question ‘Do you have any views on the proposals in relation to the Secretary of State for Health’s duty in relation to reducing health inequalities? If so, please tell us about them’: The College fully agrees with these aims but would comment that they are difficult to deliver in practice.