

Response ID ANON-2BBS-3ZUW-2

Submitted to **New data security standards and opt-out models for health and social care**

Submitted on **2016-08-07 16:04:23**

Foreword

Introduction

1 Please tell us which group you belong to.

Group title:

Professional Organisation/Association

Other - Please specify:

On behalf of the Royal College of Ophthalmologists

2 If you are a member of an organisation or profession, please tell us if you are responding in a personal or private capacity.

Capacity in attending:

3 If the Department of Health or other organisations were to create further opportunities to engage on data security and the consent/opt-out model, would you be interested in attending? If so where would you find it helpful an event to be held?

Yes

Event location:

London

Data Security

4 The Review proposes ten data security standards relating to Leadership, People, Processes and Technology. Please provide your views about these standards.

Which Standard Do You Wish To Comment On? - Which standard do you wish to comment on?:

Comments:

All 10 standards are appropriate and necessary.

5 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:

10

Please provide examples which might be shared as best practice:

Mostly not applicable for a Royal College. We do however oversee a national audit which utilises IG compliant pseudonymised data.

6 By reference to each of the proposed standards, please can you identify any specific or general barriers to implementation of the proposed standards?

Please provide your views about these standards.:

3) Annual testing of all necessary staff would be costly and may be difficult to achieve on the ground.

Which standard do you wish to comment on? - Which standard do you wish to comment on?:

3

7 Please describe any particular challenges that organisations which provide social care or other services might face in implementing the ten standards.

Please provide your views about these standards.:

8 Is there an appropriate focus on data security, including at senior levels, within your organisation? Please provide comments to support your answer and/or suggest areas for improvement.

Yes

Please comment on your answer:

CEO, President and Committee Chair levels.

9 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?

Please provide your views about these standards.:

Simplification of the S251 exemption process.

10 Do you agree with the approaches to objective assurance that we have outlined in paragraphs 2.8 and 2.9 of this document?

Yes

Please comment on your answer.:

Appropriately pseudonymised data should not ALL need to go via HSCIC as this will produce a barrier to national audits and other quality improvement initiatives. For example, audit data can be pseudonymised prior to leaving a trust IT system so that patient identity never leaves the host trust.

The importance of data sharing

Proposed Consent/Opt-out Model

11 Do you have any comments or points of clarification about any of the eight elements of the model described above? If so please provide details in the space below, making it clear which of the elements you are referring to.

Which standard do you wish to comment on? - Which standard do you wish to comment on?:

5

clarification of the eight elements:

Implementation of a mechanism where a patient may express an opt out to any health professional which will then be visible across the health and social care system will be impossible to implement. There is much more to health and social care than a digital tick somewhere in an HSCIC computer.

12 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?

Yes

Please comment on your answer:

This should apply to the act of de-identification of data and not to the use in good faith of data which, if subjected to sufficient targeted analysis, could be capable of revealing an individual's identity.

13 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:

Nothing specific at this time.

14 If you are a patient or service user, where would you look for advice before making a choice?

patient or service user, where would you look for advice :

GP

15 What are your views about what needs to be done to move from the current opt-out system to a new consent/opt-out model?

What are your views about how the transition from the existing objection regime to the new model can be achieved?:

The proposed new model is more complex, would need to be explained to health professionals and the public and funding would be needed to support implementation.

Equality Issues

16 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?

Please comment on your answer:

The 'hard to reach' groups will remain hard to reach and individuals in some of these groups are likely to remain unaware of these changes.

17 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.

Please comment on your answer: